

Pediatric Palliative Care in Brasov, Romania:
Factors Enabling their Success

Dennis Johnson

Lancaster University
Faculty of Health and Medicine
Lancaster, Lancashire, England

June 2013

The copyright in this thesis is owned by the author. Any quotation from the thesis or use of any of the information contained in it must acknowledge this thesis as the source of the quotation or information.

ProQuest Number: 11003802

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest 11003802

Published by ProQuest LLC (2018). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code
Microform Edition © ProQuest LLC.

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 – 1346

ABSTRACT

Background/Aims: Prioritization in healthcare systems may result in few resources being available for the care of children with life-threatening and life-limiting diseases particularly in resource-poor countries. The aim of this thesis is to understand the purported success of pediatric palliative care (PPC) in Brasov, Romania, as it is portrayed as a beacon of palliative care in Central and Southern Europe despite the paucity of healthcare resources.

Methods: This qualitative study takes an iterative, reflexive approach to gathering and analyzing the data. Semi-structured interviews with a wide range of participants were used. Ethnographic observations were recorded in the inpatient unit, in the Children's Day Care Center and their wheelchair trips into the city, and during homecare visits. The observations and transcribed interviews were methodically and reflexively reviewed; categories which might yield factors contributing to success emerged. Excerpts were taken from the triangulated data and submitted to a process of filtering and sorting that facilitated identification of similar phrases, themes and patterns. Higher level themes emerged from the alignment of the categorized data and were then interrogated by further data collection and analysis to the point of theoretical saturation.

Results: The factors that enable the success of PPC in Brasov are a unique paradigm of PPC, an undying image, compassion, solidarity, and power equity. Foucault's power framework was used to shape an explanatory theory for their success. Power

imbalances were redressed by avowing transnational citizenship in addition to nationality, targeting the effects of power rather than the power authority, contesting what is thought to be known, engaging the immediate problem at hand, opposing efforts to isolate individuals from the society that nurtures them, and resisting attempts to control “who we are”.

Conclusions: Brasov PPC provides a medical home for children with life-limiting illnesses. This new, integrated standard of care offers seamless, continuous, and equitable healthcare at a reasonable cost and has the potential to transform the care of children with life-limiting and life-threatening diseases elsewhere. The findings of this study suggest that a culture of competent and compassionate care is created by embracing these transformative changes in healthcare delivery and complementary changes in the education of healthcare professionals.

Acknowledgements

This thesis could not have been produced without the help, support, encouragement and input of many people. Dr. Anne Grinyer has been an invaluable resource and incomparable advisor since my work began. Professor Chris Hatton has kindly filled the void created when Dr. Iris Fineberg left Lancaster University to become Associate Dean for Academic Affairs at Stony Brook School of Social Welfare in New York. Professor David Clark guided me into the PhD program and facilitated key academic connections in Romania. For the gracious assistance of Ms. Csilla Dregus as a multilingual interpreter, transcriptionist, chauffeur, travel companion, and fellow equestrian, I give heart-felt thanks. I am also grateful to the Fulbright Commission for their support of my research on the ground in Romania. Most of all, I thank Brasov Pediatric Palliative Care – the staff, the children, and their families – for allowing me to be present and near. Finally, to my lovely wife, who managed our farm alone in my absence, your compassion for young people and your love for me have given me the strength and confidence to persevere.

ACADEMIC REGISTRY

Research Thesis Submission

Name:	Dennis L. Johnson		
School/PGI:	Lancaster University, Faculty of Health & Medicine		
Version: <i>(i.e. First, Resubmission, Final)</i>	First	Degree Sought (Award and Subject area)	PhD Palliative Care

Declaration

In accordance with the appropriate regulations, I hereby submit my thesis and I declare that:

- 1) the thesis embodies the results of my own work and has been composed by myself
- 2) where appropriate, I have made acknowledgement of the work of others and have made reference to work carried out in collaboration with other persons
- 3) the thesis is the correct version of the thesis for submission and is the same version as any electronic versions submitted*.

- 4) my thesis for the award referred to, deposited in the Lancaster University Library, should be made available for loan or photocopying and be available via the Institutional Repository, subject to such conditions as the Librarian may require
- 5) I understand that as a student of the University I am required to abide by the Regulations of the University and to conform to its discipline.

