

**PERCEPTIONS OF GIFTED YOUNG  
PEOPLE EXPERIENCING LIFE-  
THREATENING ILLNESS AND  
PERCEPTIONS OF THEIR  
CAREGIVERS:**

**A QUALITATIVE STUDY OF LIVING  
AND COPING WITH PAIN**

**Master of Arts Thesis  
Candidate: Diane Stephenson  
Thesis Advisor: Dr. Janice Leroux**



Diane Stephenson, Ottawa, Canada, 1996



National Library  
of Canada

Acquisitions and  
Bibliographic Services Branch

395 Wellington Street  
Ottawa, Ontario  
K1A 0N4

Bibliothèque nationale  
du Canada

Direction des acquisitions et  
des services bibliographiques

395, rue Wellington  
Ottawa (Ontario)  
K1A 0N4

*Your file* *Votre référence*

*Our file* *Notre référence*

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-612-15679-6

Canada



**UNIVERSITÉ D'OTTAWA**  
**UNIVERSITY OF OTTAWA**

## TABLE OF CONTENTS

	<u>Page</u>
1. Abstract	1
2. Acknowledgement	1a
3. Poem	2
4. List of Tables	2a
5. Introduction	3
Chapter 1	5
1:1 Problem Statement	5
1:2 The Research Approach	5
1:3 Qualitative Research	6
1:4 Naturalistic Inquiry	9
1:5 Phenomenology and Hermeneutics	12
1:6 Theoretical Framework of the Study	17
1:7 Guiding Research Questions	25
Chapter 2: Methodology	27
2:1 Overview of Methodologies	27
2:2 Sample	30
2:3 Data Collection	37
2:4 Data Analysis	39
2:5 Naturalistic Interpretation	39
2:6 Hermeneutic Reading	41
2:7 Validation of the Data	43
Chapter 3: The Young People's Stories	46
3:1 Susanna	46
3:2 Joey	55
3:3 Andrea	64
3:4 Scott	72
3:5 Karen	79
Chapter 4: Naturalistic Analysis and Interpretation	89
4:1 Physical Pain	90
4:2 Psychological Pain	98
4:3 Family Ties	111
4:4 School	117
4:5 Hope	123
4:6 Naturalistic Theory	131
4:7 Hermeneutic Reading	138
4:8 Humour in the Case Studies	138
4:9 Humour in Literature	140
4:10 Conclusion	156
Appendices	157
Poems	160

References

162

Statement of Independent Auditor

173

## Abstract

The research study explores and analyzes the nature of gifted young people's perceptions in experiencing life-threatening illness and the perceptions of their caregivers. The thesis is interdisciplinary in its framework and methodology. Contemporary issues in giftedness as applied to handicapped children, the nature of pain and the actualization of story-mode in conceptualizing theory are implicit in the work.

Two methodologies are used in this study and are related but distinct in their focus, analysis and revelations. The children's case studies are formulated and written as actual stories. Two forms of analysis are applied to the stories. In the first section, a naturalistic inquiry using ethnographic analysis, interwoven literature review and analysis of care giver perceptions are examined. The caregiver perceptions include illustrative examples from the researchers case studies, as well as gifted life-threatening (within the definitions of this study) children for whom they have cared in their professional work lives.

Several dominant and overlapping themes emerged and are analyzed. These include perception of pain (suffering), both physical and psychological, family ties, school and hope. A grounded theory is inducted in which the importance of the child as a whole being, interacting with all who live and work with him/her is a critical quality of life factor. All else eg) pain, giftedness, school, family, illness are processes which direct our view towards the child as a whole person. A theoretical model in which the child expressing his/her self-perceived needs interacts with circles of common human values and needs, and specific situational needs is proposed. A meta-analysis of actual and potential caregiver interaction is tabled.

In the second phase of this thesis, the researcher suspends the major themes identified in the naturalistic analysis and explores the essence of the gifted-lifethreatened children's expression and use of humour. In so doing the researcher gives a hermeneutic reading to understand the unique and fluent use of humour in the children whose stories were told, and with gifted children with whom the caregivers had interacted. This is analyzed in the light of published works of the gifted life-threatening, relevant poetry, media themes and previous research on children's humour.

### ACKNOWLEDGEMENT

I wish to acknowledge the many people who have shared in this work. My husband Bob, for whom no task in this endeavor was too menial or too often asked, has walked this journey with me. My children Ian and Kathleen have tirelessly and patiently stood by me during this educational process and stood by a table filled with books, papers and everything except dinner for years. To my thesis advisor Dr. Janice Leroux, I owe immeasurable thanks, for without her, I would never have embarked on the process at all and certainly would not have finished this portion of my learning. To the many friends who have offered and given assistance in coding, assisting with the format, reading, discussing and being confident in me, I cannot thank you enough. To the children, their families and caregivers who have shared their stories, that they may be told, I am both humbled and deeply indebted.

## EYES AND TEARS

The willow tree is like a man with a million eyes and he cries  
Not because he has too many eyes  
But because if you have too many eyes  
You have too many tears.

Adam Jed  
8 years old  
(Berger et al, 1992)

## LIST OF TABLES

	<u>Page</u>
Figure 1 Holistic Model of Gifted Life-Threatened Child Interaction with Others in Time and Space.	137a
Table I Conceptually Clustered Matrix Centrality of Expressed Themes	158
Table II Person-Oriented Meta-Matrix: Objective Impact of Interventions (Potential and Real) Based on Thematic Need Expressions	159

### Introduction

Two fields of inquiry, rarely related, are the nature of giftedness and the young person's perception of living with the pain of suffering. There is, however, a dawning awareness that in studying giftedness, some populations of young people have been under-represented, including the physically handicapped (Winzer, 1990; Renzulli, 1978). A further sub-category of young people are those who are gifted or talented, and who face the physical and psychological pains of life-threatening illness. These young people, who, according to Winzer (1990), become a minority within a minority, may or may never achieve their potential in terms of performance, and may thus be seen to add little to the study of giftedness either intellectual, creative or talented. Such was the fate of brilliant musical prodigies Juan Arriaga, George Aspull and Karl Filtsch. (Fisher, 1973). Though some of their music is

still performed and recorded today, they are essentially footnotes in musical historical biographies. In a world in which "no consensus has been reached as to whether to define giftedness, in terms of potential or performance" (Winzer, 1990, p. 220), it is little wonder that in the haze of prognostic uncertainty these children may be overlooked in the very fields in which they may display their talents. Gifted children, as all others, deserve the benefit of research which may contribute ultimately to health care and educational practices which alleviate their suffering. They may be able to articulate insights which could aid in the rapidly burgeoning search for methods of coping with pain and disease.

## CHAPTER 1

### The Problem Statement

The purpose of this thesis is to describe and interpret the experiences of gifted and talented young people who are facing life-threatening illnesses.

### The Research Approach

The researcher uses a variety of qualitative methodologies to describe and explore the perceptions of gifted young people experiencing physical and psychological pain in life-threatened illness. A rudimentary grounded theory is developed using a pattern model as described by Reason (1981) which involves "a number of phenomena", (in this case, gifted, paediatric, pain, life-threatened), "all of equal importance, then explains connections between them" (Reason, 1981, p. 186). Separately, but as well a hermeneutic reading of the meaning of the children/adolescent's experience is attempted.

The research is intended to shed light on a unique

population so that future educators, health care givers, parents, friends and researchers may develop a better understanding of the worlds which these children inhabit. In so doing, the potential for developing tools to positively enhance the lives of these children and their successors exists. This becomes "action sensitive knowledge" (van Manen, 1990).

#### Qualitative Research

The naturalistic paradigm uses qualitative methods to understand naturally occurring phenomena in their natural states. It uses qualitative methods to "expose more directly the nature of the transaction between investigator and respondent" (Lincoln & Guba, 1985, p. 41). Qualitative designs are "naturalistic" in that the researcher does not manipulate the research setting (Patton, 1990). In its broadest sense the naturalistic paradigm may include, and is labelled alternatively, "post positivism, ethnographic, phenomenological, subjective, case study, qualitative, hermeneutic or humanistic" (Lincoln & Guba, 1985, p. 7).

Jacob (1988) notes that differentiating the "qualitative/naturalistic (holistic-inductive) from the quantitative/experimental (logical-deductive) creates the impression that there are only two methodological alternatives" (p. 16). He contends that unity of qualitative approaches disappears producing great diversity meaning different things to different people (p. 16). This stems from differences in theoretical traditions and orientations (Patton, 1990, p. 66).

For example, the disciplinary roots of ethnology are anthropology and central questions relate to the culture of a particular group of people. Phenomenology has philosophical roots, and studies the structure and essence of experienced phenomenon that people live. Hermeneutics is applied to theology, philosophy and literary criticism in the context of conditions under which a human act occurred which makes possible interpretations of its meanings.

There are important differences in research design, processes and outcomes of various qualitative approaches.

In naturalistic inquiry design, which may use case study and ethnography, the thrust is in building theory. The resultant formulation can be used to explain the interpreted reality and to provide a framework for action. Researchers in this field "believe that theories represent the most systematic way of building, synthesizing and integrating scientific knowledge" (Strauss & Corbin, 1990, p. 22). Naturalistic inquiry research outcomes are derived from inductive empiricism. In the methodology of grounded theory approach within naturalistic inquiry, the researcher usually uses a team approach to identify themes during content analysis.

In phenomenological inquiry, what is important to know is what people experience and how they interpret the world. A second distinguishing and definitive characteristic of phenomenological study is the assumption that "there is an essence or essences to shared experience" (Patton, 1990, p. 70). This involves a rigorous methodological technique of bracketing to discover commonalities in human experiences.

Phenomenological hermeneutics "is the art of hearing, the art of responding to the subject matter appropriately, in a way appropriate to the subject" (Palmer, 1988, p. 167). It is a response to what is calling, pulling us, making a claim on us (p. 165). To be more specific about the differences in naturalistic inquiry and hermeneutic reading as they are theoretically applied in the body of this research, both naturalistic inquiry and its grounded theory and phenomenological hermeneutics will be described separately.

### Naturalistic Inquiry

Key axioms which underpin naturalistic inquiry include research in the natural setting, use of the researcher him/herself and other humans as primary data gatherers, use of tacit knowledge, qualitative methods, purposive sampling and inductive analysis (Lincoln & Guba, 1985). A grounded theory approach is integral and an accepted mode of

qualitative analysis (Strauss & Corbin, 1990). Other important characteristics of naturalistic inquiry are an emergent design, negotiated outcomes, case study reporting mode, idiographic interpretation, tentative application, focus-determined boundaries and special criteria for trustworthiness (Lincoln & Guba, 1985).

The naturalistic method uses a "systematic set of procedures to develop an inductively derived grounded theory about a phenomenon" (Strauss and Corbin, 1990, p.24). It was originally used by Glaser and Strauss (1967), and includes their first works which are monographs of the dying (Patton, 1990).

Patton (1990) notes that the development of grounded theory occurs when general patterns across cases may be identified during content analysis, but the original focus is on full understanding of individual cases before those unique cases are combined or aggregated. Findings then become grounded in specific contexts, and subsequent theory development will be grounded in real world patterns (Glaser

& Strauss, 1967).

The development of grounded theory may involve various approaches. These include case study methodology and the interpretative use of story. Case study research is the reporting mode of choice for naturalistic inquiry. It is appropriate when the researcher is looking for insight, discovery and phenomenon interpretation (Merriam & Simpson, 1989).

Yin (1989) describes case studies as the preferred method when the focus is on a phenomenon with some real life context. He differentiates between explanatory, and descriptive case studies. Case study research frequently combines several methods of data collection and analysis (Eisenhardt, 1989). Case study research in the field of the gifted learner and prodigy are increasingly evident in the literature and include studies by Hauck and Freehill (1972), Feldman (1986), Lovies (1925), and Gottfried, Gottfried, Bathurst and Wright-Guerin (1994).

Lincoln and Guba (1985) use the term naturalistic paradigm and describe it as "a better fit" to socio-behavioural phenomena than traditional scientific research. It is a method in which theory can inform practice.

#### Phenomenology and Hermeneutics

The aim of phenomenology is to describe the interrelated meaning structure of lived experience. "Phenomenology is a creature of ambivalence. Like the serpent who lives in both water and on land, or the salmon who dwells in both salt and fresh water, phenomenology crosses boundaries... Like the serpent handler and the fisherman, phenomenologists require special knowledge and meticulous training" (Brenneman, Yarian & Olson, 1982, p. 1). Giorgi (1970) confirms this when he comments that it is characterized by the presence of an involved scientist. This is reinforced by Spiegelberg (1976) who adds: "Phenomenology begins in silence. Only he who has experienced genuine perplexity and frustration in the face

of the phenomena when trying to find the proper description for them knows what phenomenological seeing really means" (Spiegelberg, 1976, p. 672).

Of the multiple methodologies in qualitative research in the human sciences, hermeneutics is a fast rising influence (Aanstoos, 1987). Hermeneutics is the theory and practice of interpreting the expressions of lived experience. Palmer (1988) states that hermeneutics "goes behind the surface meaning, the surface interpretation, that which is suggested in the text. Dilthey (1985) states that "lived experience is to the soul what breath is to the body" (p. 36). It is the "meaning" of the experience which is the essence of this kind of research, and its form is narrative description. Polkinghorne (1988), notes that the realm of meaning is "best conceptualized through qualitative nuances of its expression in ordinary language" (p. 10). He claims that "language is commensurate with meaning and the hermeneutic understanding uses processes such as analogy and pattern recognition to draw conclusions about the meaning content of linguistic messages" (p. 7). This corresponds

with the advocacy which is growing for the use of story-telling as a legitimate tool in the research field (Carter, 1992). According to narrative theory, a human study should focus attention on lived experience interpreted by the human person. "The interpretation finally involves the processes of language as well as the order of meaning which interacts with and brings to language the physical and organic orders" (Polkinghorne, 1988, p. 125).

Van Manen (1990) furthers the understanding of hermeneutic research by noting that lived experiences gather significance as we gather them and give memory to them. "Through meditations, conversations, day-dreams, inspirations and other interpretive acts we assign meaning to the phenomenon of lived life" (p. 37). He aligns this to artistic endeavour, a "creative attempt to capture a certain phenomenon of life in a linguistic description" (p. 39). In addition, van Manen notes that doing hermeneutic research is "an attempt to accomplish the impossible: to construct a full interpretive description of the lifeworld and yet to remain aware that lived life is always more complex than any

explication of meaning can reveal" (p. 18).

Hence, hermeneutic research differs from naturalistic research in that its knowledge is grounded in lived experience but not derived from inductive empiricism. As this occurs, the interaction between interpreter and the phenomenon in which each side reveals itself to the other demonstrates the process of the "hermeneutic circle." It is the interpreter's risk in exploring a theme not identified in the inductive empirical approach which allows the phenomena to reveal itself and ultimately be reflected in his/her own being. The created certainty of what is seen results from a vigorous focussing on one dimension of a phenomenon, while simultaneously mirroring self-understanding. This shifting of a peering eye and a listening spirit, of looking at a separated part and a united whole, of text and interpreter becomes an attitude which van der Leew would consider "an intention to understand rather than explain" (Brenneman, Yarian & Olson, 1982, p. 18). Its focus is to accurately and contextually describe the significance in meaning or essence of case

studies.

In many ways, the naturalistic and hermeneutic researcher has come to recognize the difference in qualitative methods metaphorically. The naturalistic paradigm is the accomplished instrumentalist in an orchestra. The musician has studied all of the scores before him/her and developed technical mastery of decoding the notes and harmonies and interpreting them in one of the various ways that they have been coded. In close association with his/her instrument, music is produced which may vary in a hundred shades of colour and which is examined, understood, played and at times even improvised to produce new sounds or theories of both expression and use of the instrument. A whole becomes the piece which is played out.

The hermeneutic researcher is however the conductor. Conducting, as we know it, means both keeping time and interpreting whole sound. It implies being together with the musicians and intimately appreciating the music that

they play, and interpreting it in a meaningful way for the audience. It is an act of living and being and reflecting the composer's work and the individual musician's craft in the wholeness of the orchestra. Without the musicians there would be no conductor. Without the conductor there would be no orchestra. This is the theoretical springboard from which this particular piece of research arises.

#### Theoretical Framework of the Study

There is yet no science that has fully articulated and expressed paradigms for the systematic and disciplined study of particularly human phenomena (Giorgi, 1970). There is no known theoretical model which describes or interprets the perceptions of gifted/talented or creatively endowed young people as they cope with serious illness. Originally, the naturalistic mode of inquiry was chosen as it is considered to be optimally suited to health related research as a "complimentary" form of qualitative analysis (Munhall and Oiler, 1986). Many researchers have noted the appropriateness of a qualitative approach in health related research. Lincoln (1990) insists that it is relevant

particularly in this field. Yin (1988) notes that case study research is appropriate when a "how" question is being asked about a contemporary set of events over which the researcher has no control.

There are, however, designs and methods of case study research described by Yin (1989) which develop a theoretical framework, whether the study is explanatory, descriptive or exploratory. Exemplary case studies, as described by this author, involve unusual issues.

Increasingly, analysis of vignettes, accounts or stories are evident in the research in the fields of giftedness and children's perceptions. Case study designs have been used to describe the forced choice dilemma of gifted children in the pursuit of excellence or search for intimacy (Gross, 1989). Feldman and Goldsmith's (1986) longitudinal case study research is unparalleled in providing insight into the world of particular gifted children in the context of their social and educational worlds. The highly gifted autistic writer of Nobody nowhere

(Williams, 1990) shares her experiences of being both gifted and life-threatened (suicidal) and provides a perceptive glance of a mystifying disease (autism).

Although Feldman's subjects were measurably identifiable as highly gifted according to the common method of most school boards who define giftedness in terms of IQ level. Williams, by virtue of her autism could not be so identified. Welsh (1986) notes that reliance on IQ scores excludes many children with special competence and abilities whose talents may be overlooked if there is no opportunity to express it (Welsh, 1986). Williams' unique ability to articulate in her own way can, by virtue of transferability, help the non-autistic to understand and care for others, similarly affected.

The use of story has long been known in diary, biographical and autobiographical works in which the character of a famous or exceptional person was illustrated through description or self-report. A greater formalization of this method is evident in the research work of Gilligan

(1982), D. Ross and S. Ross (1989), and Karnes and Schwedel (1983).

A recently published book details the stories of seven life-threatened child poets (Berger, 1992). The profoundly inspirational insights from these children's stories and their published poetry have not been developed into a grounded theory, but serve as a reminder of the potential of "story" as a research tool. This approach is gaining advocates. For example, Carter (1992) has stated that "story telling is now a central focus for conducting research in the field" (Carter, 1992, p. 5).