** Please note that it is the responsibility of the candidate to ensure that the correct version of the thesis is submitted.*

Signature of Candidate:		Date:	December 2, 2013
----------------------------	--	-------	------------------

Submission

Submitted By (<i>name in capitals</i>):	
Signature of Individual Submitting:	
Date Submitted:	

For Completion in the Student Service Centre (SSC)

Received in the SSC by (<i>name in capitals</i>):			
<i>Method of Submission</i> (<i>Handed in to SSC; posted through internal/external mail</i>):			
<i>E-thesis Submitted</i> (<i>mandatory for final theses</i>)			
Signature:		Date:	

CONTENTS

Chapter 1. Introduction

Chapter 2. Review of the Literature

- [2.1] Pediatric palliative care (ppc) defined
- [2.2] Specialization
- [2.3] The medical home
- [2.4] PPC and the medical home
- [2.5] PPC in other parts of the world
 - [2.5.1] Australia
 - [2.5.2] South Africa
 - [2.5.3] United Kingdom
 - [2.5.4] United States
 - [2.5.5] Poland
 - [2.5.6] Hungary
- [2.6] 21st Century challenges for PPC
 - [2.6.1] Understanding the needs of children
 - [2.6.2] Adequate care of the suffering
 - [2.6.3] Advancing strategies that support caregivers
 - [2.6.4] Strategies to support health-care providers
 - [2.6.5] An inclusive approach
- [2.7] The orphan problem
- [2.8] Power
- [2.9] Summary of major points

Chapter 3. Methodology

- [3.1] Disciplinary origin
- [3.2] About reality and truth
- [3.3] Traditions of qualitative research
 - [3.3.1] Ontology: idealism
 - [3.3.2] Ontology: realism
 - [3.3.3] Epistemology: Positivism/empiricism
 - [3.3.4] Epistemology: Critical emancipatory positions
 - [3.3.5] Epistemology: Constructionism/interpretism
 - [3.3.6] Epistemology: Postmodernism

Chapter 4. Research Process and Methods

- [4.1] Epistemological integrity
- [4.2] Gatekeeping
 - [4.3.1] Data sources: interviews
 - [4.3.1] Data sources: interviews – researcher inexperience
 - [4.3.1] Data sources: interviews – poor quality translation and transcription
 - [4.3.1] Data sources: interviews – language selection and exclusion

[4.3.2] Data sources: ethnographic observations

[4.3.3] Data sources: archived documents

[4.4] Data collection and analysis

Chapter 5. Findings

[5.1] Financial stability

[5.2] The Roma 'problem'

[5.3] Unique paradigm of pediatric palliative care

[5.3.1] Physical layout

[5.3.2] Paradigm of care: homecare, inpatient care, day care

[5.3.3] One last 'point'

[5.4] "Children don't die here!"

[5.4.1] Public perspective

[5.4.2] Standpoint of the professional caregivers

[5.4.3] Viewpoint of the children and their families

[5.5] Compassion for abandoned and unwanted children

[5.5.1] Compassion

[5.5.2] Abandoned and unwanted: 'irrecoverables', Roma, CHILLD

[5.6] Solidarity: like-minded people joined together in meaningful activity

[5.6.1] These children have value and worth

[5.6.2] Serving the family and the child supersedes treating the disease

[5.6.3] Children come here to be better . . . not to die

[5.6.4] God's work

[5.6.5] Not always perfect

[5.7] Equitable Balance of Power

[5.7.1] Knowledge

[5.7.2] Expertise

[5.7.3] Moral persuasion

[5.7.4] Group dynamics

[5.7.5] Group/personal charisma

[5.8] By way of summary

Chapter 6. Discussion

[6.1] The research question

[6.2] Theoretical foundation, methods, and methodological problems

[6.3] Summary of findings

[6.4] Findings in context

[6.4.1] Empirical success claimed by Clark and Wright

[6.4.2] Actual success: unique paradigm of care: under one roof, just like at home; regularly scheduled, routine hospicization 24/5.

[6.4.3] Real success

[6.4.3] Real success – non-dying image

[6.4.3] Real success – compassion

[6.4.3] Real success – solidarity

- [6.4.3] Real success – equitable balance of power
- [6.5] The medical home model: a standard for PPC success
- [6.6] Power equity, *ex aequo et bono*: an explanatory theory of success
- [6.6.1] Transversality
- [6.6.2] Avoid direct confrontation with the power elite: target the effects of their power instead
- [6.6.3] Treat the immediate problem
- [6.6.4] Oppose efforts to separate the individual from traditional social milieu
- [6.6.5] Contesting the privileges of knowledge
- [6.6.6] Right of self-determination
- [6.7] Implications for practice
- [6.7.1] Children with life-limiting vs. life-threatening illnesses
- [6.7.2] A place to call home
- [6.7.3] A safe haven
- [6.7.4] Routine in-patient admission to maximize quality of life
- [6.7.5] A 24/5 in-house program complemented by 24/7 home care
- [6.8] Suggestions for educators
- [6.8.1] Teaching compassion
- [6.8.2] Compassion burnout
- [6.9] Future research

Chapter 7. Conclusion

- [7.1] Targeting the effects of power
- [7.2] Contest the privileges of knowledge
- [7.3] Treating the immediate problem
- [7.4] Preserve the right of self-determination and control of who we are
- [7.5] Opposing efforts to separate the individual from the society that nurtures it
- [7.6] Transversality
- [7.7] Full circle

Appendices

- A. Ethics application
- A1. Application to amend research ethics approval
- B. Information sheet for children and families
- C. Consent form
- D. Brasov case mix
- E. Interview list
- F. Interview with Oana
- G. Homecare visit
- H. Children's Day Care ethnographic observations
- I. Inpatient ethnographic observations

References

ABBREVIATIONS

AAP	American Academy of Pediatrics
ACT	Association for Children’s Palliative Care (England)
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
CDCC	Children’s Day Care Center
CEO	Chief Executive Officer
CHILLD	Children with Life-Limiting Diseases
CHILTD	Children with Life-Threatening Diseases
CHPCC	Children’s Hospice and Palliative Care Coalition (Australia)
CMSN	Children’s Medical Services Network (US)
EAPC	European Association for Palliative Care
ECEPT	Eastern and Central Europe Palliative Care Task Force
GOSH	Great Ormond Street Hospital
HCS	Hospice Casa Sperantei
HHHH	Helping Hand-Healing Hearts (US)
HHI	House of Health Insurance (Romania)
HIV	Human Immunodeficiency Virus

HRQOL	Health-Related Quality of Life
NHF	National Health Fund (Poland)
PC	Palliative Care
PPC	Pediatric Palliative Care
PPPCC	Pittsburgh Pediatric Palliative care Collaboration
RCH	Royal Children’s Hospital (Australia)
TB	Tuberculosis
TR	Transcendental Realism
UK	United Kingdom
US	United States
VPPCP	Victoria Pediatric Palliative Care Program (Australia)
WHC	Warsaw Hospice for Children
VSK	Very Special Kids (Australia)

Chapter 1. Introduction

This thesis is about the factors that enabled the success of pediatric palliative care in Brasov, a city of less than 280,000 people in the middle of Romania. The study was based primarily on interviews with professional caregivers, family caregivers, and a few children and upon ethnographic observations in the in-patient unit, in the Day Care Center, and during home visits with nurses. This first chapter of the thesis presents the background of study and why Brasov, Romania was chosen as its site. The chapter then provides a road map for the remaining chapters in the thesis.

[1.1] Background

Considerable preparatory groundwork went into developing the research process and methods used to collect and analyze the data.

[1.1.2] Context and Preparation

In 2009 I made an exploratory trip to Brasov which achieved two important objectives: 1) the research question was narrowed and focused on the factors that contributed to the success of pediatric palliative care (PPC) in Brasov, Romania; and 2) I became aware of and was able to preempt some difficulties that I would encounter with the methods.

[1.1.3] Original research question

My original research question – how are children with life-limiting disorders (CHILLD) and life-threatening diseases (CHILTD) cared for in Romania – was overly ambitious

and frankly naive. I learned from my exploratory trip to Romania that the nature and quality of care that CHILLD and CHILTD receive varies widely in Romania. For example, at St. Margaret's Hospice (supported by Children in Distress®¹) in Bucharest, the residents are limited to orphaned CHILLD whose life-limiting disorders have caused severe neurological impairment; they receive supportive care.² Their care is overseen by a social worker and a pediatrician who is certified in palliative care (after a course of study in Brasov) with a special interest in pediatric neurology. In Pitesti at St. Andrews Hospice (also supported by Children in Distress®), orphaned CHILLD have an assortment of diagnoses and receive supportive care in an institutional setting; most, but not all, are very impaired neurologically. Their care is overseen by a nurse; a hospital-based pediatrician who is not certified in palliative care (PC) is available for consultation. In Tirgu Mures, only CHILTD with cancer receive palliative care and only as outpatients; no home care or inpatient residential care is available. Both pediatric oncologists are PC-certified. In Timisoara, CHILLD are seen in consultation by a physician (PC-certified) at the hospital, but there is no homecare infrastructure; orphaned CHILLD care is provided in small home-sized facilities (residential). A nursing

¹ A philanthropic foundation based in Glasgow: "The Charity is dedicated to helping suffering children in the Balkans and Eastern Europe. We work with the sick, the incurably and terminally ill, those with HIV AIDS or Autistic Spectrum Disorders, the physically handicapped and those who face a daily challenge for life as result of accident, infection, genetic or birth defects, those who daily race discrimination or religious persecution, the socially excluded, the desperate and disadvantaged children and families, the poorest of the poor".