The stories which are shared in this paper are neither duplicable or generalizable because the children and their illnesses are individually unique. They will be examined by two related but distinctly different research approaches, ie - naturalistic and hermeneutic. "Paradigmatic or scientific explanation requires consistency and noncontradiction. Story on the other hand, accommodates ambiguity and dilemma as central figures or themes" (Carter, 1992, p. 5). The

dilemma of physically and psychologically thwarted giftedness lends itself more obviously to the story mode. Moreover, if the aim of study is to direct positive change or "action sensitive knowledge", then the use of these methodologies may shed light on our ways of caring for and teaching gifted children who are challenged by illness.

Recently, the author had the opportunity to conduct a pilot study with a prodigiously gifted cellist, a child who subsequently succumbed to cancer (Stephenson & Leroux, 1994). The child transformed his creative outlet into telling his story in the form of a published book, and in my observation, controlled his pain in extremely unconventional ways. In sending his parents a copy of a published essay review (Leroux & Stephenson, 1993), his parents have written to describe the letters that they in turn received from young people whose lives have literally changed course as a direct result of the "story" that this child told (Froment-Savoie, 1993). This is consistent with the assertion that stories have the power to direct and change our lives (Noddings, 1991).

When identifying children as gifted, it is important to consider current definitions of such individuals. Renzulli (1978) defines giftedness as "the interaction among three characteristics: above average intellectual ability, creativity, and task commitment" (Renzulli, 1978, p. 261). Karnes and Schwedel (1978) call for a broader definition which encompasses the whole child and in which children show advanced skills attainment relative to other peers. In the Ontario Education System at the time of writing, giftedness is defined in terms of intellectual abilities. Talent refers to a very high ability in one or several areas (Goldman and Fisher, (1980). A recent and comprehensive longitudinal study of the developmental influences on gifted children acknowledged the existence of numerous definitions, but elected to use school measured IQ tests as the criterion of giftedness for the purposes of their research (Gottfried A, Gottfried A.E., Bathurst and Guerin, 1994).

Other definitions of giftedness abound. Haensly, Reynolds and Nash (1986) describe giftedness as "an ever-

widening magnificent possibility" (Haensly, Reynolds and Nash, 1986, p. 132). Likewise, Sternberg (1991) holds a triarchic theory which includes analytic, synthetic and practical abilities.

In any case, there is a myriad of recent studies which indicate that dependence on IQ scores for identification of giftedness is still the norm (Oshima, 1992; Stevenson & Lee, 1993; Yong, 1994). Such narrow measurement may inhibit identification of other giftedness. Ramos-Ford and Gardner (1991) have developed the concept of qualitative giftedness in terms of seven "intelligences" which include two forms of personal intelligence (interpersonal and intrapersonal). Feldhusen (1986) suggests that a narrow and competitive definition of giftedness limits the potential domain of giftedness. Csikszentmihalyi and Robinson (1986) further suggest that giftedness is a flexible potential and "in the last resort it is up to us to decide what talents are and shall be" (Csikszentmihalyi and Robinson, 1986, p. 284).

Haensly et al. (1986) declare that giftedness is a

union of the following abilities:

- To see possibilities where others do not
- To act upon those possibilities in an extraordinary way with exceptional skill.
- To maintain significant intensity to overcome obstacles over a sufficient period of time to produce a response.
- To share the outcome in the process with society in some temporary or permanent way (p. 132).

Many of the above authors include personality traits in describing giftedness. Dabrowski (1964) who furthered this theory, observes giftedness in terms of qualitatively distinct capacity for intensity which was "vivid, absorbing, penetrating, complex and commanding" (Piechowski, 1992, p. 181).

Clearly, for children such as those experiencing brain tumor radiotherapy, reliance on current IQ scores is inappropriate. Definitive distinction based on skills attainment relative to peers (Karnes and Schwedel, 1978),

Sternberg's triarchical theory (1991) and Dabrowski's theory (1964) approximate more closely the sample population and Haensly et al. (1986) definitions. All of the actual case studies presented, however, were identified for gifted programs within their school systems. The children described in these case studies are identified by the school system, and display the traits described by Haensly et al, Dabrowski, Sternberg and Karnes and Schwedel. Children who were unschooled and described by the caregivers meet the definitions of giftedness for the latter three citations with emphasis on Karnes and Schwedel's definition of relative peer group.

Based on the theoretical framework presented and following a qualitative research paradigm, guiding research questions were formulated.

#### **Guiding Research Questions**

The research process, and initial research data collection will be guided by these research questions:

1. How do gifted children perceive physical and emotional pain/suffering associated with life-threatening illness?
2. How do gifted children live with the psychological and physical pain/suffering?

## CHAPTER 2

### Methodology

This study uses two methodologies which are separated in presentation. Both are qualitative, the first being a naturalistic inquiry mode using exemplary case study methodology with formulation of a rudimentary grounded theory. The second is case study research using hermeneutic methodology and interpretation. The latter methodology is considered enriching for the study.

At the beginning of this research, case study was done using ethnographic approaches to code various thematic representations gleaned from the initial interviews. Using variant but prescribed methods of naturalistic inquiry, contact sheets, triangulated coding, on-going cross-case analysis technique and metamatrix display was attempted. However, as the research continued, and the researcher became more familiar with the theory of hermeneutic understanding, the work itself took on a life of its own and became redirected. The original collection of data and

analysis seemed to be too confining of the actual meaning of the experience as lived by the respondents and shared with the researcher. For example, the attempt to confine data for frequency analysis seemed a travesty to the occasional, but intense meaning of a rare anecdote and the interpretive perceptions which leant somewhat different insights into the phenomena. As the researcher's paramount (and presupposed) notion of pain was shed like a skin from the reality of these people's whole living experience, so did the rigidity of methodology which fragmented, and a richer understanding of the wholeness of the experiences shared. This is described by Patton (1990) as a focus on how information is put together in a way which makes sense of the world. Patton (1990) further noted a distinction of method in stating that "the assumption of essence, like the ethnographer's assumption that culture exists and is important, becomes the defining characteristic of a purely phenomenological study" (p. 70).

The process may be compared to a journey upon which the qualitative researcher embarks. The methodology itself

becomes emergent, not as a justification for legitimate scientific research, but as a trend towards the exemplar of holistic evaluation. This becomes inextricably interwoven with the actual conclusions of the study. Ironically, the researcher notes that it is entirely in her character that she had to participate in the "approved" methodology for the present study to prove experientially that it does not and could not provide the clearest interpretation of the phenomena under study. A second irony is thus noted. "Heuristic" is the Greek word for "discovery".

In this paper, case studies initially are analysed according to inductive empirical analysis to the point where grounded theory starts to appear. Then, a hermeneutic research methodology is used to unravel and expose some meaning(s) of lived experience.

Thus in this work, methodology which means "pursuit of knowledge" (van Manen, 1990, p.28) follows its own course which initiated and experimented in grounded theory approach and devolved into the appropriate realm of seeking essence

not from the inductive data analysis, but from a more delicate teasing and tasting of meaning from the lived experiences of the young people themselves. Essentially the researcher examined the multiple appearances of the people in this study using external methodologies to interpret data. Then the data is turned inside out to examine not only the present elements but the inside weave, the seams, knots, hems and the texture of the material itself. Once turned over again the garment is recognized as the skin of the wearer - he or she who is living the experience. The originally promised "meta-analysis" of data became for the researcher a "meta-analysis" of her own methodology. Returning to the theoretical mode this is recognized as hermeneutics and phenomenology. "Educational research is notoriously eclectic" (van Manen, 1990, p.135). The methodology and the data conclude in one intricately complex tapestry.

### Sample

Five respondents in this study were chosen on the basis of theoretical sampling as required by grounded theory

method. Consequently no random sampling was used. Health care participants included one paediatric oncologist, one nurse educator, one social worker, one paediatric clinical psychologist, one oncology clinical nurse specialist and one child life worker. This focus group interview took approximately 50 minutes and a subsequent interview with one of the participants took 15 minutes. To enrich the caregiver information, individual interviews were held with a parent of a gifted child with a life threatening congenital blood disorder and an experienced paediatric oncology volunteer.

Young people in the study who were interviewed for the purpose of this study ranged in age from 9 to 19 years. Opportunistic sampling in which the researcher was able to take advantage of unforeseen opportunities after fieldwork was begun (Patton, 1990) was done in one instance. For purposes of analysing data, the child from the pilot study was separately included, as direct quotations from his book and notes of the researcher's multiple interactions over two years with this child were available. Some of the gifted

children described in the focus group and volunteer interview were as young as three and as old as 16. With the exception of a three and five year old, mentioned by participants in the focus group, who were considered evidently gifted by the oncologist, parents and the caregivers, five of the children were tested to be in the intellectually gifted range and identified through IPRC processes to access gifted educational programs. The three year old was phenomenal in her sensitivity of expression e.g., "Maman will be so sad when I go to the angels, that I will only come for my chemo with my papa so she will not hear me cry." In addition, she has memorized extremely complex dance and musical routines, some of which were performed for Hillary Clinton. The five year old was a fluent reader who demanded to work at the desk (stamping addressographs, simple accurate filing, etc.) and who stated that she felt that the Christmas "real" paycheque of \$5.00 which the hospital gave her was "inadequate hourly pay for all of the worked hours." Both gifted pre-school children described by the focus group caregivers had terminal illnesses and were neither tested nor schooled. For the

purpose of this study, identifying features have been altered, although focus group quotes are verbatim.

An original focus in this study was pain, and it is established that the accepted age at which children can report pain using validated tools is three years (P.J. McGrath, Beyer, Cleiland, Eland, P.A. McGrath and Portenoy, 1990). Three years is also the earliest accepted age for using perception interventions such as hypnosis to alleviate pain. From a practical viewpoint of obtaining verbally rich descriptions it was obvious that despite the linguistic capabilities of gifted children, older gifted children and adolescents yielded more verbally rich descriptions.

Recent medical and psychological research recognizes "that only in the last decade has there been agreement about the importance of subjective reports of pain in children" (D. Ross and S. Ross, 1988, p. 35). Furthermore, it is newly acknowledged that "children from pre-school through adolescence are competent discussants of pain" (D. Ross and S. Ross, 1988, p. 311). Children can describe their pain

qualitatively and rate it quantitatively (P.A. McGrath, 1990).

Child participants in this study were identified by teacher, physician or psychologist referral with one exception. The latter was referred by a parent who heard about the study through a presentation on qualitative research which was given by the researcher. The criteria for inclusion was according to a pluralistic definition of giftedness. First, the children were previously identified through testing in the school system with the above noted pre-school exceptions who were not included as actual case studies. These children were identified by Karnes and Schwedel's "relative peer group" criteria. The peer group of gifted life-threatened is necessarily small. The usually accepted norm for giftedness of the general population is between 2% and 5%, and the incidence of cancer, as an example, in children, is a mere .13% (Pizzo, Poplack, 1993). The respondent group was both small and unique. The use of extreme-case selection is supported by Marshall and Rossman (1989) and Lincoln and Guba (1985) who recommend maximum

variation in order to provide the widest possible range of information.

Secondly, the children were identified for giftedness as described by Haensly, Reynolds and Nash (1986) which holds the synergistic combination of ability, context and internal dynamic direction with clear alignments of their union of descriptors.

Thirdly, the children were selected according to Dabrowski's (1968) capacity for intensity (Piechowski, 1992). As well, the giftedness intelligence of interpersonal and intrapersonal as described by Ramos-Ford and Gardner (1991) were selection considerations. Informed consent was obtained prior to the interview and was reviewed at the beginning of the taped interview. Open-ended questions framed the interview process. Confidentiality was ensured unless the participant chose to be identified, which all except one did. This proved to be an interesting feature of the research as the need for children to identify themselves individually and by name surfaced in many

previously published case studies. For example "my real name is Joe Louis Lopez. If they change my name, then it's not me, it's somebody else. But it is me. It's a fact. People are afraid of Aids, but it's a fact" (Berger, Lithwick, 1992, p. 48). Even the child who chose to have his name changed in the thesis made the researcher promise that if he were being quoted to doctors or nurses or people that really knew him, that his real name would be used. Participants had the option of withdrawing from the study at any time.

"Life-threatening illness" refers to disease which has death as a distinct possibility resultant from the disease, disease-related complications or treatment of the disease. In this study, most of the children have experienced cancer, one has a severe congenital blood disorder and one has severe asthma (which is becoming the fastest rising cause of childhood mortality in Canada).

### Data Collection

Participants in this study included the children who are described in the case studies, focus group participants and individual interview respondents. The purpose of the study was clearly explained to them, and where relevant, to their parents prior to setting of the interview time and site.

The interviewer used face-to-face interviewing, the child's home or a location selected by the child and parents. Interviews with the young people took 30-60 minutes and were terminated when the child showed signs of fatigue or disinterest. The parent and volunteer interviews were held in the respondents' homes as was their preference. The focus group interview was held in a workplace conference room for the convenience of the participants.

Semi-structured age appropriate interviews were used. The interview process was, however, non-static and was revised in each case to reflect the emergent needs of the investigation (Eisenhardt, 1989; Sandelowski, 1991).

Qualitative research is a means of describing multiple realities, in this case children of various ages and stages, giftedness and suffering. It is "ideal for providing the thick description thought to be so essential for enabling transferability judgements" (Miles & Huberman, 1984, p. 214). The use of interwoven literature review which is reported after, rather than before the data collection, is supported by Wolcott (1990) Strauss and Corbin (1991) and Patton (1990). In the hermeneutic interpretation section the integration of works of poets, artists and writers is incorporated in the interpretation. This is in keeping with the notion that "the human scientist likes to make use of the works of poets, authors, artists, cinematographers, because it is in this material that the human being can be found as situated person" (van Manen, 1990, p. 19).

Case reports have long been accepted in the health care fields as a means of portraying the intricacies of complex human situations and as useful instructional tools for apprentices of health science. The use of case studies in

this research is not entirely unfamiliar to the respondents who have experienced voluntary participation in rigorous clinical trials, educational teaching sessions for medical and nursing staff and/or participation in "being" the case-study for the medical examinations. By nature of their disease processes and exposure to treatment in a teaching institution, the children are for the most part comfortable talking about their disease, and their perceptions.

### Data Analysis

#### Naturalistic Interpretation:

At the time of interaction with the participants in this study, a contact summary form (Appendix 1) was initiated so that field notes were kept to record type of interaction, who was involved in the interaction, date and time, main themes and on which research question the contact bore most centrally. As well, notations of salient points or issues of particular interest were noted with some target follow-up questions. Use of a contact summary form is

advised by Miles and Huberman (1984), as "a rapid practical way to do first-run data reduction without losing any of the basic information (the write-up) to which it refers" (p. 51). This proved to be extremely advantageous in one case where tape quality was poor.

As well, the researcher's recording of immediate impressions and reflections proved serendipitously, to be a useful underpinning for further reflection and analysis in the hermeneutic methodology. All interview tapes were transcribed producing Wollcott's (1990) proverbial "wheelbarrow" full of data. All information was then line numbered and coded by thematic representations which appeared. The method of coding was ethnographic in basis with a series of colour coded theme identifications. These were then charted on a matrix display noting evident themes and source of themes. From there, a conceptually clustered matrix to determining the centrality of expressed themes was devised. Taking the themes which were evident as both frequent and high in intensity of expression, a grounded theory was inducted and subsequently written.

### Hermeneutic Reading:

Using the original case study data, the researcher concentrated on a reflective reading, rereading and in some cases re-listening to the taped interviews. Much reflective time was spent in culling the information for its essential meanings. This process involved what Aanstoos (1986) calls a reliance upon "pre-understanding or foreknowledge to provide an entry point." In more than 25 years of health care the researcher has had much interactive opportunity to share intimately in the process of walking along together with patients who experience life-threatening situations. Their living/dying time has been shared.

In reflecting on the past, the researcher immersed herself in the hermeneutical notion that "intuition is knowing through direct experience without concept. It is a past infiltrating the present, a duration which is the continuous process of the past which gnaws into the future and which swells its advances" (Polkinghorne, 1988). It

became startlingly clear that the past included the researcher's lengthy and close experience with a child prodigy who initially sparked her interest which resulted in the research itself. This child, who was the centre of the pilot study, became a public figure as the protégé of internationally acclaimed cellist Yo Yo Ma. In the course of his terminal cancer, the child transposed his musical talent to writing and published his autobiography. As well, he dealt with pain in ways which were both unconventional and creative (Stephenson & Leroux, 1994). For the researcher, it led to clarity of a lifetime of unexplained fascination in reading the unique biographies of the gifted and talented, particularly in the fields of music and poetry. It allowed the researcher to reframe actual experience of working with both concrete and complex realities of the participants in a way which might be expressed more communicatively through hermeneutic than the naturalistic method which was originally attempted. At the very least the idea that in the use of a language text "multiple or conflicting interpretations are possible" (van Manen, 1990) are both explored and experientially tested in

this thesis.

In relooking at the data, the researcher intentionally suspended presuppositions, some of which were included as part of the research question e.g. the notion of "pain". The conclusions of naturalistic inquiry which shed light particularly on the first question did not adequately answer the second, which concerns how gifted children and life-threatened children live with their suffering. In using the phenomenological technique of bracketing to suspend all of the presuppositions, which, in this case included all of the conclusions from the naturalistic analysis, another key feature appeared. While this separating of strands became difficult at times, an interesting, perhaps even peripheral phenomenon kept incorrigibly coming to the fore. The more the researcher pondered, the more everyday examples surfaced and the narrative subsequently wrote itself.

#### Validation of the Data

The researcher validated the data by checking back with the original participants to the degree possible, caregivers

from the focus group and colleagues working with qualitative research. For the purposes of triangulating the original themes expressed in the raw data, three people besides the researcher independently coded the data line by line. A health care worker and research assistant who is widely acknowledged for her gifts in understanding and working with life threatened children, independently reviewed the materials and selected the most obvious themes. Those which matched the researcher's were used. There was 80% congruence in theme recognition. An example of theme exclusion is the inability of the child to recognise his/her giftedness. Similarly, the process of bracketing, although much less consistent in agreement was achieved and triangulated. A full-time health care researcher from the University of Ottawa Research Institute was engaged to examine and affirm the authenticity of the data, its transcription, multiple codings, and use of quotes and themes within the document. All of these materials remain with the researcher with one exception, and as per the original consent, will be destroyed upon completion of thesis defence. The exception is a tape which the parent of

a deceased child requested, and which the researcher naturally felt was best placed in the requesting parents' possession. Authenticity of the tape and its transcription has been verified.