² The World Health Organization defines 'pediatric palliative care' as an approach that improves the quality of life of CHILLD and their families. 'Supportive care' maintains life with food, hygiene, and shelter but makes no claim to improve quality of life. 'Residential care' refers to community-based supportive care in 'homes'. 'Institutions' serve the community but are not funded by or based in the community (for example, St. Margaret's Hospice and St. Andrew's Hospice are sponsored by Children in Distress, a philanthropy which is based in the UK). In this context, both 'residential' and 'institutional' imply that the care is detached and more impersonal.

infrastructure is absent in both Tirgu Mures and Timisoara. In Oradea at Hospice Emanuel, CHILLD (26%) and CHILTD (74%) care is provided by a home care team of nurses and a PC-certified physician. The nurse/administrator is also educated in social work.

Brasov has the complete package: comprehensive homecare, periodic and routine inpatient care and evaluation, outpatient and inpatient consultation, and day care are available for all CHILLD and CHILTD (that is to say, the full spectrum of diagnoses) in their locale. The work of caring is shared by pediatric nurses, a pediatric social worker, a psychologist, nursing aides, and a pediatrician. One of the nurses is also certified in social work, and one of the social workers is qualified in nursing as well.

Each location is distinctive, and might merit a separate study, but the success of pediatric palliative care in Brasov stood out from all the others. The question was then narrowed to what factors contribute to the success of pediatric palliative care in Brasov.

By refining the research question, the process of reducing the available data and bringing it together was initiated.³ This first visit to Romania also provided a prelude to the methods difficulties that would need to be addressed when I returned to Romania in 2010 (see **Chapter 4. RESEARCH PROCESS and METHODS**).

Before this study was initiated, CHILLD care in Brasov was considered such a success that it promised to serve as a beacon or shining example for other countries in South-central and Eastern Europe (Anon., 2003). However, the factors that enable the success

³ Miles and Huberman define 'data reduction' as a part of data analysis that occurs continuously throughout the research project. (Miles & Huberman, 1994, p. 11)

of pediatric palliative care (PPC) in Brasov were not known. Since a storybook declaration of success may conflict with the reality on the ground, I set out to substantiate their success by examining and understanding the contributing factors.

Before providing a road map for this thesis, a few introductory remarks are in order to help position the study, namely why was Brasov targeted for the study and how did it become a 'beacon' for PPC?

[1.1.4] Why Romania and why Brasov?

An international map of palliative care services in 2003 showed a conspicuous void in the Balkan countries with the singular exception of Romania (Clark & Wright, 2003). That same void persists a decade later (Centeno, et al., 2013, p. 24). This observation is not at all surprising in light of the age-old supposition that the Balkans lie on the periphery of the 'civilized world', spinning in unending cycles of internecine hatred and war (Kaplan, 2005, pp. xlv-iv). The Balkans lay in a fault line between the East and the West where the two great political grinding stones turn on one another – where religion, culture, and strident nationalism are thrown into the mill and produce unpalatable grist. 'Balkanization' has become a synonym for reversion to the primitive, the tribal, the backward, and the barbarian (Todorova, 2009, p. 3). A Balkan mentality implies deceit, exaggeration, and unreliability (Glenny, 1999, p. xxi). I was naively drawn to look more deeply into this void for three reasons: 1) only Romania met the criteria used by Clark and Wright (2003) for PPC but I assumed there must be some provision for dying children in the face of such endless suffering in other Balkan countries such as Serbia and Croatia; 2) if such care could be brought to light, our

cosseted and privileged healthcare systems ought to have something to learn from how they care for these children; and, moreover, 3) might the exposure of such kindness, compassion, and humanity be the beginning of an end to the senselessness of cyclic hatred, war, and poverty. My naivety on the third count was shattered when I learned that the first acts of inhumanity in the Balkan War of 1992 were the napalm bombing of an orphanage and the burning of a Lipizzaner brood (horse) farm in Lipik, Croatia. Nonetheless, my commitment to study pediatric palliative care in the Balkans hardened. Professor David Clark, who was my PhD mentor at the time, suggested exploring PPC in Serbia since he had good personal contacts in Belgrade. I applied for and was granted a Serbian-US Fulbright Research Scholarship. Unfortunately, I was forced to decline the scholarship because there was no nursing or social welfare infrastructure through which I could identify and gain access to CHILLD in Serbia. Moreover, the necessary administrative support from the Serbian government was wanting. My remaining naivety melted like an ice cube.

Romania is the one Balkan country which has a PPC infrastructure. What is more, Professor Clark described palliative care in Romania as a 'beacon' or shining example for the other countries in the region to follow. Needless to say, PPC in Brasov, Romania is not representative of the other Balkan countries. Part of the explanation may be that Romania lies on the north side of the Balkan Mountains and is sequestered from the Balkan Peninsula countries; however, Brasov PPC is exceptional even in countries north of the Balkan Mountains.

On this occasion, Professor Clark's contacts also enabled my study in Romania. Instead of exploring the palliative care void of the Balkans, I set out to identify the factors that contributed to the success of the Brasov PPC on the rim of the void.

[1.1.5] Beacon of PPC

After an extensive review of palliative care services in the 15 countries of Central and Eastern Europe and the 13 countries that made up the Commonwealth of Independent States, Clark and Wright identified five outstanding examples of hospice/palliative care development which they designated "beacons" for the region (Clark, 2003, pp. 176-179). The five beacons were located in Brasov (Romania), Poznan (Poland), Warsaw (Poland), Budapest (Hungary), and St. Petersburg (Russian Federation). Each of these beacons provided some variation of PPC, but only Brasov and Budapest provided an inpatient PPC unit.

The 'unit' in Budapest at Bethesda Children's Hospital consisted of 6 beds allocated for a palliative care unit on a pediatric oncology ward. Since the publication of their report in 2003, the 6 beds have been absorbed back into the general pediatric oncology ward (Anon., n.d.). The Budapest pediatric oncologists considered that a separate palliative care specialty for children with cancer was redundant; the pediatric oncologists already provided palliative care! This observation highlights a critical differentiation to be made in children who are candidates for PPC: those children with life-limiting illnesses (CHILLD) and children with life-threatening illnesses (CHILTD) such as cancer. This differentiation will be expanded upon in the review of the literature and examined at length in the discussion and conclusion of this thesis. The unequivocal conceptual

limitations of the Budapest PPC are pointed out and contrasted with the PPC unit at Hospice Casa Sperantei in Brasov.

The remainder of this introductory chapter provides an overview of the content and structure of the thesis broken down in traditional themes: review of the literature, methodology, methods, findings, discussion, and conclusion.

[1.2] Chapter 2. Review of the Literature

This chapter defines pediatric palliative care and the need for yet another specialty. The significance of specialization to healthcare policy in general and to the findings of this study holds special emphasis in this chapter. Since one of the findings of the study involves providing both an accessible and familiar healthcare environment, the recently popularized concept of the medical home and attempts to incorporate PPC into the medical home panel are critiqued.

To put the findings of this study in perspective, this chapter presents PPC in different parts of the world – both the developed world and the developing world. The discussion of the further significance of this study is set up and introduced by a review of future challenges for PPC.

Since the orphan 'problem' is so pervasive in Romania and especially in PPC, the review of literature would not be complete without a frank evaluation of the problem.

Finally, since power relations pervade the findings, discussion, and conclusions of this thesis, a theoretical framework for the analysis of these power relations is detailed. I

have leaned heavily on Foucault's theory of achieving power equity in contextualizing the findings of the study and in discussing their significance.

[1.3] Chapter 3. Methodology

This chapter makes the methodological origin of study transparent and situates this study within the transcendental realism tradition of qualitative research. The chapter also provides justification for the methods chosen to collect and analyze the data.

[1.4] Chapter 4. Research Process and Methods

This chapter describes the research process and methods used in this study, namely the sources of data, data collection, and data analysis. This chapter also attends to the formidable issue of gatekeeping and addresses the epistemological integrity of the study.

[1.5] Chapter 5. Findings

This chapter provides answers to the research question "What enables the success of Brasov PPC?" These findings are contextualized in terms of the national financial crisis and the omnipresent Roma 'problem'.

[1.6] Chapter 6. Discussion

This chapter discusses the significance of the findings. The research question is restated and the study's theoretical foundation, methods, and methodological problems are briefly reviewed. The five major findings are summarized and then further contextualized into Bhaskar's (2009) second and third domains of transcendental

reality. From this complex multi-leveled reality, a model or standard of pediatric palliative care and a causal theory of success emerge. The causal theory of success is measured against Foucault's (1994) theory of overcoming power imbalances and provides further insight to the applicability of Brasov's success across different communities. Implications for clinical practice are spelled out and linked to the present-day and future challenges of PPC. Suggestions for educators are also included.

[1.7] Chapter 7. Conclusion

This final chapter reflects on the importance of this study to me in my personal journey and its significance for the delivery of compassionate care for children. Again, Foucault's (1994) theory of achieving power equity is used to align my journey with this study. This chapter strikes the parallels between my journey and the findings of this study and brings them full circle.