## CHAPTER 3

## The Young People's Stories

## Susanna's Story

At 12 years of age, Susanna noticed that she was tired and not very hungry. Just walking to school became an effort, and she increasingly became listless and disinterested in school and her family. Her mother and father were concerned, but thought that perhaps it was a phase of development on the cusp of puberty. Susanna did not think she was sick and was not receptive to early suggestions to go to the doctor. One day, her mother watched her drag herself up the stairs of their front porch, and made an appointment for her to be seen by the family doctor. In a haze which is now a blur for Susanna, she was taken for blood work, and immediately brought to the Children's Hospital. She says that "the lumbar puncture really hurt me. I didn't know what they were doing and I had to be all rolled up in a ball with people all around me and a big needle in my back. I hated that." She was diagnosed as having acute myelogenous leukaemia and

immediately embarked on a round of aggressive chemotherapy. Susanna, always a shy girl, became more and more withdrawn and resistant to going to school. When asked about that she becomes tearful and notes that "it was awful. Now I know that children are cruel, but I had no hair and even my best friends teased me, calling me horrible names and not including me in things. It was very painful and my mother and the principal had to intercede. It was very hard to be sick and also to be rejected by your friends. Only one friend stuck with me and remained friends through high school." Remission of the disease was achieved but short-lived, and the only medically advisable course was a bone marrow transplant.

Fortunately, Susanna's only sister proved to be a perfect bone marrow match, and the transplant was performed in June of 1988. A bone marrow transplant is at best a risky but life-saving procedure. In order that the marrow not be rejected or seeded with new cancer cells the recipient must undergo total body radiation. The implications of this can (and did) include long-term

physical and cognitive disabilities.

Susanna, a serious, intelligent and introspective person asked penetrating questions about her disease and treatment, and was given accurate information about the potential side-effects of the cure. She says however, that although she knew that her disease was serious, she felt confident that she would get better even after relapse, and during the period of both physiological and psychological depression. She became acutely interested in the details of the blood counts and she and her mother kept a daily diary of the experience of her illness. When Susanna became too ill to write it herself, and concurrently sick of being asked the same questions over and over, she devised and utilized a daily checklist which she ticked off and signed. This was posted daily on her door and she requested that health care personnel read it before they came in.

(Appendix 2). The ability to devise such a tool, which included a numerical rating of her overall self assessment was considered both original and remarkable. It gave Susanna a measure of control over what was a highly

regimented and ordered period of gruelling treatment, a time in which it was uncertain if she would survive. Would the marrow take?

Susanna did survive and continuously demonstrated both her confidence and the fact that she would do it her way. On the day of discharge, her health was still fragile, and it was necessary for her to maintain an intravenous line going into the major vein into her heart should she need immediate treatment, e.g. if she suddenly haemorrhaged from low blood counts. Her transplant team advised against her going to the cottage as the risks were still high. With characteristic intensity and persistence, she finally persuaded her family to take her to "see" the lake which she had so often dreamed about while she was in hospital. On arrival at the cottage she ran down to that lake, jumped in and swam briefly. She then got out and announced that she was ready to get on with life "outside the hospital".

For the most part Susanna has been able to do this. She has a strong aversion to hospitals (the "odour"

stimulates bad memories) and will not visit the survivor's clinic because it is housed in the hospital where she was transplanted. Annually she breaks her resolve and brings flowers to the oncology staff at the Children's Hospital. As well, although she "hates the wards," she never refuses a request to meet with an oncology patient about to be transplanted or one whose hope is sagging. She, although shy, participates on panels for health care givers and/or families on bone marrow transplants, and she is known for the unvarnished truths about the experience from a client viewpoint. Her willingness to participate this way generously helps many others to understand the many intricacies of this still unique treatment, but more importantly gives inspiration to those who need to undergo it. Her very presence and articulateness give hope, meaning and determination, for those caregivers in the field who daily work with children, some of whom will not have favourable outcomes.

Lest one think that all was rosy for Susanna's post transplant, she and her family viewed life on the "outside"

differently. It is noted (Kauffman, 1995) that "school takes up more time than anything else for the adolescent than sleep." School for Susanna, a bright and exceptionally conscientious student, became a painful reality in which she had to compensate for some physical losses (treatment related hearing impairment, growing cataracts, sparse hair, no puberty, and short term memory loss related to radiation-related cognitive impairment). She had to learn to deal with social isolation and a peer group of students (gifted), who had congealed in both their friendships and educational aspirations during her long time out.

Susanna coped by spending long hours on the phone with her few "true" friends (one in particular). Her relationship with her family deepened at a time when many of her friends were going through the tensions of conflict and separation. It became apparent to both Susanna and her mother, who self-describes the situation as "being joined at the hip", that it would be important for Susanna at some stage to leave the family unit for post-secondary education. This was made somewhat easier because her closest

friend/sibling donor decided after their experience to enter nursing and had gone to the Maritimes to do so. Susanna tried to cope with the in-school isolation by taking a co-op option in which she worked in an archaeology museum lab and then a genetics lab. She subsequently won the award for the best co-op student at her high school. This is especially impressive because testing in Grade 12 indicated that her ability at verbal recall had deteriorated to a Grade 7 level.

Susanna rarely went out and never dated in high school. Nonetheless, she had the pride and confidence in her great achievements, to attend her graduation prom with other "uncoupled" friends. The researcher observed her crossing the commencement stage to the sound of more than the average bounding applause from both those who had been unable to include her in the normal social groups and the parents and teachers, many of whom were brought to tears in seeing this diminutive, determined and spunky scholarship winner.

How did and does Susanna succeed? She had determined

that nothing will prevent her from pursuing a career in science. She attends Bishop's University and at the end of her second year she has achieved an 80% average. She is exceedingly conscientious in taking notes (both by hand and tape recording) and she meticulously, multiple times over, hand transcribes them to compensate and retrain her memory. She made friends with her room-mate, but remains largely socially disconnected, partly she thinks, because she "lives on another planet" from others who have not/do not share her experiences. She says she has no interest in the bar or party scene which makes up so much of the social fabric of college life. " Why would I consider voluntarily putting poisons into my body when I had no choice in doing it?" On her one experimental foray to the student pub the noise and ringing in her ears became so painful that she had to leave, but not before observing that these students "live for the moment and don't know the value of life". She will be living in an apartment by herself next year, which allows her to pursue her note transcriptions and view more distantly the lives of other students. She was disappointed that university students, whom she assumed would be more

mature than public school or secondary school students, were unable to be empathetic to her. She notes that on getting up the courage to share her story with her resident mates that she felt them wall her off. They simply, in Susanna's perception, did not want to think about or hear about things like cancer. Despite self-imposed rules never to mention her story again or even include in her vocabulary words such as "treatment, doctor, nurse" which were so much a part of her life, she never could make sustained social friendships except with one girlfriend who is married and therefore she assumes, more mature.

Susanna, however, is observant and thankful for the understanding and treatment that she receives from health care workers and teachers. They have helped her she says, and they "recognize" what she is doing, and that it is not easy. She maintains absolute confidence that she will graduate and pursue a career in some avenue of science which ~~can both~~ accept and benefit from her "gaps". She is spending the summer doing volunteer work at the Museum of Natural Sciences at the time of writing.

### Joey's Story:

Joey was born in January 1983 after his mother experienced a normal pregnancy and delivery. Shortly after birth when the parents took him to "show him off" to his relatives, they noticed that he looked very white. He was seen in an Emergency department and immediately given a blood transfusion. Three months later he had a routine check-up in Trenton and was immediately sent to Toronto Sick Children's Hospital. Initially, medical staff advised his parents that Joey had a serious disease, possibly leukaemia. After a week of testing they concluded that Joey had Diamond Black Fan Syndrome. This is an extremely rare congenital anaemia which occurs when a body system does not produce red blood cells. At present there is no cure for the disease and bone marrow transplants attempted in this population have a high mortality rate. The treatment is supportive and means that the children must be frequently transfused to maintain normal blood counts. Transfusion has in the 80's proven to be a risk for HIV infection and Hepatitis C, a concern which is an added burden to consider.

The parents knew that Joey was advanced for his age when he started to talk before the age of one. His first word was "exit" and he could say it pointing to the hospital exit signs. By the age of two, Joey had a large vocabulary and could easily recite the alphabet both forwards and backwards. He was able to read and played (as often as permitted) computer games. The first week in Kindergarten, the teacher called and asked whether the parents were aware that he could read everything on the blackboard and in the teacher's books. There was no potential for testing in his kindergarten, but the teacher agreed to do what she could to keep Joey from being bored. In Grade 1, Joey was sent for testing and the parents were advised that he was in the gifted range for all areas of testing, and that his oral comprehension levels were above the level that could be measured on the instrument used for his age. The parents, one of whom had experienced being so frustrated with boredom in high school that he quit in Grade 12, requested that Joey's boredom be relieved and that he not be treated as "an oddity".

In his early years of schooling, Joey's Mom stayed home with him instead of pursuing business interests for which she was educated. Joey needed constant attention to monitor his physical condition, to take him for tests and treatments and to assist him in adjusting to the many different schools that he attended due to his father's frequent military postings. Since 1994, by mutual agreement, the father has retired so the mother can take up her career and one of them can "always be there for Joey". They feel strongly about this because they see that even in the best school situations, Joey is "totally ostracized" from his peer group because of his giftedness and his illness.

At the age of six, Joey began asking about his disease and became "down about it", constantly asking the classic "why me?" question. His parents responded then as they do now: "That's your little thing. Why are you so smart in school?" Although Joey has found no answer to his own enigmatic question, he refers to himself as a "one in a million kid", referring to both good luck possibilities and

the actual probability of anyone having his rare disorder. He recently contacted the Ottawa Citizen to talk to Dave Brown (columnist) on the occasion of Joey's 100th transfusion (all of which he tracks by date, numbers, blood counts that day etc. on his own computer). Joey now 12, "figured it was a good time to praise Canada's beleaguered blood supply system" (Brown, 1995).

Joey now lives in a small rural town. He describes himself thus: "I have glasses and a few freckles but not much. I'm the average height of people of the 11 year olds and my hobbies are playing on my computer and going for a nice bike ride". He also notes that he has been involved in a play called "Wretched Stone" that was "really neat."

When discussing his disease he can clinically detail, but put in "layman's description", his disease. He immediately adds that "for my friends I keep my disease as low, only my closest friends know. It's just that, I don't want everyone to know about it. There are lots of kinds of pain in other areas that hurt more than that the nurse can't

find a vein. Like losing someone that is close to you, tiny pets. Once you're forward to the future, but in pain you only think of right now." When asked what pain actually means Joey responds, "patience."

Joey loves sports and with his photographic memory, has absolute recall of all the rule books, page, rule and supplementary conditions. He, however, believes that he can play them and that he is an "up to scratch" athlete. His father describes the fact that he, himself, who was on the Canadian National team, and has elected to help keep Joey's dream come alive, but not too far. "Like next year he has to move up in baseball to another league and the bases are just too far for him to make it". However, in coaching the team he has enough expertise to know how to fit him in (usually in hockey or soccer as goalie) to be able to manage. He has respected his son's wish to "low key" the problems, but smiles at the fact that when the pressure comes and Joey doesn't perform, the team either tells him to "go for a top up or to go get (blood) doped". Although he is obviously aware of his son's special gifts, the father

expresses some puzzlement: "Go to the sports, he's a smart kid, yet he can't do it and he can't see it. That's a real pain because he sees himself playing competitive hockey. I'm as good as the best, my team won, we won 10 games in a row, undefeated all year. Wow! Being a coach, I'm protecting my kid back there, so you develop a game plan accordingly - four or five shots a game, you know, he gets a shutout but it's a pain in that way, and I tell Connie (wife) and I will look at each other and say.... what a pain. Even the teachers and I chuckle because he goes out for the school volleyball team."

Joey loves and feels best when he is visiting his cousins in the Maritimes. None of them, according to the parents are considered gifted, but the fact that Joey considers his cousins "automatically they're friends, automatically", is a natural and wonderful balance according to his parents.

Joey's school experience has been transient but steady in some ways. He has always and immediately been recognized

by teachers as having exceptional abilities, and the parents have had the patience and wisdom and trust to recognize this before meeting with the teachers to plot out Joey's course for the year. In Joey's perception, he is given inordinate amounts of homework to do. Nonetheless, he delves into the job and refuses to turn any of it out until it is perfect in his view. He claims to hate the work, with the exception of using the internet, but he loves to grapple with challenge particularly on individual projects.

Joey is the only identified gifted child in his school, but nonetheless, he is given a day a week of withdrawal enrichment with a teacher who is extremely interested in helping him and who has asked to have him in her homeroom next year. She describes his work as phenomenal, although he invariably refuses to use the steps which they mutually work out as the plan of action for a project. He is a computer whiz and recently produced computer graphics of his school and every room in it with several potential renovation plans which would enhance functionality.

Joey reads a book a day, has memorized complicated rule books of every game that he plays, and is addicted to anything "futuristic" such as Star Trek or transformers. His parents claim that they cannot keep him supplied in books, but that as he reads them all eight or nine times they are worth purchasing. His favourites are a series of 50 "transformers". If asked what was in Issue #34 for example, he will instantly recall a story and correctly identify the page numbers. Joey has already researched the universities in Ontario and narrowed his choice to Waterloo for computers or Wilfred Laurier for business leading to a law degree. He took into account his interests, class size and access to medical facilities and is leaning towards the smaller university.

Joey has by nature an outgoing personality, but would not be described as merry. His parents describe his humour as "subtle and twisted" and he is invariably quiet and polite when undergoing painful procedures. He has great difficulty making friends because his abilities and interests are so different or extreme. His parents note

that he "will do anything" to have a friend and they surmise that that is why he is blinded to his inability in sports. His teachers have made exceptional efforts to help him be accepted, including this year's teacher who went for a blood donation and then told the class that he and Joey had become blood brothers. Whenever Joey comes to hospital, he is armed with the schoolwork that he would have been doing at school and he is diligent in doing it so he won't be different from the others when he gets back.

Periodically, Joey will mull over some worries such as what would happen if he gets blood-acquired diseases. He scours the internet for medical news and is cognizant of everything currently in print or on electronic or research bulletin boards about his disease. He discusses his worries with his parents who listen and reassure him about the testing which he has, and the fact that blood is handled with extraordinary care. If he becomes too focused, they redirect him by telling him that "you can't start worrying about that. Once you start worrying about that you worry about everything". He then refocusses on his futuristic

books.

Joey's parents elected to have no other children, because the disease, although previously unknown in their family, is carried genetically, and because they are dedicated to making Joey's life as rich, happy and normal as possible. They have supported his choice to find a high school with a gifted program and will transport him to it. They are actively involved in any endeavour which will help him make the social links that are important to him, and though they find it hard to watch, they encourage him in activities which he chooses such as bike riding and sports. Joey, in fact, lives life to the fullest.

#### Andrea's Story:

Andrea was born in 1982 to Chinese Canadian parents. She has a sister who is two years older than herself. Andrea, who is now 12 years old, is a bright-eyed, quiet almost serene child who is extremely meticulous in her appearance and who has been described as "both complicated and simple at the same time" (S. Lawson, personal

communication, Aug.26, 1995).

Andrea remembers her early childhood as a time where school was always good, especially since grade three, when she was placed in a gifted program where Andrea perceives "the teachers are a lot smarter and a lot more fun." She likes work which "stretches our minds and is challenging and exciting like puzzles and stuff." Andrea, at age 12, is a pianist and violinist of some repute and is currently completing preparation for Royal Conservatory Grade 8 violin and Grade 10 piano.

Andrea describes the process of her illness in these words: "I knew there was a bump on my arm, like in November of '92. But I didn't pay much attention to it because I had one in my palm first and that just went away, so my mother and I were not very concerned about it. So we went to the paediatrician just in case and she said we'll just go and see the surgeon at CHEO. Then we go and she said, I'm just going to take it out, and I had an ultrasound done. It wasn't liquid like a cyst, so she did a biopsy and it turned

out to be Ewing's Sarcoma. Practically right away I started chemo, for two days every three weeks for a year and that all happened in April of '93. All that stopped at April '94 and there was still a little, like a little bit of mass on my forearm, so we got other opinions to discuss about it and in the end I had surgery in Vancouver at B.C. Children's and they took it out. They worked around it too because Ewing's Sarcoma is a bony cancer, but mine was in the soft tissue. They did a lot of reconstruction around tendons and stuff but I think that my arm is practically back to normal except for my thumb which I can't stretch as far as nine note octaves. In September of '94 I started chemo again until February and everything's been pretty fine since then."

Despite Andrea's absolute control and calm acceptance of her disease, her relationships with her close family and her friends seem paramount in her life. Her oncologist notes that despite her extreme brightness and talent which sent many doctors and specialists in Ottawa, Toronto, Chicago and Vancouver into vigorous debate and dithering over the dilemma of whether they could/should operate on

her, Andrea's "need to be on par with her friends is more important than her knowledge of anything medical. She gives up that part. She doesn't want to know anymore and she concentrates on everything that she wants to do."

When Andrea, who practices her music many hours of the day, and is taught at the University of Ottawa is asked if she sees a musical career ahead, she thinks not "because it's kind of unstable and I'm not that good, maybe something on the side for marriages or theatrics part-time. Now that I've been an oncology patient I was thinking about going into the medical field, but that's what my sister wants to do, and I don't want to do exactly the same thing as her. Two of my cousins are doctors and it feels like too many in the family. Anyway, I wouldn't like life-threatening things or things frightening. If somebody died or something, I would feel kind of responsible for it. I guess if you're a doctor you're not supposed to get attached to anything, but my feelings would still hurt still doing it."

Andrea does not initiate any conversation about her

illness, but is politely articulate and almost detached when she describes how it felt. On describing her first reaction she says "I guess I was scared, a little. Not like terrified or anything, just a bit scared. I did not like throwing up from the chemo but the ondansatron and decadron (drugs to control nausea) looked after that. I wasn't scared I was going to die or anything, I was scared about losing my hair which is growing back although I wish it were straighter." Even when she relapsed and was awaiting the operating room to see if the cancer had spread to her lung or recurred in her arm she maintained total control.

A volunteer who has spent many hours with Andrea, and who is probably as close to Andrea as anyone outside her family, describes it this way. "Her mother was beyond it, starting all over again. On that day she was mad, she was sad she was upset and extremely nervous. When you talked with Andrea that day you would never have known the difference. She was sitting on the bed, just calm, calm, reacting the same way emotionally as any other day that I had ever seen her.