Chapter 2. BACKGROUND and REVIEW of the LITERATURE

The purpose of this review is to provide a background that will put the findings of this study in perspective and provide the grounds for a discussion of their significance. This review of the literature begins with a foundational definition of pediatric palliative care (PPC). A frank discussion about the need for yet another specialty ensues. Since the findings of this study offer elements of a solution for the social injustices wrought by specialization, an overview of both specialization and its consequences is presented. A critique of the medical home model of care is included because of its value in healthcare reform and its relevance in the discussion of the findings. To place Brasov PPC in perspective with PPC programs in other parts of the developed and developing world, PPC in Australia, South Africa, the UK, the US, Poland, and Hungary are reviewed. To bring this review of the literature up to date, the challenges which PPC faces in the 21st century are also examined.

Since footprints of power can be followed throughout this thesis, a theoretical framework for the analysis of these power relations is presented to enable a more creditable understanding of the findings. The background for discussion of the findings would not be complete without critiques of the orphan and Romani 'problems' in Romania.

[2.1] Pediatric palliative care defined

In 1628 Francis Bacon gave us a venerable definition of palliative care:

"A wise physician will consider whether a disease be incurable; or whether the just cure of it be not full of peril; and if he find it to be such, let him resort to palliation; and alleviate the symptom, without busying himself too much with the perfect cure: and many times, (if the patient be indeed patient,) that course will exceed all expectation (Bacon & Loewy, 1628, p. 267)."

Bacon's genius and timeless advice "*. . . whether the just cure of it be not full of peril . . . without busying himself too much with the perfect cure . . . and many times that course will exceed all expectations*" is relevant to the pediatric neurosurgeon considering reoperation for an invasive malignant brain tumor or the oncologist considering yet another round of 'salvage' chemotherapy for a child with leukemia. The parents and the practitioner are grasping for the fleeting hope of a miraculous cure and compelled by the "technological imperative" (Callahan, 1993, pg. 89) – any technique offering the possibility of saving or prolonging life. Decision-making is not evidence-based but rather charged with fear and potential loss. Each attempt to save or prolong life with technology is fraught with the increasing prospect of hastening death and decreasing the quality of life which remains to be lived. More neurological deficit (for example: facial palsy, inability to swallow, paralysis, coma) after trying to remove tumor that invades the brain or systemic complications (for example: nausea, vomiting, sepsis, pneumonia) after chemotherapy may require even more futile use of technology (for

example: artificial respiration, tube feeding, intravenous nutrition). In both the case of the child with recurrent malignant tumor of the brain and the child with relapsing leukemia, the prospect of cure is nil and "full of peril". The child is not a hapless victim but rather joins in the "mutual pretense"⁴ with the family and medical staff to maintain their identity and membership in society (Bluebond-Langner, 1978, p. 232).

The term "*palliative care*" is commonly thought to have originated with the Canadian urologist Balfour Mount (Duffy, 2005, pg. 1). Mount was asked by colleagues to host a lecture by psychiatrist Elisabeth Kübler-Ross "On Death and Dying" presuming (wrongly) that he would be familiar with the subjects of death and dying and that as a well-respected physician he would help attract a wide audience for the address. In her lecture, he psychiatrist reflected

"Is our concentration on equipment, on blood pressure, our desperate attempt to deny the impending death which is so frightening and discomforting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being which would remind us once more of our lack of omnipotence, our own limits and failures and last but not least perhaps our own mortality? Maybe the question needs to be raised: are we becoming less human or more human? . . . It is clear that whatever the answer may be, the patient is suffering more – not physically, perhaps, but emotionally. And his needs

⁴ Mutual pretense: each party knows the child is dying but act as if he is going to live (Bluebond-Langner, 1978, p. 199).

have not changed over the centuries, only our ability to gratify them.”

(Kubler-Ross, 1969, p. 23)

This haunting question, “Are we becoming less human or more human?” will be re-addressed in the Discussion and the Conclusion of this thesis.

With that little bit of history, definitions of palliative care abound. The Oxford Textbook of Palliative Care (1998) provides the standard scholarly definition:

“The study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life.” (Doyle, et al., 1998, p. 1)

This definition pedantically addresses eligibility, prognosis, and general focus (“quality of life”) . . . as if the patient is to be studied and managed as a textbook specimen in a glass jar. The definition does not include the family nor other key elements of PPC: symptom management, respite, and bereavement.

In the Oxford Textbook of Pediatric Palliative Care (2006), Lenton et al. defer to the Royal College of Paediatrics and Child Health for a definition:

“Palliative care is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite, and care following death and bereavement (Lenton S. , Goldman, Eaton, & Southall, 2006, pg. 6) .”

This definition acknowledges the multi-dimensional aspects of caring for children with terminal illnesses.

The World Health Organization's (WHO) definition of PPC is more comprehensive:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers and even in children's homes. (WHO, 2010, p.1)

'Life-threatening' is an apt term for many children who are eligible for or who would benefit from PPC. Even then the threat may not be constant and may even disappear. Children with life-threatening diseases (CHILTD) have potentially curable diseases but still have a significantly high risk of mortality (for example: cancer, meningitis, HIV/AIDS) (Knapp, Thompson, Madden, & Shenkman, 2009, p.419).

'Life-limiting' designates those children who will die in childhood or early adulthood. Children with life-limiting diseases (CHILLD) include the following categories:

- Likely to die from a severe congenital anomaly, for example, single ventricle cardiac syndrome
- Progressive condition with intermittent crises, for which there is currently no cure; for example, neurodegenerative disorders
- Irreversible but non-progressive condition causing severe disability leading to susceptibility to health complications and likely premature death; for example, spina bifida, and severe cerebral palsy. Technology-dependent children (for example, respirator-dependent) would also fit in this category or the progressive condition group.
- A rare disease, for which there is little data to guide management. This category would include severely affected children for whom there is no diagnosis.

Knapp et al. (2009) added the last category (rare diseases) to the classification originally spelled out by the Royal College of Pediatrics and Child Health (ACT/RCPCH, 2003). Disease is a means to identify who is eligible for PPC and may seem more 'objective' for provider reimbursement. However, as Knapp et al. (2009) point out, many children with life-limiting conditions have no diagnosis. Moreover, within every diagnosis there is a range of severity. Milder forms of some diseases are neither life-limiting nor life-threatening. Indeed, some milder forms are easily treated and others are preventable.

The importance of differentiating CHILLD from CHILTD will become evident in the discussion of the findings and the conclusions that I draw in this thesis.

As the literature strives to define PPC as a specialty, the reader may be left wondering how PPC is different from the primary care provided by a general pediatrician, especially in light of the definitions proffered by the Royal College of Paediatrics and Child Health and iterated by WHO:

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family (Anon., 2010).

What could be more 'primary' or general than this statement? Indeed, I will present evidence in this thesis to suggest that PPC is not so much a specialty as it is primary care for CHILLD but not CHILTD.

Paradoxically, specialization has generated remarkable advances in medicine and yet has opened the medical profession up to the harshest criticism: that we have become less human (Callahan, 1993) (Kubler-Ross, 1969) or forgotten what it is to be human (Hunt, 1990). Since specialization plays a critical role in the ensuing discussion of this study's findings, some background is proffered.

[2.2]Specialization

Specialization certainly dominates medicine in the developed countries of the UK (Stevens, 1966) and US (Stevens, 1971). However, a deeper layer of truth which is rooted in social structures and causal mechanisms⁵ underpins this ostensibly self-evident necessity.

⁵ The 3-layered ontology of transcendental realism – empirical, actual, and real – will be fleshed out in the **[3.4] Traditions of qualitative research**.

Weisz argues that in the 19th Century advances in medical science depended on bringing together many similar cases for empirical observation and clinical research. At the same time, he argues that the 'administrative rationality' of managing large populations was to classify and then separate them by class. Accordingly, the most efficient way to manage the large populations of patients that were accumulating in public hospitals⁶ was to separate them by disease classification (Weisz, 2003, p. 539). In France, for example, the immense size of the public hospital Hotel Dieu prompted reformers to recommend that it be replaced by 'specialty' hospitals for maternity patients, for the insane ("lunatics"), for 'fetid' (causing offensive odor) diseases, and for contagious disease. Thus, institutional specialization was a rational response to an enormous socioeconomic problem (Goldstein, 2001, p. 60) and, at the the same time, served the advancement of medical science by clustering patients with similar diagnoses.

The elite in medical education resisted specialization because they recognized that organs were interconnected in systems, and knowledge of a single organ and its diseases was not complete without the knowledge of other systems. There was also the holistic notion that "the science of man is one": all parts of medicine were linked, and the physician ought to have a unified fund of medical knowledge (Weisz, 2003, p. 556). Nonetheless, to support the theory that advances in medical science could be achieved by concentrating the number of similar cases 'for study', specialist hospitals or

⁶ Especially in the mid-1880's, the casualties of the American Civil War and the French Revolution were overcrowding public hospitals with wounded soldiers, contagious patients, mental cases, sick children, et cetera. Hotel Dieu in Paris (the oldest hospital in Europe), for example, had 1400 beds with up to 6 patients per bed during the French Revolution.