A few months later, I said to her 'Andrea, weren't you scared to think you were starting all over again?' She stared at me a moment and said 'No, no because what can I do about it. There is nothing I could do to change what was happening to me.' The volunteer believes that Andrea either willed or continued to practice her calm to protect her mother, and that if she cried her mother would be more upset. Certainly, it was unusual if not unheard of, for a 12 year old girl capable of comprehending the situation, not to have displayed any emotion.

Andrea talks about wanting to spend time with her friends and about the great amount of time and fun that she has with her sister. She does not, however, spend a lot of time with friends, and made little attempt to make friends in the hospital. In the playroom/craft area she would quietly observe or sit near the others, but she rarely participated or initiated conversation with roommates. She always however, wanted to ensure that she had craft materials or nintendo to work on in her room. The natural

interaction and banter that occurs on a paediatric ward were all around her but she seemed isolated within it. She describes her "hospital friends" and her "school friends" as being different, but she routinely and with amazing diplomacy does not discuss her friends' reactions to her disease or hair loss, despite experienced practitioners trying to get her to "open up". In some ways she seems so involved, as in the decision making about whether to have surgery, and deals with it in a conversant intelligent adult way, while at other times she will say that what she wants the most is just to learn to cook.

Andrea startles and unsettles others around her because she is so obviously talented and yet her choices are frequently unusual. She never chooses to play the piano for others, but if asked will do so, and seems oblivious to the fact that her listeners are stunned. She routinely plays in her church and is happy to do that, only because she gets a chance to play duets with her sister Melanie.

Andrea was presented with the option of "making a

wish." This is something provided by the Wish Foundation for children with life-threatening advanced disease. Most children of her age are excited about this possibility and choose a trip to Disney Land with their family, a stereo system etc. She was shown pictures of Disneyworld and encouraged to consider it and she calmly noted that the whole thing did not appeal to her. She stated that she didn't like travel, didn't want to go away and would rather just live her life the way it was. Going away would mean possibly missing something that was happening now.

At the time of writing, Andrea is well and being followed medically very closely. She continues her music lessons and practice and can hardly wait for school to start. She says she was bored in Grade eight, but expects high school will be a lot more fun than "just the summer". She says she is considering talking to two friends from her class last year about doing a project on optical illusions. She claims that her friends from her class and she differ from other kids only in talking more about the teacher. She says that she doesn't think much about having a serious

illness "because I'm just a regular person."

Scott's story:

Scott (pseudonym), sits in front of me peering intently from his piercing blue eyes. His head is almost completely bald except for a few soft wisps of pale down. He is thin and has the expressive long fingers of an artist and/or invalid. Scott gives the appearance of a wise old sage, and is capable of self-transforming a deep, sad pathos into a sharp-witted gleeful barb in a mere instant in time. Scott chose the name Scott Patterson for the purpose of this story ("because it will be read by strangers") as Scott is his middle name and Patterson's Berry Farm his favourite place. Scott says that he is not sick right now.

Scott was born in 1985. His father is a diplomat and his mother a pharmacist. At the time of diagnosis, (age six), Scott had a three and a half year old sister, and a two year old brother with Down's syndrome, who had recently died following heart surgery. Scott learned English in the home, a functional level of Chinese picked up from house-

staff in China (where his father had been posted), and attended a French school where he quickly picked up the language. He was identified as gifted in Grade one, just prior to becoming ill. Scott at that time was a lego fanatic and an avid reader of books, particularly about motorcycles and weapons.

In 1991, Scott was experiencing frequent morning headaches which had previously been diagnosed as migraines. He said that they were different headaches and before going to his new school would frequently vomit and refuse to go to school. His mother took him to the family doctor who examined the child and listened to his "whining and clinical" description of the headaches, and concluded that they were psychogenic in origin and probably related to full days in a new school.

A month later his mother took him to an ophthalmologist who immediately referred him to a neurosurgeon. A large medulloblastoma, a malignant childhood brain tumour was found. Scott had surgery in which 98% of the tumour was

removed. Following surgical recovery, radiation was recommended because there was residual tumour and some small metastatic sites throughout the brain. A 60% chance of cure with this regimen was predicted, and the family was advised that almost certainly there would be, particularly because of the brain tissue to be radiated, long term effects of the treatment which would likely include learning disability, decreased cognitive functioning, short stature, pituitary insufficiency and possibly secondary cancers. Scott received treatment and amazed doctors, nurses, teachers and his parents by his continued aggressive learning. His ability to play sophisticated word games and to use and incite humour became trademarks of his visits.

Scott went into remission and remained symptom-free for three years. He was accelerated in school and given "special work" which he loved. His ability to write and describe was considered exceptional and at times he would try to draw pictures of what he imagined in his head. School, friends and making people laugh seemed to be the priorities for this sensitive, creative boy.

At the time of first relapse, Scott was most upset about missing school, and asked a nurse to come and talk to his teacher and his class about his illness. Many questions were asked and answered, some by Scott himself, who would claim to be saving trees because he could write on his bald head. Despite vigorous chemotherapy, Scott kept pace at school and maintained a brave face for the people he met in the hospital.

Scott devised many games and collected jokes which he invariably told. He developed a sophisticated "dry-man Gotcha!" brand of humour for which even those who knew him were unprepared. At one stage he developed a name game and would delight in making food jokes out of names. One nurse of whom he was particularly fond was named Pat McCarthy. He determined to find an Irish food joke on her name, and came up with "Pat...Pat...Patata Chip!"

Following a brief second remission, the cancer returned and prognosis became much worse. A very experimental

therapy was started and as well the parents used alternative immune stimulating therapies. At this point, multiple options of stimulating hope and health seemed appropriate to them. While Scott was aware of his medical deterioration, and as neurological impairments became noticeable, he maintained his determination to be hopeful and to deny that he was ill with hospital staff. On the trips to and fro, he would say to his mother that he "really wanted to live, he didn't want to die because there was so much to live for."

At the time of interview Scott was having some difficulty grasping words, but his ideas were remarkably clear. He understood his cancer to have been "one cell which changed into a million cells". On a rational level he understood the potential threat of the disease. He said, "I understand that if they keep on growing they can like, destroy your brain and probably kill you - well, not stick 'em up kill, but they can make you really sick and so sick that you can die, though I understand a President had it and didn't die."

He describes being able to "look" inside his skull and brain and find weapons to use. He said "Well, I just look in my eyes and it kind of looks like a big large hole. Like, my head is like a big large hole and there are some red lights in there and there are some yellow lights right in it. The red light is my brain but there are a few little tiny yellow dots and I think that's the cancer - well, it looks like it anyway.

I play Super Mario golf. He (icon) uses a stick to, like hit the cancer cells that bounce off my skull and it dies. There is a star that touches and eliminates it and also a fireball. The fireball becomes a mushroom getting big and stomping on it, and then there is an axe that twirls and it kills it and it comes back to him like a something sonic which even though it runs out of the line of fire can make it disappear. There is someone who has a poker stick and hits it with an cane and of course there is a pac man (and his wife). They are in there to eat them all up."

Scott knew that he had special abilities which he

described as "more humour, more mentally mobile and more knowledge about medicine". When discussing his future, he is vividly able to describe what rationally he suspects won't happen. He saw himself in three years at the age of 12: "I'll have more hair - maybe a beard. I'll have a leather jacket, a motorcycle and five girlfriends, that's all. I'll have five girlfriends, so every few weeks they'd all have a chance to go out unless I get a combination Chinese thing/motorcycle where they would all fit."

When Scott was asked what he would tell someone who had just found out that he/she had cancer, he became intensely thoughtful. Then, sounding quietly authoritative he stated: "I would say that if it's in your brain, just try to keep on going as normal life. It will be okay. Once you have it, it's tough, but once you get over that big lump, big hill, it's good, it's okay. It's pretty hard to handle, but once you get over that hill, it's easier because you're just sliding down. It's much like the roads of life. There is a hill somewhere in there and when you get cancer you have to climb it and then you just slide down. You don't really

care if you have grass stains. Grass stains mean you are back to real life. You are more playful and you can run."

At the end of the interview Scott said, "Like I don't want hard feelings telling you this, but I don't want you to thank me for helping you. Like, don't say thanks. I just enjoyed talking."

Just a few weeks after this interview, Scott passed away. The day before he died he came to see me and asked how my work was coming. He said that the people who knew him could know his real name and if it would help we could tell his story to doctors and nurses. I asked him how he felt. He said with his usual sophisticated and barbed humour that he had a headache and a fever. "But you know, the fever is no sweat. Like your name Diane doesn't mean what the first part sounds." He then proceeded to tell one of his favourite "Pearly Gates" jokes.

#### Karen's Story:

Karen is a sturdy, clear eyed nineteen year old, who

looks robust and healthy and who seemed to have a quick ability to connect with the interviewer. She talked freely and thoughtfully, thinking and expressing her feelings as she talked. Karen experienced her first major asthma attack at seven years of age, and attacks since, although not frequent, have been severe and have included collapsed lungs.

Asthma is an inflammatory disease in which the airways react to triggers or allergens and become filled with mucous. It is a disease which has been known for centuries and which has an alarming increasing prevalence associated with increasing mortality rates (Phalen, Olinskay, Robertson, 1994). In 1684 an English doctor described it like this: "An asthma is a most terrible disease for there is scarce anything more sharp and terrible than the fits thereof" (ibid, p. 113; Willis, 1684, p. 78). In a recent newspaper article, Kanata's mayor, who suffers from the disease, describes it as "the scariest feeling in the whole world. You feel like you're going to suffocate. You can't get any breath" (Buchanan, 1995).

Karen's extended family is in the Maritimes, but she was born in Ottawa where she lives with her father who works with the RCMP and her mother who is a nurse. She also has two sisters, one older, one younger. Karen is entering her second year of University and is studying journalism.

Karen remembers her first few years school as a time in which she "was bored out of her skull". She describes having been able to read little novels at age five and then having to read "the cat, the rat and the mat". She says that despite her mother asking the teacher to give her more appropriate reading for her abilities, "she wasn't as concerned with the children as she should have been". Essentially, Karen considers her first few years of school as "a waste of time". She was tested and recommended for both acceleration and enrichment. She remembers discussing "skipping" grade three with her family and not wanting to leave her friends, a decision which was supported by her parents.

Karen did go to enrichment classes which she felt were better than the "in-class segregation for red, blue and white groups". She says that everybody knew which group was "the smart group", though no one said so. "We didn't mind because we were in the smart group, but everyone else would feel bad because they weren't. Some kids resented it and every now and then you would get comments like, "she thinks she's so smart" and then you think, "I don't act like that do I?" I don't try to act like I'm better or smarter than others, it's just having an easier time catching things than other people."

In the end however, Karen also became disillusioned with enrichment because it was like, "skip out and do puzzles, word games and pointless stuff, not useful skills that we would use later on like essay writing and computers." She decided not to go into the available "gifted" program in high school, but when she became bored was able to obtain the work units, study independently and fast track, so that she finished in December instead of June. In an independent study, Karen at the age of 16 took

on the subject of death and dying because a child, who was very close to their family, had died suddenly.

Karen describes her feelings by saying "when you're 16 you don't have a lot of experience with death. I was six when my Grandma died and I can hardly remember that. When you're little, your parents shelter you from that kind of thing. I found myself not knowing what to do to help in a situation that is the worst thing that can happen to anyone. You still want to do what you can. I talked to my Mom a lot, and went to Ottawa University and researched it in psychology books, and I learned things like, it's not going to make her Mom sad to talk about Jenny, she is already sad. I wrote a children's book on dealing with death to help them when someone dies in the family, and I gave it to someone at the Children's hospital who is going to have it published."

In regards to her own illness, Karen did not, as one might have expected, research it. In considering why, she says "I don't know what it was, it's like a form of self denial, but I never thought about this as I just wanted to

pretend it wasn't there." She remembers that she wasn't happy to have asthma because "you don't like to be different, especially when you are young. You know when you are seven or eight, you get singled out because you're sick and you can't go out for recess because every time I went out I would seize right up, and at that age you care about what people think. You care about how your peers think, how you fit in, every one wants to do the same thing, dress the same way, listen to the same music. If you're singled out for whatever reason it makes you different and it makes people notice you and what you want is just to fit in. I don't think you always realize how sick you are."

Karen describes her first hospitalization at age seven as being frightening and notes that it's scary "because you're young and you don't understand what's happening. For some reason I thought that the IV (intravenous) was going to kill me. I was afraid that my blood would leak out of it. When you are older it's not so traumatic because you understand everything that is happening, what drugs they are giving, and mostly you're just bored because you have to be

there".

Karen describes the importance of knowing when to get help and the fact that usually you get good immediate care. She does however describe one time in which she was both frustrated and frightened. "I started crying because I couldn't even talk any more, my breathing was so bad and I thought why, why isn't anybody helping me, like I'm going to die here and they're not going to do anything. I didn't know what to do because I was where I should be and I was supposed to be taken care of and that wasn't happening. I think there have been other close calls and I don't think I realized it as much. My Mom would tell me after that she was scared I was going to die. Mostly you just trust it, that people are taking care of it and that you'll get through it just like you do all the other times.

Karen believes that her experience has caused her to grow up faster and to think about things differently. "You get a good scare and a jolt and I think that I must be more careful with my life and tell my mother I love her. You

become more conscious of things so you grow up differently, faster and more mature than other kids".

Despite her own experience with asthma, Karen seems to downplay it, and states that her sister, who was chronically ill most of the time of their growing up, had a much greater influence on her. Her sister had severe juvenile arthritis which required months of hospitalization over numbers of years. "In grade 10, she spent the whole year at home, we had to take her in a wheelchair and my friends carried her up and down the stairs. We had to learn to do things for her, put her socks on in the morning because she couldn't bend over. When it's yourself, it's not a big deal but when it's someone else, it's harder to watch." Karen researched arthritis extensively and studied the immune system. "I got a model knee from the hospital and talked to my Grade four class all about how swelling in a joint happens."

Karen obviously copes well with her own illness but perceives that she could not have handled arthritis. "Lot's of times I would think, 'God I couldn't deal with that'.

You know I have the greatest respect for her because of all the stuff she went through. I couldn't be in a hospital for three months and I couldn't like, not go to school and not go out with friends. She always had good friends, though when you're home for a whole year people have other lives to live. It's the same at the clinic where I work, seeing people come with breast cancer or serious illnesses and I think I would go crazy, I would go nuts and couldn't handle it."

Karen originally and actively considered a career in medicine and then, having taken all of the science prerequisites, decided that what she loved the most was not chemistry but English and Art. She continues to work in a medical clinic as a receptionist/assistant and feels that her experience with asthma and seeing her sister in pain has helped her to help others in that situation. She says that "people don't realize the potential they have or the courage until they get into situations. I picture myself that way though I don't consider asthma such a life-threatening thing. My sister though, that's different. When I was

little I thought she was like God or something because of all the stuff she had to go through. She had a lot of pain for a lot of years and I know I couldn't go through it and she did. She's like a hero or something" she said, crying.

Karen presents as a young woman who is intellectually, socially and emotionally well adjusted. She is optimistic about the future and thankful for the experiences that she has shared with her family. "Pain," she says "gives you an opportunity to see what you have inside of you. You don't know what kind of a person you are until your values and your strength is actually challenged. Once you have that challenge, then you see that you can get through it , then you know that you are strong and you know that you have what it takes to get on in the world."

## CHAPTER 4

## Data Analysis and Interpretation

Although multiple sub-themes of intriguing interest emerged from the data, the most frequent themes which suggested themselves were the childrens' perceptions of wanting to be normal. The frequency and intensity of psychological suffering and means of coping was evident to a high degree in the case studies, the developmental case study, the focus group and from parent and volunteers. Some central themes, although identifiable on analysis, become inextricably interwoven with others. The child's need for friendship, for example, is inseparable from school. The centrality of the parents' and family ties is, as the research will show, a strong anchor in both studies of gifted and handicapped children. The possible theme that life-threatened children might experience physical pain differently or more intensely was evident only in the historical case study of Mathieu. It was moderately evident as a central theme only for three of the case studies and the parent study and was rarely evident in two of the case

studies, the caregiver focus group and the volunteer interview. Indications of the child's need to maintain hope were evident to a high degree in all but one of the case studies, in which a moderate frequency and intensity was noted. Curiously, school became a central theme to all except the care givers. A conceptually clustered matrix of central themes according to how frequently the themes occurred and/or elicited reaction from the analyst is charted seen in Table 1.

In this analysis the central themes will be looked at independently, and interpreted in the light of the literature review on both gifted and life-threatened illness in children. The researcher then devises inductively a theoretical naturalistic analysis melding together these themes.

### Physical Pain

Physical pain has long been associated and assumed to be present in life-threatening illnesses, particularly in ailments which affect joints (arthritis, blood diseases) and

tumours (which may press on nerve endings or impinge on or cause tissue damage). Despite the most recent decade of interest and study of pain in children the actual study of pain in children is in its infancy (McGrath, 1989). There are less than ten articles concerning sensory and physical disabilities in gifted children since Whitmore's review in 1981 (Johnson & Corn, 1989). McGrath and Hillier (1989) note that the lack of study about children's pain is understandable because ethical concerns limit the use of children in many of the experimental studies. Pain in children is described similarly to pain of adults as an unpleasant sensory and emotional experience. Their perceptions are "subjective, similar to their perceptions of color, sound, smell and taste" (p. 7). Like other perceptions it is impossible to know exactly what a child's pain experience is like, despite objective measurement tools (McGrath and Hillier, 1989). Wall and Melzak (1994) note that situational factors vary extensively among children experiencing the same tissue damage as well as for the same child experiencing the same damage at different times. The study further notes that these factors also refer to the

"effects of prolonged or recurrent pain on children's lives, including their ability to attend school, participate in sports and social activities with peers and assume typical family and household responsibilities" (p. 1406).

When physical pain was described in the case studies it was most often related to technical procedures. Susanna described her first lumbar puncture, Joey the "nurse who couldn't find a vein", and to Andrea it was the vomiting associated with chemotherapy. Likewise Mathieu Froment-Savoie (1991) a child prodigy cellist who was afflicted with a particularly painful cancer, frequently described pain in his book as associated with technical procedures. Scott was afraid of needles and, as well, experienced severe headaches for much of his life. Karen's experience with pain was related to her intravenous, though was described more in terms of fear than hurt.

The psychologist in the focus group stated that he did not think that gifted children experience pain any differently than other children, but that their

"verbalization of pain makes it a little easier for a practitioner to try to nail down what is going on so they can intervene appropriately". He noted that he had seen some gifted children where it is almost like working with an adult in terms of what they can abstract. Imagery and language "are very powerful tools. You very easily can underestimate and you start talking to them and their verbal skills are often acute and they start using the skills and applying it in different ways."

This is what was demonstrated in Scott's transformation of his fascination with weapons to the imaginative use of them to fight the cancer cells. Dr. Manion, the psychologist, notes however that the opposite side is a chance that the child will over-analyse as they can have an "autogenic kind of maturity for their level of sophistication." He describes a gifted six year old who picked up a side comment about responsibility for something that was going on. She felt that she was responsible and never gave it up. She held on to that framework when her care plan deteriorated to the point where he had to involve

the surgeon who had made the comment. No other child would have picked that up, but her sensitivity to verbal content caused her to listen and take everything too seriously" (I. Manion, personal communication, February 27, 1995).

The concept that it is the verbal skills, not the physical pain itself that is different in the gifted, life-threatened, was further supported by the stories of other caregivers. Dr. Hsu, the oncologist, noted that she finds it a lot harder to deal with gifted cancer patients because "they perceive everything you say at an older level. Normally, when you use the word cancer with a five year old, it's just a word, but I've actually seen the other side. Gifted children can get very sad because they understand and they can become withdrawn compared with somebody else to whom you say great day today, no needles" (E. Hsu, personal communication, February 27, 1995).

There is some indication in the literature that low fantasy patients have "less vivid emotional expression" (Copeland, Pfefferbaum & Stovaly, 1983, p. 90). Though the

studies were inconclusive, they surmised that creative imagery may have a role in treatment though its "serious study and clinical use requires the courage of a soldier, the patience of a scientist and an artist's appreciation of ambiguity, as well as the limits of his art" (p. 96).

Although Terman discredited the myth that giftedness was accompanied by illness, social failure or compensatory deficiency (Hauck & Freehill, 1972), there are a combination of factors. In dealing with their pain, the children may be both advantaged and disadvantaged by their situation.

On the one hand, it is known that some children communicate their distress through words. One might then surmise that those with verbal fluency may more overtly exhibit their distress. Many pain researchers have noted that the more overtly distressed a child is, the greater his or her pain (Katz, 1980; Jay, 1983; Schechter 1985; McGrath & deVeber 1986; Kuttner 1988). In the observations of the researcher, the child in the historical case study was extremely verbally distressed when in pain, and did choose

to control it in extremely unconventional ways (Leroux & Stephenson, 1988). The children in the reported case studies of this research, whose physical pain was coded at the lowest level were Andrea, who remained calmly quiet through most procedures, and Joey, who was accepting of the physical pain, often describing other kinds of pain as more real.

On the other hand, the gifted may be advantaged by their ability to verbalize and access creative imagery to deal with physical pain. Scott, who was highly visual, could verbalize and use his own imagery of weapons at a sophisticated level. While pharmacological analgesia clearly has a role, recent research touts the benefits of allowing children more choice, increased participation and better understanding of invasive procedures. This has been shown to "dramatically reduce children's overt distress, anxiety and pain" (Wall & Melzack, 1994, p. 1416).

The idea that utilizing to best advantage the children's abilities with words was supported by other

members of the care giver focus group. It was a teacher who recognized that when Mathieu was unable to express himself through music, he could write about his experiences in book form. Mathieu then wrote clearly about his experiences throughout his disease. (Froment-Savoie, 1988). Karen chose to write about the pain of bereavement. The child life worker described her experience working with one gifted child like this: "I think they are able to verbalize better, how pain feels to them, and they cope better if you give them the tools. With one child we were playing a tape and then we were hearing about this purple, peanut butter-eating monster that was going down a road. She was having a lot of pain, and we would play this tape and would imagine this purple, peanut butter-eating monster going down this lane and what he would see to the left and what he would see to the right until she got carried away in this tape. It worked for a while and then we had to use another tape, with another song and imagine that gooey stuff with it. To me she was able to verbalize her pain so much more in depth than other very young children so what I could offer her was very different" (M. Glavin, personal communication, February

27, 1995).

There is no conclusive evidence in the case studies of this research or in the described experience of health therapists who work with gifted life-threatened children to suggest that physical pain itself is experienced differently. There is some evidence to suggest that the depth of understanding which the child has may cause increased sadness or anxiety. It may be the case that the caregiver working with the child may therapeutically use the verbal precocity of these children in developing positive intervention tools to distract the child from the pain or to help him/her to articulate it.

### Psychological Pain

The psychological pain of being both gifted and life threatened was evident in all of the case studies, and most often related to "being different" or "needing friendships". Susanna's abandonment by her friends is still exquisitely painful and close to the surface of her memory. Joey "will do anything for friendship" according to his father. When

asked what he would like teachers and health care workers to know about gifted children with serious illness he responded "tell them we're just the same as everybody else". For Scott, being well enough to have his one close friend come and play at his house was so important "because even though he's not into all weapons he loves guns and we can play." Scott's illness was so advanced that large periods of time were needed for treatment. The policy of the particular school board was that he could no longer be in the classroom, but needed the individual tutoring that he was getting. A letter on file from the Clinical Nurse Specialist to the school noted that for Scott, his life was not the tutoring, but the need to be with his friends at school. This was arranged, and both Scott and the Clinical Nurse Specialist once again went jointly to the school to teach the children and teachers about his disease and his needs. To Andrea, friends are "more important than knowledge". Karen constantly put her social needs ahead of her needs for educational enrichment and vicariously experienced her sister's pain at having limited friendships. Mathieu described that although cancer has given him a life

which was not normal, he could play with his friends as he always wished he could (Froment-Savoie, 1988).

Stories of published child poets living with life-threatening illness (Berger & Lithwick, 1992) resonate with the experiences in these studies. Adam Jed, a precocious eight year old, suffered a massive meningococcal infection at the age of five. In order to save him, his legs and fingers had to be amputated and he continues with grafting and prosthetics. Sensitively, he says: "When I got sick, we all learned who our real friends really are. Our real friends stood there with us and our not-so-good friends would just say hi once in a while (p. 25). For me, life goes on. Let me just go along with my friends and do what I would do before" (p. 19). Tina, a cancer patient and prolific poetry writer, says that "it's really important for me to go out and party a lot. I like spending a lot of time with my friends because I miss them and am afraid that everything is going to happen when I'm not there" (p. 52).

These anecdotes are similar to the doctor's observation

in this study that Andrea's great need is "not to miss out on anything with her friends." The volunteer who befriended Andrea said "she acts so mature, you forget she is a child. Sometimes I saw her wanting to be a child, but you forget that she is." Other researchers and observers of gifted children and life-threatened children have observed the need for normal friendships and need for play to supercede either their gifts or their illnesses. Kaufman, (1995), in her book for teens living with chronic disabilities, states that "it is clear to me that most of them do not see themselves as particularly disabled and sick. They had decided to get on with their lives" (p. viii). She quotes one teen as saying "you would think teasing is mostly for little kids but I find I still get tormented about how I look, especially if I am not with friends. It scares me to be the object of hostility" (p. 31). Susanna would no doubt share her sentiments.

Dickenson (1970) notes that gifted teens may have problems compounded by their insight, sensitivity and unevenness (p. 68). She ascertains, however, that the

gifted child is no different from any other in his/her need to get along with others (p. 21). In the Fullerton longitudinal study, it was concluded that gifted young people, other than those above IQ of 160, were not social isolates, were socially capable and engaged in friendships and social interaction with others (Gottfried, Gottfried, Bathurst & Guerin, 1994). In Feldman's comprehensive case studies of child prodigies, he noted that friendships were important to all of the children studied, but when the friendships became "a major preoccupation, the pursuit of mastery became correspondingly less central" (Feldman, 1986, p. 160).

If Feldman's observations are correct, the painful, psychological dilemma created has been illustrated in autobiographical and biographical information of gifted performers and scholars. Mozart is classically portrayed as an exploited child prodigy who squanders his gifts and becomes friendless and socially diseased (Fisher, 1973). Joey, in this research, was pleased to learn that Yeheudi Menuhin was determined to cycle with his friends and

"secretly learned to ride a bicycle against the wishes of his parents" (p. 95). The intellectually brilliant musical prodigy, Ruth Slenczynska was "not permitted to spend a moment of her life playing with dolls, tricycles, skipping ropes or other children" (Fisher, 1973). So great was her pain, that she walked away from her publicly acclaimed musical career and her family at age fifteen. In her poignant analysis of her situation in her autobiography Forbidden Childhood (1979), she illustrates the need for the child to be a child first and a gifted performer only if childhood itself is not sacrificed. This is a risk for intellectual geniuses like Ghanaian prodigy Kwabana Asante, who at eight years of age, in post-secondary college, is "being weaned of his carefree playfulness which threatens to distract him from academic work" (Maayang, 1990).

The children and caregivers in this research rate the need for friendship and normalcy uniformly high. The potential and actuality of psychological pain, if emphasis is placed on giftedness rather than the child him/herself, becomes evident in their stories and the historical

experience of others. One can postulate that the added dimension of life-threatening illness accentuates this and tips the balance away from achievement in the academic or performance realm. The uniformity of similar perceptions directs attention to the child as a whole being.

It is clear to the researcher that there is a delicate and fine line which separates the nurturing of gifts and the interference of adults in a child's potential to live life as a happy child. Similarly, we must balance the need for the ill child to be treated with the respect that allows optimal choice without burdening him/her with the "agony and responsibility" of independent adult decision making. There is a role for play, but as the Los Angeles little leaguers who played a charity game for the dying brother of one of the players found out, even play and moral generosity can be destroyed by inappropriate sanction of what's important to children. Team members were banned from competing in the finals because they had participated in a non-official game during the playoffs. The sensitive interaction of children's need to be generous was, in this case, eclipsed

by the judgement that particular rules apply. It was fortunate for Scott that the educational system was able to break the red tape and permit him access within the school classroom.

A second area concerning the perception of children and caregivers to psychological pain related to life-threatening illness is the fear of dying. Scott, on a cognitive level, knew that his death was impending but maintained that he was well, while connecting with others by use of gallows humour. Joey, worried about blood borne disease, educates himself about the current status of blood products and advances in genetic engineering. Susanna maintains confidence about living. Karen describes the fear of dying during an acute episode, but comes back to the reassurance that the patient herself must recognize "that you can go downhill in two minutes, from not too bad to almost beyond help" and then to "trust those professionals who are there to help you."

The suffering in which a gifted child deals with the

spectre of impending death is both painful to observe and inspect. Often it gives the sensation of probing a boil. Sometimes there is festering, sometimes release and sometimes a continuum of opening and closing, heating up and soothing, wounding and healing. Scott's pain in facing death was known to all but he chose to deal with it on a personal level with his mother, and obliquely via humour with others. Says the nurse case manager who worked closely with him: "I was worried about him when he became palliative because he was so smart and sensitive on the pick-up. How would we tell him there was nothing more to do? I don't know how he would deal with it but I felt it would be extremely difficult for him." The oncologist noted that she deals differently with gifted children, giving them more choices and treating them more like adults. "Some of them end up agonizing over decisions that parents usually make." The fear of dying may be magnified by the respect for the child's ability to reason. This contrasts sharply to the child for whom the parents assume decision-making responsibility.

It was noted by caregivers in the focus group that many of the children want to protect their parents, a phenomenon also described by Kaufman (1995). One child life worker in the focus group described a situation which she encountered with a gifted five year old, who knew she was dying, but did not discuss the topic of death. "This girl was so angry, angry, angry at everybody in the clinic and angry at her parents. Before she was good natured, but when she realized she was dying, she just turned on everybody and would call you all these names when you came into her room. Shortly before she died, I asked her father if he wanted to go down for coffee and we were left alone and she started yelling away at me. I just sat on the bed and said "you know (name), I love you no matter what, I will always love you", and she just burst into tears and held me and cried and cried and cried. We both cried and her father came into the room, she pushed me away from her and started yelling at me again. As if that was nothing. She was so concerned I think about hurting them." Likewise, Andrea remained uncommunicably calm, but intellectually astute, in facing relapse. Karen vividly described her anxiety in trying to

get others to shed their worry about her and Scott diverted the obvious to laughter.

In the perspective of an oncology social worker, few dying children talk openly of their dying, but many develop a need to "do things". One teen refused to open up verbally but obtained a week-end pass, went home, cleaned his room and spent the time with his brothers, saying "Remember the time that I was five and you smashed my face into the wall? I did not appreciate that very much", and then he told his brothers what was on his mind.

Some gifted children carry their need to "tell" further. Many in the focus group recalled another young boy who was dying from leukaemia. His "make a wish" was to see the Prime Minister. The Prime Minister came to the hospital and the child said that he wanted to see him because he wanted him to do something that he would not be able to. "Make World Peace happen". Similarly, Mathieu, in our pilot case study, carried his need for both "public persona and legacy." In the observation of his social worker, "This

person who would have left an incredible musical legacy, left a written legacy for other kids, particularly with the same disease." Historical figures who have been both handicapped and gifted have often succeeded in recognizing and giving legacies to the world. These include Hellen Keller, Thomas Edison and Phillippa Schuyler. More recently, they include gifted artist and author David Salzman, who died at 22 after sharing "urgent, explosive talent" (Sendak, 1995, p. 31).

Dabrowski described five levels of independent development which culminated in "the point of realization of one's true self....life inspired by a powerful ideal, e.g. equal rights, world peace, universal love" (Piechowski, 1992, p. 181-182). Miller and Silverman, (1987), contend that there is potential for "higher level development in gifted children and adults" (p. 221). The Fullerton studies conclude that "gifted IQ is associated with superior social reasoning" (Gottfried et al, 1994, p. 133). Schweitzer, Martin Luther King and Hammarskjold are among those of the gifted population who have achieved world recognition for

their efforts to extend their care to humanity itself. A musical prodigy, Phillipa Schuyler died committed to a cause, bringing a child out of Vietnam. In her book Adventure in Black and White, she describes that the people to be most admired are those who "do their best to shape a new world" (Schuyler, 1960, p. 161).

Perhaps that same drive is evident and even accentuated in the gifted life-threatened individual. Though the case studies in this research are individual cameos, and despite the expressed need of the children to be treated as "regular kids", there also is an expressed need to reach out to a wider world. Karen was driven to teach others about her sister's disease and to help others understand about ways to cope when a child dies, hence the writing of her book. Scott wanted his story told "to help doctors and nurses." Joey went to the press to share his positive experiences in receiving blood and deflecting public anger from the provider of his lifeline. Susanna overcomes horrendous disabilities to fulfil her dream of contributing in the field of scientific research. The

implication for teachers and caregivers in understanding this, is the recognition that among them there may be giftedness to be shared with the world. This is what was recognized by William's doctor and from which our view of autism has been expanded (Williams, 1990). This is what ailing scientist Steven Hawking's professors recognized could open new horizons in theoretical physics.

The children in this study have experienced psychological suffering and also have had the opportunity to experience life differently, but in a rich and fruitful way. Through their multi-talents, they share their experiences and, in so doing, enrich the lives of those who follow.

### Family Ties

The importance of family support is well documented in the literature in the fields of both gifted children and paediatric health care. Feldman (1986) notes that "it would be difficult to overestimate the amount of time, energy, commitment, and emotional support required from one or more members of the child's family" (p. 95). This is mirrored in

the family whose child is physically life-threatening. Kaufman (1995), repeatedly notes the impact of family on children with severe chronic disabilities. Family is "the powerful agent in focusing the work of creative people" (Goertzel & Goertzel, 1962, p. 5). Hauck and Freehill (1972) in their case study research, note "experimental and survey data which show again and again that gifted and creative persons have unusually intense relationships (not necessarily wholesome or pleasant ones) with parents or teachers" (p. 8). Fisher (1986) claims that it takes gifted parents to raise gifted children, particularly if they are multi-talented. Goffried et al (1994) conclude that gifted children grow up in families which "have a greater degree of cohesion and less conflict... and greater promotion of cognitive growth" (p. 18).

The children in this research reaffirm the importance of family. In the case studies, family was a recurrent theme. Scott shared his fears about dying, directly spoken only to his mother. Joey's parents nurtured him early by helping him to read, teaching him the computer and generally

following and accomodating his interests, even in sports. They are constantly attentive to his physical, cognitive and emotional well-being and make personal sacrifices to ensure that he is stimulated, allowed to follow his interest, and to "fit in."

Karen's text is full of references to her family, which she speaks of with great admiration and respect. She acknowledges the stimulation she had in her early years and the constant support during both school and illness. She says that her Mom "always gave me books and taught me to read when I was little," and that "my Mom was really good. She kept me from panicking when I had trouble breathing". She describes, at age seven, discussing accelerating at school and respect for her parents' support in deciding "not to take her out of her group of friends," but agreeing to enrichment withdrawal. She is in awe of her sister's courage, but describes typical childhood pranks like "playing wheelies with her wheelchair in the driveway," and teasing "squeamish Dad" when it was his turn to come to hospital.

Susanna is convinced that she would not have survived without her family, and years after transplant, her Mom still reads the diary. In fact, all family members including her sister asked to be included in the research and to share their perceptions of Susanna's experience. Likewise, Andrea's transcript is full of references about talking or playing with her sister, and her interactions with her parents. Her volunteer friend describes the family: "The family dynamics are very, very, very close. Her sister is close to her and caring. She's close to her father and all of them. They were going through this together. There wasn't one that was walking down that path (her cancer) alone. They were all doing it together" (S. Lawton, personal communication, August 20, 1995). Selection of music teachers and medical specialists is an intense family effort which takes the family far afield to provide the best for Andrea.

Mathieu described in his book his close and valued relations with both his immediate and extended relations.

Throughout his illness his family constantly supported his idiosyncratic ways, and following his death, his mother wrote and performed with members of the National Arts Centre a musical requiem mass. As well, his parents have been active in the establishment of a francophone hospice named for their deceased child (P. Froment-Savoie, personal communication, July 17, 1994).

Other case studies and stories confirm the importance of family in providing an environment either conducive or destructive of the children's gifts. Feldman's studies confirmed the devotion of families to the child, noting that, "the literature is rife with examples of prodigies who were so dependent on their families and teachers that they were utterly helpless or incompetent without" (p. 214). Hauck and Freehill (1972) provide contrasting examples in which they analyse family importance. For example, they describe the success story of the outstanding nuclear physicist Bob Charpie who attributes his success to "a family in which there was genuine intellectual curiosity and interest in anything and everything which might stir the

imagination of a child" (p. 13). In contrast, they detail the case of "Dick", who at the age of five, "had already known too many homes, allegiances and hopes" (p. 105). Despite provision of gifted programming, he had a progressively delinquent course, ending in a maximum security adult prison.

The children who have confronted life-threatening illnesses, and whose stories are told in "I Will Sing Life" (Berger & Lithwick, 1992), also confirm the critical importance of family in their experience. Pia, age 14, who suffers severe Sickle Cell disease with significant complications, such that she will probably never grow up, is raised in profound poverty. She has been described as having the gifts of making people laugh and of "slowing each moment down so she can look around inside it. If she rushes, she might miss that perfect detail for one of her stories." Here is how Pia describes her mother: "Ma holds my hand, and when she knows I'm hurting she squeezes harder. Sometimes to take my mind off the pain, we'd play this game where she would have to follow how many times I squeezed,

and then she would return it. She always knew when I needed to feel the warmth of her, and she would just touch me, and that's all I needed. I'd be able to smell her. It's Ma, and nobody else has that smell. She cried when I cried, but when she noticed I was watching, she would give me this bright smile with a tear running down her face. To distract me, she would tell me I'm making a beautiful park and it could have the craziest things in it. I'd put elephants walking around with lions' heads and it was always beautiful" (p. 76). Like Pia, all of the children case-studied for this research affirm the value and importance of their family in supporting them with the love that they need to face their daily life challenges.

### School

The centrality of school as a theme in the case studies was highly evident in the children's transcripts and those of their parents, but rated low in the content of the caregiver focus group. In the view of children and parents, going to school seemed an important marker of "normalcy". The caregivers, aware that tutorials exist and are important

for children in some phases of illness, may not perceive the need as strongly, given the focus of "getting the child well again." In case studies of gifted girls, Hauck and Freeman (1972) note "the futility of separating the academic from the social development and their interactions with each other" (p. 74). This is supported by Gallagher (1991), Goldsmith (1987) and Leroux (1992).

Susanna wanted to go to school and has made exceptional efforts to excel, even though socializing has been difficult. Her parents spent a lot of time at the school, informing teachers about her disease, and working with the school to minimize the pain that Susanna was experiencing, and to accommodate her needs. Despite working with the teacher and groups of children, the teacher recognized an impasse between Susanna and her friends, and alternate arrangements for her to attend the gifted program in a different class alleviated some of the discomfort which was robbing her of both her academic and social advancement.

The volunteer notes the complexity of Andrea's

personality, describing her "at once simple and complex." This we see in Andrea's reactions about school. She "can't wait to get there in the summer, but then it is boring." She enjoys music and studies intensely, immersed in it at the University and in her daily piano and violin practice, but says she would "prefer to learn to cook" (S. Lawton, personal communication, 1995). Andrea describes her few hospital conversation with other children as "away from sick stuff and about school things." Andrea sees a future in which advanced education will definitely play a role and it would not be to her advantage to get behind in school. Andrea, though now the age at which Susanna experienced the greatest school/social distress, does not indicate that there is any social disharmony for her at all. The volunteer observed the following: "Her big thing was never missing school. Sometimes she would come at lunchtime the day before to get her blood work done, so that when she came (for chemo), everything would work like clock-work, so she wouldn't have to stay longer....I would be hard pressed to say that Andrea actually developed a friendship. She could have because there were times when there were a lot of other

children around her age." Andrea's fear was of losing her hair, and one time the volunteer asked her what her friends' reaction was. "Andrea was very quiet and serene and she never answered. I don't know whether it hurt too much to tell me. She was always very, very careful, and I never saw her look unhappy. Never, never, never."

Andrea sees herself as happy in her friendships and her zealous intrinsic commitment to her various studies. To others, she appears to value her friendships most deeply and to have such utter self-control that no one will ever know for sure.

Karen appeared to have an analytical and mildly cynical view of her own school experiences, some of which were related to what she believed to be bad teaching or inappropriate subject matter for learning. She was self-directed in seeking alternative approaches, and yet saw school as an important part of her life which she could not miss.

Joey was totally involved in his school from the physical functionality of it to all aspects of learning, and extracurricular activities. He researched and scouted out the high school and universities that will best suit his needs. Clearly, school is central to his sense of well-being, and he has been fortunate in being situated in numerous schools which have provided a richness in both sensitivity to his needs and educational optimization. Again it is evident that his parents have been heavily involved in striking a balance in feeding his intellectual hunger, as well as his desire to be physically and developmentally "normal". The teacher, who saw him as friendless and pronounced him as a "blood brother", creatively succeeded in making a bond of friendship that could be a role model for other educators.

For Scott, being at school became a primary goal, even when it would have been obvious that he could not function in a gifted or advanced program. His need to be with friends was critical. His need to contribute to their understanding was apparent in his efforts to teach them

about his limitations. At his funeral, it was his school friends who spoke eloquently about what this "boy who knew so much, and laughed so much and always gave us humour" was all about.

In Mathieu's case, he was so highly individualistic that he rarely, if ever, related to children or acted as a child, although he was articulate about what children needed. In his book, he himself becomes teacher and educates the medical world about better ways of dealing with children. For example, he heard the doctors discussing his "tumour", and instructed that this was exceedingly terrifying for a francophone child who would interpret "tu mour" (you die). He credits the teacher, who, on a one-to-one basis, provided the tools for him to tell his story, and who helped him move from an idea and ideal to a published reality. For Mathieu, who had little tolerance for others less intellectually able, and little time in which to make his mark in the world, clearly the tutorial option was beneficial. For him, "schooling" was the important tutor in the hospital setting.

This study points to strongly attached families and children who see education as important goals and a hopeful indicator of health. Going to school was evidently a symbol of normalcy and an opportunity for regular friendships which ranked paramount in the children's perceptions of themselves. In a sibling interview subsequent to the first writing of this paper, Erika, Susanna's sister, validates this concept. "I was two years older than her, and I couldn't stand the idea that she couldn't go to school. School meant her friends, and time going on the right way, not the sick way. Sometimes, I would almost drag her, even if she would barf on the side of the sidewalk and other kids would say yech, we still had to go" (E. Lee, personal communication, October 10, 1995).

### Hope

"Hope" has been described by a qualitative researcher as one of those words which once "reverberated with lived meaning, and reveal a living world now have become lame,

limp, mute, emptied, and forgetful of their past power" (van Manen, 1990, p. 58). This is the challenge of the qualitative researcher. To exempt hope as a theme is to ignore both the childrens' lived experience and their unique situation. It is to ignore the reality that poets have been able to frame into words or song. One strong example, is taken from Emily Dickenson:

"Hope" is a thing with feathers-  
That perches on the soul-  
And sings the tune without the words-  
And never stops - at all.

(1861, p. 62)

All of the children in the study both lived for the moment and saw themselves in the future. All propelled their imaginations to think towards an integrated future with friends and in school. Two of the children frequently used the imagery of hill climbing as analogy, and none ever directly spoke of the possibility that they would not survive to experience a full future. Hope is not only exhibited by these children, it is expressed in a way which reminds one of a poet who describes in his poem "On Mere

Being" as

"the palm at the end of the mind  
beyond the last thought rises  
in the bronze distance,"

(Stevens, 1954, p. 169)

In her extensive studies and interviews with dying persons, Kubler-Ross describes hope as the staple which must be both maintained and nourished. She notes that "if a patient stops expressing hope, it is usually a sign of imminent death" (Kubler-Ross, 1972, p.140).

This was evidenced in Scott's last day, although his dying seemed precipitous to the care-givers. Scott had a brain tumour which was resistant to multi-modal therapies. He maintained an unusually high degree of cognitive functioning, and was joking in a macabre way about impending death to the researcher, who only appreciated it, as did so many others, in retrospect. Scott was trying to tell his caregivers that he no longer held hope for his life on earth. Within hours after his regular treatment, he suddenly deteriorated, became unconscious, and died.

Mayeroff (1971) identified essential elements of caring which included both hope and courage. These connected themes arise in the children's stories and in their lives. Mathieu, knowing that his treatments had not been successful, states: "I must redouble my courage and determination to scale the last snowy peak. The last ascent will not be easy. I will start like an alpinist and find my friends who will encourage me. I will carry a four leaf clover which my friend found in the Gatineau park where I spent my best moments with my friends and family" (translated, Froment-Savoie, 1991). Equally eloquent was Scott's description about sliding down the hill and "getting grass stains." Karen's open admiration of her sister's courage in facing chronic illness and Susanna's constant confidence in her own survival, Andrea's resolve to live in her present space (refusing "the wish" which denotes to her another reality), and Joey's love for anything futuristic, all speak to the reality of hope in these children's lives.

In the limited published studies of gifted life-

threatened children, others affirm the necessity of hope. In Tina's story, she says "you can never give up. I'd go to a faith healer if I had to. As long as you have something to look forward to at the end, there is a reason to keep going. Like, when I first got sick it was, we're gonna have a big party. We're going to go out to dinner in a limo. Just something to look forward to and to keep going for."

Poetically, Tina adds:

Limbs

The trees begin to dance  
with every gust of wind  
you hear them sing.  
They cheer you on how glad they are  
to be here.  
The cracking and snapping are  
not cries but excitement bursting  
within themselves.

(Berger & Lithwick, 1992).

The elusive quality of hope with its almost indistinguishable element of courage is evident in the world around us, the diary of Anne Frank (1952), the letters of Deitrich Bonhoeffer (1939) and the letters of Hellen Keller (1897-1902). Cinematography abounds with examples, from

Scarlett O'Hara's "tomorrow is another day", to movies such as My Left Foot (1993), Rudy (1994), and Schindler's List (1994). Its simplicity in the present is evident in the portrayal of Forrest Gump (1994).

It was the observation in this study by some of the care givers that faith was a component of hope which is characteristically beneficial to the ill child. Says the oncologist, "No matter how bright, faith may be a important variable. Definitely I have seen that some people have faith of any kind and they seem to handle it a lot better." The social worker, likewise, notes that faith taken in a very general sense, not necessarily religion, but faith in some ultimate purpose, eases the child's journey. She notes that "Children often express it in terms of heaven or saying they are going to be an angel. There are very few children who have not seen some sense of beyondness. Part of their hope is in being able to leave a legacy to other kids, particularly with the same disease."

Many caregivers in the focus group recalled a child who

had several primary cancers and multiple relapses. By the age of nine, one child "had lost his Mom to cancer when he was a baby, his brother to cancer during the course of his early childhood and had cancer himself as a baby and had lost his leg." The social worker describes a conversation in which she asked him "Why do you want to keep going" to which he replied "Kathy, there is so much I want to do there is no way I'm giving up hope". At his funeral, his priest read a poem that the eleven year old had written about his own vision of being free to fly with the doves of peace (K. Irwin, personal communication, February 27, 1995).

It is possible that children themselves have the innate potential to maintain hope until they choose to connect it to beyondness. One small, particularly verbally able, preschooler was described by the worker in this way: "Her mother was actually quite open, and asked her if she wanted to go to see baby Jesus, and she said 'no she didn't, thank you very much because you can't come with me'." This gifted child loved books and repeatedly refused to hear a story about a dolphin that starts spreading wings and whose mother

finally understands that his time has come to fly away. Finally, she announced to her Mom that she was ready to finish the book. Less than twenty four hours later, as she was dying, she took her mother to the end of the hall and showed her the blue skies and said, "Now I'm ready to see baby Jesus."

This resonates with Kubler-Ross' contention that hope is time-bound with life itself (1972). In this research, it is confirmed by Susanna's, Andrea's, Joey's and Karen's refusal to consider the possibility of dying and with Scott's hope. It is evident that the life-threatened children who have survived steadfastly maintain their hope. Scott, who had cognitively recognized that his physical condition would only deteriorate, abandoned hope and, mercifully, died peacefully soon after.

The relationship of pain and hope is knotted within the tapestry of each child's experience. In, The Problem of Pain, Lewis (1969), describes the quality in which man is able to foresee his own pain, which henceforth is preceded

with acute mental suffering and to "foresee his own death while keenly desiring permanence" (p. 2). The gifted child, like Andrea, while wanting "to be just a regular kid", will explore this psychologically painful reality in his or her unique way. The experience and expression of hope become necessities of which the parent, care giver and teacher must be aware, empathetic and nourishing.

#### Naturalistic Theory

The themes which have been explored in this paper overlap and interweave. When broken down by frequency of centrality within the transcripts they can be grossly grouped. (Table 1). It is evident that dissection of the child/young person into parts which are either gifted or life-threatened or in pain, eclipses the reality of the child living and situated in his or her own world. This phenomenon viewed by the person whose reality it is to share their experience, is consistent with the idea that "the person is inevitably enmeshed in the surrounding world... and that the phenomenological prescriptive be generous in allowing phenomena to speak fully" (Munhall & Oiler, 1986,

p. 60).

Nonetheless, themes were discernible and interpretable for each of the children described. The importance of family support, school accommodation, pain relief and the maintenance of hope emerged as important tenets in helping the child reach his or her optimal childhood regardless of difference in emphasis. An attempt to look at either, actual interventions or proposed interventions according to expressed themes can be seen in the person-ordered meta-matrix (Table 2). Clearly, the individualized analysis is based on researcher interpretation which in the real world of care planning could not be independent of the perceptions and planning of others involved in teaching and care and the child him/herself.

In developing pattern codes for inductive inquiry, the researcher moves from what is depicted in field notes to a more general explanatory mode. "Pattern codes are inferential codes that identify an emergent theme or explanation" (Miles & Huberman, 1984, p.67). Its functions

are to reduce larger amounts of data into smaller analytic units, to get the researcher analysing during data collection to enhance later focus, to help the researcher evolve a schema of understanding and "to lay the groundwork for cross-site analysis by surfacing common themes" (Miles & Huberman, 1985, p.68).

Glaser and Strauss (1967) who developed the term grounded theory, describe it as one that "fits", in that its categories readily (not forcibly) apply to the data and which "must be meaningfully relevant to and be able to explain the behaviour under study" (p. 3). The information is used by the researcher to build a model to describe and explain the phenomena. The explanation occurs by connecting themes which "result in an empirical account of the whole system" (Lincoln & Guba, 1985, p.206). The explanations can be described as a "pattern model" in which the pattern itself "has a place in the larger whole" (Reason, 1981, pp. 185-186). It is important to note that "no theory is logically determined by data. Every act of theory development in grounded or a priori is creative in nature"

(Lincoln & Guba, p. 207), extending the empirical data or conceptual ideas which suggested it.

In this research, the themes were determined by multiple coders, an independent researcher familiar with the young people and the field (life-threatened) and the researcher herself. The early emergent themes (family support, school importance and hope) were consistently identified and swelled to multiple sub-themes, for example a theme which suggested that in areas away from school, the child became less aware of giftedness. Ultimately, some, but not all of the themes panned out when checked or qualified with the research team, including the adolescents (three participated in feed-back sessions) and the caregivers. Some themes, when sorted, did not ring true for some respondents or research coders. In the end, a few pattern codes or "hunches" grew to several, which included humour, pain as heroism, alpine imagery. These themes which were identified in most cases more obviously with one particular child, are identified under "other" in Table I. Only the themes which were consistently identified for

frequency and intensity by all of the group who were examining themes and evident in all respondents' interviews were utilised in using this methodology. One of the other themes, that of humour, continued to surface in the researcher's perception of the data, and was given a hermeneutic reading as later described.

In the process of using the pattern-coded themes of pain, family, schooling and hope to describe the perceptions of gifted life-threatened young people and their caregivers, a conceptual model emerged. The fragmentation of the young person, in the perceiver's eye, into a "gifted" or a "life-threatened" (being) interfered with understanding of the whole person and what it was that the young people were, saying. In viewing the young person differently as a whole being first, we come to realize that all else, such as giftedness and illness, become processes of their living.

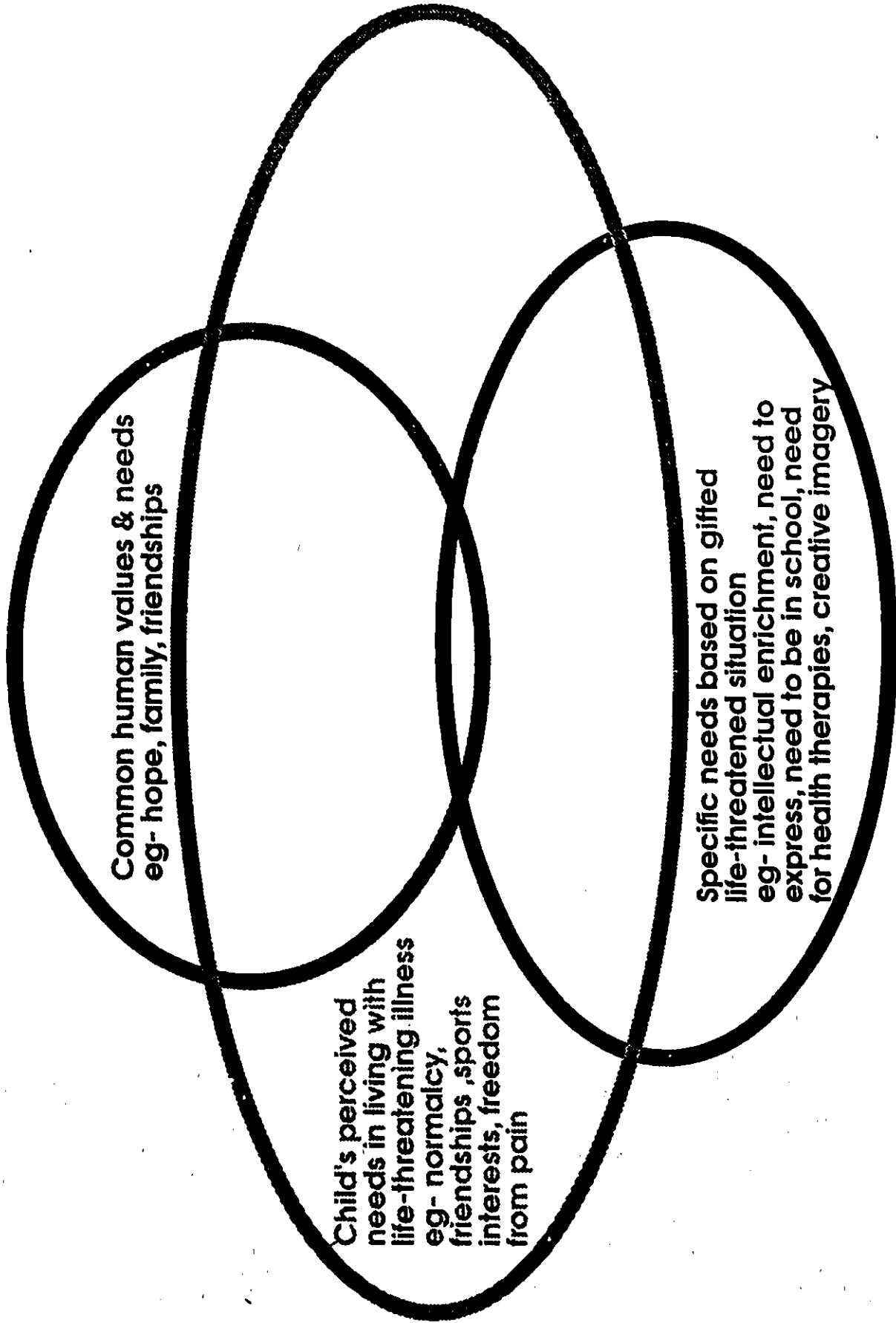
Munhall and Oiler (1986), note that the positing of states such as illness on an artificial continuum of polar

opposites "propagates human suffering" (p.61). The advantage of looking at health, pain, hope and giftedness as processes which interrelate and affect the child's life directs our view to the child's holistic experience as a living person. In developing this view of the young person, we temporarily peer past the labels which confront us and become aware of the young person him/herself. The patterns themselves reintegrate and take their place in the larger whole.

I propose that through the stories of the children, as interpreted in my experience and the experience of other children, researchers and writers, we learn somewhat of the perceptions of gifted children who are life-threatened. In this research these perceptions include a sense that they are "regular kids" who appreciate close family ties, who need to be in school and accommodated by school, who need modulation of both physical and psychological pain, and for whom hope must be nurtured. The conclusions are not generalizable even within the group, but involve a constant swirling of interactive elements working among people who

are with the individual child. On paper, although the reader must imagine that the lines and patterns are in constant motion, a theoretical model of working with gifted life-threatened children can be seen in Figure 1. In this model, the child is symbolically (because he/she is uniquely different on a number of planes) elliptical in shape. The children appear whole and interactive and blended with the circular representations of other humans and their specific learning and health environment and open to the temporal external universe of the unknown. The strength of the theory is that it can address the interaction of the child as a whole being, whose potential we have the ability to share and encourage.

Wolcott (1990) asks the question of how one should conclude a qualitative study and then, gives the answer. "You don't" (p. 55). I see myself now, edging into hermeneutics, the process ends, not with research, but expression. Poems inspired by and emerging from this research are included in appendix 3.



# HOLISTIC MODEL OF GIFTED LIFE-THREATENED CHILD INTERACTION IN TIME AND PLACE WITH OTHERS

### Hermeneutic Reading

The traditional concept of science and phenomenology converge rather than complement or supplant each other (Munhall and Oiler, 1986). One must respect the view of Merleau-Ponty that the difference between induction and phenomenological reduction is a matter of degree.

What has painstakingly, and with difficulty, been bracketed are the central themes which were previously described and were expressed in a diagrammatic theoretical model. The bracketing permitted a reflective gazing, in which a central meaning of the phenomenon of gifted, life-threatened children frequently floated to the surface and broke through. An overriding quality of humour displayed itself freely. Revealed as the burbling of laughter and the sardonic sword, these children are perceived by the researcher to have a humour with which they cope with their giftedness and their life-threatenedness. This was found to be integral in the child as a person.

### Humour in the Case Studies

On one of Scott's last clinic visits, he met with his doctor who asked him how he was. Scott responded, "Well, this is it, I finally realize what the world has come to, and it is a sad, sad place. Actually, I just feel really mad and really sad."

The doctor stopped looking at Scott's chart, riveted her attention to him, pulled up her stool close to him, and hand on his shoulder said empathetically, "Tell me about it." "Well, the Maple Leafs lost last night!" This was followed with gales of laughter, and was independently repeated to several others, including the researcher.

Joey's Dad described Joey's humour as "subtle and twisted", and Karen described the humour in her family as "kind of what some people would call morbid". Susanna's humour almost always rebounded around something that her sister would do to take her mind off her situation, such as taking all of the food on her hospital tray, none of which she was intending to eat, piling it in one sloppy bowl and then pronouncing it "a single dose". This is humorous only

if one appreciates the multiple "doses" in modalities of treatment that someone who has had a transplant must endure. Andrea, the most restrained in her emotional expression, talks about "being able to laugh at myself, like not having any hair and stuff like that", but notes that she is more comfortable doing "weird and silly stuff at home, even though Melanie and my parents are pretty straight."

#### Humour in Literature

The researcher took a side road at this point and diverted from hermeneutic methodology and reviewed some of the literature to clarify the intuited theme. The literature which is briefly reported resonates with the identified theme.

Alas, a review done by MacGhee and Chapman (1980) reported "that only a handful of studies have focused on the humour of atypical or exceptional children. Moreover, a number of these studies were simply descriptions of humour as a therapeutic tool and/or of children's joke telling" (p. 191).

Further, they report that despite many scientific observations and experimentation, the researchers essentially are ignorant of the processes and factors related to this phenomena. Hetherington (1964) hypothesized that children with polio or cerebral palsy might prefer cartoons which showed motor activity compared to normal children. This hypothesis was partly proven in his work. Zigler, Levine and Gould (1996), studied the humour responsiveness (also through cartoon presentation studies) to children labelled as mentally retarded, compared to those who were not, and concluded that the normal children had a higher humour comprehension.

Others have attempted to link humour either with intelligence or creativity. McGee and Chapman (1990), support the reports of many researchers in linking humour with intellectual competence, but remind that humour is "a complex function of a number of variables including methods of testing, response measures, and the child's cognitive and developmental level" (p. 180). McGee (1990), in independent

studies, concludes that humour in both sexes was interceded by a higher quantity and quality of speech, and children who used and appreciated humour more talkative, expressive and generally precocious in their long term development than peers" (p. 232).

Brodzinsky and Rightmyer (1990) studied the expression and meaning of humour in children and they believe that cognitively advanced children "are more likely to comprehend the basis of humour than their less bright counterparts" (p. 206). They further assert that children who are reflective in their cognition are better able to understand jokes than impulsive children. An earlier researcher postulated that "comprehension of jokes was significantly related to intellect and to the ability to think abstractly" (Onwake, 1939).

Some researchers look at humour more from a psychoanalytic viewpoint. Brodzinsky and Rightmeyer (1990) claim that the research on atypical humour is too sparse to generalize, but they suggest that humour is a means of

coping with stress. McGee (1990), considers humour as "an ideal means of gaining favourable adult reactions", thus stimulating production of more humour (p. 232). Wolfenstein (1954) posited that humour, even among individuals whose cognitive ability was limited, is used as a means of coping with stress. He further contended that a basic motive of children's joke telling is a wish to transform the painful experience into the pleasurable. Kris (1940) considered humour as derived pleasure from mastered skills. "What was feared yesterday is mastered and laughed at today" (p. 341). Freud considered humour to be liberating (Levine, 1990). Weeks and Mach (1990) consider it a means in which young children can communicate via play rather than conversation, emotional conflicts and feeling.

Several researchers discuss the use of humour in therapeutic situations. (Winnicott, 1971; Brenman, 1952; Redl and Wineman, 1952; Levine, 1990). These discussions vary from controlling temper tantrums to the effectiveness of banter.

Having taken this foray into self-reassurance that the researcher's intuition was not totally in error, I became excited about the possible connections of gifted intellect, illness, and coping with pain which seemed to come together in this essence of the original work. Thus freed, I was able to consider the children in the case studies as they displayed the humour resonating throughout their experience.

Author and cartoonist David Saltzman died at the the age of 23 from Hodgkins disease after a brief but brilliant academic career and what critics called, "an exploding talent" (Sendak, 1995). His book The Jester Has Lost His Jingle was written a year prior to his diagnosis and contains the line, "Here I lie, I have a tumor... And where you ask is my sense of humor?" (Saltzman 1995). In that book as in his later life, the humour was found in a hospital.

From Pia, quoted previously, we heard, "I want to keep laughing. Keep me laughing." (Berger & Lithwick, 1992, p. 72) The notion of laughing at what you can't change

surfaces again and again. Andrea talks of laughing about her hair loss. Another child poet, Rena Parab, put it this way.

Hair hair everywhere  
in my lap and on my chair.

(Berger & Lithwick, 1992)

Karen notes that some of their family humour would be considered "morbid" and "appalling" to others, but that it was a constant at home. "We used to laugh all the time. You have to." She then describes her mother making "Kelly" (a local funeral home) jokes, or tell tales about wheelchair patients which evoked much humour within the family of a girl confined to a wheelchair. Karen describes having funny names for things, making fun of the doctors, and of her Dad at the hospital. "Better," she says, "to laugh than cry."

Likewise, Joey uses humour which is sophisticated and subtle and has a dark lining at times. Constantly he requires things which could be dangerous, such as blood and

iron products "fed" into him. He will winkingly carry on to his mother that the less than sweet, rhubarb dessert that he is eating is an attempt to "kill him". He is not a jovial joker, but a quietly sharp wit. His parents describe it as a humour that goes over your head until you later reflect and see its meaning. Joey's unusual early language fluency was manifested into multiple-meaning humour.

Mathieu describes many humorous instances in his book, but the one that he is most remembered for, is his own description of an interaction with a nurse who was learning French and also was tasked with taking a blood specimen from him, a task which he particularly loathed. One of the "vampires" as he called them, asked to take a specimen of "sein" (breast) instead of "sang" (blood). He thought it was so funny that he didn't tell her so that he could hear it again the next time, and finally he could no longer contain his laughter. His book chronicles the poignant and serious descriptions of his many painful misadventures with blood-taking and intravenous procedures.

Scott's humour expressed itself in a way which was increasingly filled with the nuances of impending death. He sought out and created pearly gate jokes, his favourite being God greeting a bearded man whose hands and feet were pierced with holes. "My Son, he said, you are home at last. Welcome home...Pinnocchio!"

He would try out his jokes, test them, and then circle the clinic evoking laughter from any that he could. Perhaps it was a way of coping with painful realities, perhaps it was a way of connecting with his caregivers, perhaps it was illustrative of his intelligence and creativity. Even when in pain, Scott could find a name, or tease in a way which caused a shocked laughter response. Around us we see examples of the use of humour to deal with painful realities. The Montreal Gazette cartoonist Aislin, is known for his passionate contempt in observing the major powers not effectively intervening in the atrocities being committed in warring countries (Bauch, 1994).

We see examples of humour which come forth at times

when there is just nothing to be done about a situation. Sometimes laughter occurs when one hears of death. It is the kind of humour which diffuses tension, and which is currently being touted as a remedy for negativity in the workplace, and the sprouting of "Humour rooms" for the sick. Listen to the silly competitions which seek entries for the world's worst boss, and publish hilarious books such as Bosses and other Reptiles (Zolkos, 1994).

It may be that the children in this study are able to turn their giftedness to advantage because they have the advanced verbal capacity and creative flexibility to integrate humour into their daily living as a natural method of dealing with their pain and isolation. It may become a tool in which they fight back, much as Scott's images of headweapons give him power to control. It may be that tapping into the child's humour we can "see" what it is the child chooses to unveil, while respecting the child's wish to distance the pain. It may be that giving full expression to the child's humour without the tendency sometimes seen, to curb what becomes uncomfortable for the listener, the

caregiver provides an arena in which the child can play out his/her creative potential.

On a cautionary note, the researcher would emphasize that the potential for stereotyping may be real and harmful for the child, and that much more research into how humour is used and its relationship to wellness must be done before it is used as a singular instrument targeted at a particular educational or health goal. It would be repugnant to see the "fat/jolly" stereotype applied to the gifted, life-threatened child coping with his/her situation. The children want most of all "to be regular children."

Their humour is, however, observable and displayed uniquely. It is both bright and dark together with many shades blending or standing in hooped lines of distinct colour in the rainbows children so often paint. It is somehow perhaps that symbol which is related to hope. It is here and beyond. It is Hegel's definition of humour itself: "the creative power of the artist's soul over all content and form." It is the child with the happy face. This is

the lasting conclusion, the legacy of the children whose lives inform our own.

The implication of the theoretical model is very simple, that the ministrations of teachers and health caregivers, such as nurses, are meaningless if not understood in the context of interactiveness. Our chance for human contribution lies in our opportunity to witness the child's world by taking advantage of sharing a full range of awareness. Our helpfulness to the child (and his/her family) lies not only in our recognition of his/her own self, but is situated in our using of ourselves in part of that world.

While this interpretation illustrates the need to view any life-threatened child with a holistic view, it is through the insights of these gifted children that a conclusion which has relevance to teachers and caregivers evolves. ~~The~~ The child, although cognizant of both illness and giftedness, perceives him/herself just "like other kids."

The message that these children bring about the importance of school in their lives comes at a critical cross-roads in Canada, and particularly Ontario. In the spending spree of the seventies, elaborate health and educational opportunities, particularly oriented towards individually optimized health and education, were accentuated and in some cases introduced. Programming for gifted children grew and flourished in a variety of methods. The battle still rages about segregation or integration of exceptional children, with champions of each plan claiming that theirs is the one which promotes greatest self image (Seigel, 1974). The concern of "labelling" children particularly as "gifted" has had an offensive and elitist taint to some parents and educators, and it would take little in today's milieu of fiscal restraint and anti-individualism to dismantle the very systems which have opened up opportunities for those children who, however labelled, are markedly different. The minority within a minority of gifted, life-threatened children may doubly suffer from funding withdrawals in both the health and school systems.

Already in Ottawa, the hospital based, McHugh school, has closed, despite vigorous parent and teacher protests. A one-day, well-advertised program offered to all school boards in the region to teach teachers about various chronic and life threatened illnesses complete with handouts, tips, panel discussion of care givers and children, was grossly undersubscribed because, as one principal put it, "there is not enough time or money to send teachers to something like this" (P. McCarthy, personal communication, February 27, 1995).

The concept of joint-partnered action for children and of the children themselves being involved in their own choices resonates with the nineties' trends in education, health care, business, politics and the law. Changes in the Regulated Health Care Act of Ontario demand for broader application of consents for medical procedures to include children who are deemed competent, not chronologically, but in their ability to comprehend what is happening to them. Educators and parents note the challenge of all

professionals, including teachers and health care therapists, to work together for the child (Pander, 1995).

As partnerships form between educational and health agencies and parent/child involvement are strengthened, there are implications for potential changes in curriculum. Some researchers on the subject of childhood pain, recommend teaching within the school system, an instructional preventative program about pain prevention and intervention, noting that ten percent of children suffer from chronic pain, and all children will eventually experience it and need a means of coping (Ross & Ross, 1988). This is highly controversial as subject content, which is not surprising, given that most people prefer, like Susanna's friends, not to think about it. Dollars are being poured into technological advances in pain management but little into its research, and less into its prevention.

"Webbing" on the information highway seems to have occluded our vision of the obvious webs which must be delicately and strongly constructed, so that the world in

which the gifted life-threatened child lives, can be one in which there is co-operation, contact and joint efficiency in providing an optimal environment for the child's health, growth and learning. The child, parents, teachers, professional caregivers must work in such an inter-related way that no child falls through the cracks. The researcher notes that in research of this nature, at least on the theoretical plane, the crossover between education, health care and psychology can be non-competitively interwoven. The challenge is to make this happen for the child in the real world of home, hospital and school.

The need of the child to be perceived as a child who participates in normal childhood activities like bike riding and being with friends at school, is something that must be remembered by all of those who share the child's world. Caregivers, whose primary focus is on health, need to refocus to see school as another option. Teachers, who may see tutorials as a preferred option, may need to look at reintegrating the child into the classroom, and seeking opportunities for the child to both learn and teach in the

educational setting. Professionals and caregivers must participate in practices which include new models of living and working as both professionals and partakers of learning and health. Educators and caregivers must be spurred to action to critically analyse what is best and maintainable, and what is emergent and important in providing optimal quality of life services to all children, including those in this study.

Always, the balance of being a child versus a recipient of a collection of fragmented services is important. So, too, is recognition that what may enhance one child's living at a point in time may detract from another's quality of life. The current buzzword of "outcome" in these children will necessarily be idiosyncratic, not to mention coldly impersonal, according to the personal realms in which they live out their lives, the environmental context and the teachers, families, friends and caregivers with whom they interact.

## Conclusion

Wolcott (1990) asks the question of how one should conclude a qualitative study, and then gives the answer. "You don't" (p. 55). Poems inspired by and emergent from this research are included in Appendix 3. The young people themselves continue to teach us by their inspiration.

TABLE I

CONCEPTUALLY CLUSTERED MATRIX

CENTRALITY OF EXPRESSED THEMES

Theme	Names									
	Sussana	Mathieu*	Scott	Andrea	Karen	Joey	Focus	Parent	Volunteer	
Physical Pain	M	H	M	L	M	L	L	M	L	L
Psychological Pain (Need for friendship, Need to be normal)	H	H	H	H	H	H	H	H	H	H
Family ties	H	H	M	H	H	H	L	H	H	H
School	H	H	H	H	H	H	L	H	H	M
Hope	H	H	H	M	H	H	M	H	H	M
Other	Aware of life worth	Alpine imagery	Humour		Pain as heroism	Sports	Dilemma of choice			Palliation

\* - Mathieu: Historical Perspective

**Legend**

H - High

L - Low

M - Moderate

**TABLE II**  
**PERSON-ORIENTED META-MATRIX: OBJECTIVE IMPACT OF INTERVENTIONS (POTENTIAL AND REAL) BASED ON THEMATIC NEED EXPRESSIONS**

Cases	Enhanced Family Support	School Accomodation	Pain Relief	Maintaining Hope	Side Effects
Susanna	Family very strong. Support in TIC education/some participative research/family interest sustained.	Critical difference in tolerating psychological trauma, Disability exemptions	Appreciated accurate information and support.	Critical factor	Adult adjustment?
Mathieu*	Incredibly high degree of support needed and demanded.	Individual tutoring/computer program adjusted to permit goal of writing book.	Control tools. Morphine pump.	Indefatigable, Requiem Mass, Hospice building.	Positive for patients who will enter hospice. Father especially sustains grief.
Scott	Provided by Social worker and Clinical Nurse Specialist. Still necessary in bereavement phase.	Active aggressive efforts to re-integrate into school program successful and created joy for child.	Partially achieved. Precipitous death.	Response to humour. Grass stain imagery.	Conflict between hope vision and reality awareness.
Andrea	Close-knit family. Sufficient/keep external assistance at bay. Stimulate Candlelighters?	Very important. Tutoring in hospital. School visits to explain to class hair loss, etc.	Of minimal expressed concern or intervention.	Encourage free expression of pain	Child is secure and extremely controlled in her own environment. Tampering may upset her individual personality and cultural norm.
Karen	Evidence of sturdy supportive family.	Rarely necessary. Gifted program and encouraged to follow her choices.	Assurance given re triage assessments and rapid ER intervention program.	Encourage balance and joy in hope.	Nil
Joey	Family giving "all" to support only child. Rarity of condition limits support group.	Gifted programming to continue. Hospital tutoring also necessary.	No intervention currently needed.	Support for child and parents optimism. Computer tracking of transfusions. Publicity - Dave Brown.	Nil, although adjustment to independent living and increasing inability to play sports will be challenging.

**CONTACT SUMMARY FORM**

(from prototype Miles and Huberman, 1984, p. 52)

**Contact Visit**

Site \_\_\_\_\_

Visit \_\_\_\_\_

Contact Date \_\_\_\_\_

Phone \_\_\_\_\_

Today' Date \_\_\_\_\_

Written by \_\_\_\_\_

1. **What were the main issues or themes that struck you in this contact?**
  
2. **Summarize the information you got (or failed to get) on each of the target questions you had for this contact.**
  
3. **Anything else that struck you as salient, interesting, illuminating or important in this contact?**
  
4. **What new or remaining target questions do you have in considering the next contact?**

**Concern:**

**STOP**

## Poems.

## For Susanna

They are attached  
    angels with skin  
Silken green flags  
    fluttering and twisting  
On a birch twig  
    elegant and white  
Detaching bark in  
    in a natural world  
The sunshot pigment of  
    hope  
nubbled with experience.

## For Joey

Scampering brighteyed  
He's the one in a million kid  
To be the first to connect space  
on the electronic highway  
Which he cycles through  
Engineering a Rudy future.

## For Andrea

She skitters shimmering  
    water beetle  
on blue green surfaces  
    winging worriless  
fathomless beneath  
    engulfed in velvet  
as each other slides  
    its random path  
colliding, rebounding  
    friends swimming  
in a fluid globe.

## For Scott

Eyes sagely piercing  
 Soul shining through  
 pearly bones  
 bloodless and solid  
 infrastructures  
 of a weakened flesh  
 temporal cages  
 whose bars bend  
 and straighten  
 in gates of pain  
 who's peace opens  
 by the swinging of  
 the Pearly Gates  
 through which he rides  
 on a motorized rickshaw  
 with 5 resplendent angels  
 to a bald God  
 of chortly warm hugs.

## For Karen

Snuggled cosily  
 in a family duvet  
 teasing and laughing  
 living and ribbing  
 elbowed thoughts  
 dug deep realms  
 of care and conscience  
 future and presence  
 and writer's essence.

## To All

They stand tall  
 As Great Blue Herons  
 Surveying land and lake  
 Peering starkly  
 Diving and divining  
 sharply focussed  
 "Furank, Furrank"!!  
 breaking silence  
 speaking beakons  
 of simply complex  
 pain and peace  
 past and beyond  
 unruffled presence.

## REFERENCES

- Aanstoos, C. (1986). Qualitative research methods. Themes and variations. Speech: Symposium for Qualitative Research, Italy, 1987.
- Bauch, H. (1994). Put up & Shut up. Outremont, Quebec: Robert Davies Publishing.
- Berger, L., & Litwick, D. (1992). I will sing life. Boston: Little, Brown and Company.
- Brenneman, W., Yarian, S. & Olson, A. (1982). The seeing eye. London: University Press.
- Brenman, M. (1952). On teasing and being teased. Psychoanalytic study of the child, 7, 262-285.
- Brodminsky, D., & Rightmeyer, B. (1980). Individual differences in children's humour development. In McGhee, P. and Chapman, A. (Eds.). Childrens humour, Chinchester: John Wiley & Sons.
- Brown, D. (1995, Aug. 12). Joey fights condition with humour and praise for blood supply system. The Citizen, C3.
- Buchanon, C. (1995, Aug. 25). Asthma's rapid advance alarming. The Citizen, C3.
- Carter, K. (1992). The place of story in the study of teaching and teacher education. Educational researcher, 22(1), 5.
- Cramer, J., & Oshima, T.C. (1992). Do gifted females attribute their math performance differently than other students Journal for the Education of the Gifted, 16(1), 18-35.

- Csikszentmihalyi, M., & Robinson, R.E. (1986). Culture, time and development of talent. In R.J. Sternberg and J.E. Davidson (Eds.), Conceptions of giftedness (264-284). Cambridge: Cambridge University Press.
- Dabrowski, K. (1964). Positive disintegration. Boston: Little Brown.
- Dennis, R., Williams, W., Giangreco, M., & Cloninger, C. (1993). Quality of Life as Context for Planning and Evaluation of Services for People with Disabilities. Exceptional Children, 59(6), 499-512.
- Dickenson E., in Johnson, T. (Ed.) (1970). Final harvest: Emily Dickenson's poems. New York: Little Brown.
- Dickenson, R. (1970) Caring for the gifted. North Quincy, Massachussets: Christopher Publishing House.
- Dilthey, W. (1985). Poetry and experience. Selected Works, Vol. V., Princeton N.J.: Princeton University Press.
- Eisenhardt, K. (1989). Building theories from case study research. Academy of management Review, 14(4), 532-50.
- Feldhusen, J.F. (1986). A conception of giftedness. In R.J. Sternberg & J. Davidson (Eds.) Conceptions of giftedness. (112-127). Cambridge: Cambridge University Press.
- Feldman, D. and Goldsmith, L. (1986). Nature's gambit. New York: Basic Books.

- Fisher, R. (1973). Musical prodigies. New York: Association Press.
- Flagg, F. (1988). Fried green tomatoes at the whistle stop cafe. New York: McGraw Hill.
- Frank, A. (1952). The Diary of a Young Girl. New York: Pocket Books.
- Froment-Savoie, M. (1991). Le Cancer à Onze Ans. Montreal: Lemeac.
- Gallagher, J., (1975). Teaching the gifted child, 2nd Edition, Boston MA: Allyn and Bacon Inc.
- Gadamer, H. (1975). Truth and method. New York: Seabury.
- Gadamer, H. (1986). The relevance of the beautiful and other essays: Cambridge: Cambridge University Press.
- Gilligan, C. (1982). In a different voice. Cambridge, MA: Harvard University Press.
- Giorgi, A. (1970). Psychology as a human science. New York: Harper & Row.
- Glaser, B.E. Strauss. (1967). Discovery of grounded theory strategies for qualitative reasons. Chicago: Aldine.
- Goertzel, V., & Goertzel, M. (1926). Cradles of eminence. Boston: Little Brown.
- Goldsmith, L., (1987). Girl prodigies: Some evidence and some speculations, Roeper Review 10(2), 73-82.

- Gottfried A., Gottfried A., Bathurtic K. and Guerin D. (1994). Gifted IQ early development aspects. New York: Plenum Press.
- Gross, M. (1989). The pursuit of excellence or the search for intimacy? The forced-choice dilemma of gifted youth. Roeper Review, 11(1), 189-194.
- Haensly, P., Reynolds, C.R., and Nash, W.F. (1986). Giftedness: coalescence, context, conflicts and commitment. In R.J. Sternberg and J.E. Davidson (Eds.), Conceptions of giftedness 28-148). Cambridge: Cambridge University Press.
- Hauck, B., & Freechill, M. (1972). The gifted - case studies. Dubuque, Iowa: Wm. Brown Publishers.
- Heatherington, E. (1964). Humour preferences in normal and physically handicapped children. Journal of Abnormal and Social Psychology, 69, 694-696.
- Howe, M. (1990). The origins of exceptional abilities. Oxford: Basil Blackwell Ltd.
- Jacob, E. (1988). Clarifying Qualitative Research: a focus on traditions. Educational Research. 17. 16-24.
- Jay, S. (1983). Behavioural management of children's distress during painful medical procedures. Behavioural Therapy. 23. 513-552.
- Jenkins-Friedman P. and Tollefson N., (1992). Resiliency in cognition and motivation: Its applicability to giftedness. In N. Colagela., S. Assouline and D. Ambrason (Eds.). Talent Development. Unionville: Trillium Press.

- Karnes, M. & Schwedel, A. (1983). Assessment of preschool giftedness. In the Psychoeducational Assessment of Preschool Children. New York: Grune & Stratton.
- Katz, E. (1980). Behavioural distress in children with cancer undergoing medical procedures. Journal of Consulting and Clinical Psychology, 48, 356-365.
- Kauffman, M. (1995). Easy for you to say. Questions and answers for teens living with chronic disability. Toronto: Key Porter Books.
- Kramer A. Bitan D., Butler-Pov N., Evyatar A, and Landan E, (1981). Gifted children. New York: Trillium.
- Kris, E. (1940). Laughter as an expressive process. International Journal of Psychoanalysis, 21, 314-341.
- Kubler-Ross, E. (1972). On death and dying. New York: MacMillan
- Kuttner, L. (1988) Favorite stories: a pain reduction technique for children in acute pain. American Journal of Clinical Hypnosis. 2, 374-381.
- Leroux, J. (1992). Reaching beyond the barriers: A followup study of gifted females. In F.J. Monks and W.A.M. Peters (Eds.), Talent for the future: Social and personality development of gifted children (Proceedings of the Ninth World Conference on Gifted and Talented Children) (pp. 162-171). Assen/Maastricht, The Netherlands: VanGorcum.

- Leroux, J., & Stephenson, D. (1993). Reflections on the life of a young gifted boy facing cancer. An essay review of *Le Cancer à Onze Ans*. Gifted Child Quarterly, 37(2), 95-97.
- Levine, J. (1978). Humour and psychopathology. In C.E. Izard (Ed.). Emotions, Conflict & Defence. New York: Plenum.
- Lewis, C.S. (1969). The problem of pain. London: Collins.
- Lincoln, Y., & Guba, E. (1985). Naturalistic Inquiry. Beverly Hills, CA: Sage.
- Lincoln, Y. (1990). Qualitative Research in Health Care. Key-note speech: National Health Conference, Edmonton Alberta, 1990.
- Lofland, J. & Lofland, L.H. (1984). Analysing social settings -A guide to qualitative observation and analysis. Belmont, California: Wadsworth Publishing Company.
- Maaing, L. (1990). Portrait of a wonder child. Newsletter UHURU No. 6.
- MacGhee, P., & Chapman, A. (1980). Children's humour. Chichester: John Wiley & Sons.
- Marshall, C., & Rossman, G.B. (1989). Designing qualitative research. Newbury Park, CA: Sage.
- Mayeroff, M. (1971). On caring. New York: MacMillan.
- McGee, P., & Chapman, A. (1980). Children's humour. Chichester: John Wiley & Sons.

- McGee. P., Development of the Sense of Humour in Childhood. In P. McGee & A. Chapman (Eds.) Childrens humour. Chichester: John Wiley & Sons.
- McGrath, P.J., Beyer, J., Cleeland, C., Eland, J., McGrath, P.A., Portenoy, R. (1990). Report of the Subcommittee on Assessment and Methodological issues in the Management of Pain in Childhood Cancer. Paediatrics, 86(5), 814-817. New York: Guilford Press.
- McGrath, P.A. (1990). The Multidimensional Nature of Children's Pain Experiences. Pain in Children: Nature Assessment and Treatment. New York: Guilford.
- McGrath, P.A. & di Veber, L. (1985). Multidimensional Pain Assessment in Children. In H.L. Fields R. Dubner & F. Cervero (Eds.). Proceedings of the Fourth World Congress on Pain. Seattle, Vol. 9. 7, New York: Raven Press.
- Merleau P. (1986). Phenomenology: The Method, In Muntall and Oiler (Eds:) Nursing research - A qualitative perspective. Norwalk: Appleton Century Crofts.
- Merriam, S., & Simpson, E. (1989). A Guide to research for educators and trainers of adults. Malabar, Florida.: Kdreiger Publishing Company.
- Miles, M., & Huberman, A. (1984). Qualitative data analysis. Newbury PA: Sage.
- Miller, N.B., & Silverman, L. (1987). Levels of Personality Development. Roeper Review, 2(4), 221-225.

- Munhall, P., & Oiler, C., (1986). Nursing research - A qualitative perspective. Norwalk: Prentice Hall.
- Noddings, N. (1991). Stories in dialogue: Caring and interpersonal reasoning. In C. Witherall & N. Noddings (Eds.). Stories lives tell: Narrative and dialogue in Education, (pp. 157-170). New York: Teachers College Press.
- Onwake, L. (1939). Factors influencing the sense of humour. *Journal of Social Psychology*, 10, 95-104.
- Palmer, R. (1988). Hints for/of hermeneutics in Was *Heisst Denken?* in Joseph J. Kockelman's Hermeneutic phenomenology: lectures and essays. Washington: Center for Advanced Research in Phenomenology & University Press of America, 157.
- Patton, M. (1990). Qualitative evaluation and research methods. Newbury Park: Sage.
- Pear, C. (1959). The Helen Keller Story. New York: Crowell, pp. 168-182.
- Phalen, P., Olinsay, A., & Robetson, F. (1994). Respiratory illness in children. Oxford: Blackwell Scientific Publications.
- Piechowski, M. (1991). Emotional development and emotional giftedness. In N. Colangelo and G.A. Davis (Eds.). Handbook of Gifted Education (pp. 285-306). Boston MA: Allyn and Bacon.
- Pizzo, P., & Poplack, D.G. (Eds.) (1993). Principles and practice of paediatric oncology. 2nd Ed. Philadelphia.: J.B. Lippincott.

- Polkinghorne, D. (1988). Narrative knowing and the human sciences. New York: State University of New York Press.
- Ramos-Ford, V., & Gardner, H. (1991). Giftedness from a multiple intelligence perspective. In N. Colangelo and G.A. Davis (Eds.). Handbook of gifted education (pp. 55-64). Boston, MA: Allyn and Bacon.
- Reason, P., & Rowan, J. (1981). Human inquiry: A sourcebook of new paradigm research. New York: John Wiley.
- Reell, F., & Wineman, D. (1952). Controls from within. New York: Free Press.
- Renzulli, J. (1978). Giftedness results from the interaction among 3 characteristics: above average in ability and task commitment. What makes giftedness? Re-examining a definition. Phi Delta Kappan, 60, Vol. 8, 261.
- Rorty, R. (1979). Philosophy and the mirror of nature. Princeton N.J.: Princeton University Press.
- Ross, D., & Ross, S. (1988). Childhood pain, current issues, research and management. Baltimore: Urban & Schwarzenburg.
- Saltzman, D. (1995). The jester has lost his jingle. Palos Verdes Estates CA: The Jester Co., Inc.
- Sandelowski, M. (1989). Artful Design: writing the proposal for research in the naturalistic paradigm. Research in nursing and health, 12, 77-84.
- Schuyler, P. (1960). Adventure in black and white. New York: Speller.

- Singer & McCraven. (1961). Fantasy imagery in hypnosis, In D. Copeland, R. Pfefferbaum & A. Stosal (Eds.). The mind of a child who is said to be sick. Springfield Ill: Charles C. Thomas.
- Speight, S., Myers, L., Cox, C., & Highem, P. (1991). A re-definition of multicultural counselling. Journal of Counselling and Development, 70, 29-36.
- Spielberg, H., (1976). The phenomenological movement I and II. The Hague: Martinus Nijkoff.
- Stephenson, D., & Leroux, J. (1994). Portrait of a creatively gifted child facing cancer. Creativity Research Journal. Vol. 7, 71-77.
- Sternberg, R.J. (1991). Giftedness according to the triarchic theory of human intelligence. In N. Colangelo & G.A. Davis (Eds.), Handbook of Gifted Education. Boston, MA: Allyn and Bacon., 45-54.
- Stevens, W. (1959). Poems. New York: Random House.
- Stevenson, H.W., Chen, C., & Lee, S. (1993). Motivation and achievement of gifted children in East Asia and the United States. Journal for the Education of the Gifted, 16(3), 223-250.
- Strauss, A., & Corbin, J. (1990). Basics of qualitative research. Newbury Park: Sage.
- Treffinger, D., & Renzulli, J. (1986). Giftedness as potential for creative productivity: Transcending IQ scores. Roeper Review, 8(3): Roeper City and County School.
- Van Manen, Max. (1990). Researching Lived experience. London: The State University of New York.

- Wall, P., & Melzack, R. (1994). Textbook of pain.  
Edinburgh: Churchill Livingstone.
- Weeks, E., & Machs, J. (1978). The Harvard guide to  
Modern psychiatry. Cambridge, MA: Harvard  
University Press.
- Welsh, G. (1986). Identification of giftedness. In  
Robert T. Brown & C. Renolds (Eds.).  
Psychological Perspectives on Childhood  
Exceptionality, New York: John Wiley & Sons, 336.
- Williams, D. (1990). Nobody nowhere. Toronto:  
Doubleday.
- Winnicott, D. (1971). Therapeutic consultations in  
child psychiatry. New York: Basic Books.
- Winzer, M. (1990). Children with exceptionalities.  
Scarborough: Prentice-Hall.
- Wolcott, H. (1990). Writing up qualitative research.  
Newbury Park: Sage.
- Wolfenstein, M. (1954). Children's humour. Glenco,  
Illinois: Free Press.
- Yin, R. (1980). Case study research. Design and  
methods. Newbury Park: Sage.
- Yong, F.L. (1994). Self-concepts, locus of control,  
and machiavellianism of ethnically diverse  
middle school students who are gifted. Roeper  
Review, 16(3), 192-194.
- Zolkos, R. (1994). Bosses and other reptiles.  
Chicago: Contemporary Books.

### Statement of the Auditor

I have been charged with determining dependability and confirmation of the data and to review credibility measures in the Master's Thesis entitled "Perceptions of Gifted Young People Experiencing Life-Threatening Illness and Perceptions of Their Caregivers."

The audit has been conducted according to the qualitative methods of Guba and Lincoln (1981) and Halpern (1983). I have examined the raw data: audio tapes, diagnostic and treatment accuracies, field notes, contact sheets, private records and public documents. I have reviewed the coded transcripts and confirmed the process with the coders. Authenticity of theme frequency and intensity has been examined and triangulation of centrally identified themes by observer fully knowledgeable in the field has been verified. Theoretical notes, concept development and summary notes were made available.

Data synthesis, including connections to existing literature, has been examined. Process notes, peer debriefing interactions, and verification of participant review by two of the children (case studies), one adolescent (case study) and members of the focus group has been confirmed.

Overall, I can attest to the dependability and confirmability of the data and its credibility. The audit trail is available for replicated audit, with the exception of one tape, the authenticity of which has been verified.

As a health research coordinator by profession, I am responsible for coordinating and verifying the authenticity of consents, data, treatment notes and alignment of studies to the approved standards at the University of Ottawa Research Institute.

Date:

Signed:

Theresa Sutcliffe  
Research Institute,  
University of Ottawa

Vita: Theresa Sutcliffe is a research coordinator responsible for numerous health care research studies. She is professionally responsible for confirming consents, authenticity of data, data collection and entry techniques and alignment with research and ethics approved protocols.