'institutes' flourished in the UK and in the US; for example, St. Peter's Hospital for the Stone⁷ in 1860, the National Hospital for Nervous Diseases at Queen's Square in 1859, and the New York Neurologic Institute in 1909 (Weisz, 2003, p. 569). Lower rates of morbidity and mortality for lung resection, pancreas resection, aortic valve replacement, coronary artery bypass grafting, and esophagectomy are associated with concentrating cases in one location. (Birkmeyer, et al., 2003, p. 2117) Other studies have also shown that better outcomes from a surgical procedure are achieved by surgeons who do a higher volume of that particular procedure (Hu, et al., 2003, p. 401). And, of course, specialists are paid at least twice as much as non-specialists (Laugesen & Glied, 2011, p. 1647) – the power of financial gain is not an insignificant force behind specialization. Specialization and its tunneled focus on disease have unequivocally produced scientific and technological advances but have also generated more patients with enduring morbidity, disability, and 'stacked' co-morbidities⁸ (Starfield, 2001, p. 304). Specialization is also accompanied by the technological imperative⁹ to save and prolong life at any cost (Callahan, 1993, pg. 89). A familiar echoe resounds, "Are we becoming less human or more human (Kuebler-Ross, 1969, p. 23)?" Needless-to-say, ever-increasing specialization has wrought social problems of the first order: out-of-control health costs, health care inequalities, health care fragmentation, and discontinuities in care (Porter, 1997, p. 661). Technology alone accounts for as much as 65% of healthcare cost growth in the US (Schieber, et al., 2009, p. 14). In a recent review of

⁷ 'Stone' refers to concretions of minerals such as gallstones and kidney stones.

⁸ New diseases added on to or caused by complications associated with existing diseases create multiple, 'stacked' morbidities

⁹ Any technique offering any possibility of saving or prolonging life is offered to the patient.

developed countries, the US has the most expensive healthcare system in the world and yet consistently ranks low in all categories of performance: quality of care¹⁰, access, inefficiency, and equity (Davis, et al., 2012, p. v)¹¹.

Specialization is here to stay, but healthcare systems and health policy makers are compelled to address the attendant social issues of cost, inequity, fragmentation, and discontinuity. That being said, epidemiological data shows that morbidity clusters in particularly vulnerable subgroups of people rather than being randomly distributed (Starfield, et al., 2003). Groups of sick people with multiple illnesses rather than special groups of diseases are the epidemiological priority. Moreover, co-morbidities are the rule rather than the exception (Starfield, 2001, p. 303). People at the end of life are one such vulnerable subgroup with multiple co-morbidities, and the cost of their multi-specialty care is remarkably high. In the US, 10-12% of the total healthcare budget and 27% of the annual Medicare budget were spent on care at the end of life (Lubitz & Riley, 1993, p. 1092). Overall improvements in healthcare equity and quality are likely to require healthcare reforms which are directed at people rather than specific diseases, especially those people who suffer multiple conditions and co-morbidities (Starfield, 2006, p. 23). Thus policy reform has led to the renewed popularity and appeal of primary care medicine and the emergence of a patient-centered medical home model of care (Knapp, et al., 2012, p. 644).

¹⁰ Quality of care was assessed in 4 categories: effectiveness, safety, coordination, and patient-centeredness.

¹¹ The US ranked last of the 7 developed countries compared; the UK ranked 2nd.

PPC is a specialty in the traditional sense that it has a disease orientation – diseases and conditions which are life-threatening or life-limiting – and advances medical science through research, innovation, and education. Pediatric palliative care sets itself apart from other specialities in that its main focus is not the diseases but rather the children and their families who are afflicted by the diseases. Moreover, PPC manages the comorbidities, emphasizes continuity of care, and reduces the cost of care (Zhang, et al., 2009, p. 480) (Wright, et al., 2008, p. 1665) (Morrison, et al., 2008, p. 1783). PPC is not renowned for advanced treatment of disease but rather for preservation of the human dignity and for affirmation of the basic human right to healthcare. PPC harkens back to the notion that the science of man is one (Weisz, 2003, p. 556) and avows that we are becoming more human . . . not less human (Kuebler-Ross, 1969, p. 23).

This review began by attempting to define palliative care as a specialty and was ‘paused’ while a critical review of specialization and the socioeconomic problems which it has created was done. It becomes clear that PPC is not just another niche specialty. PPC has strong similarities with primary pediatric care.

To complete the definition of PPC Meier adds,

“We are all in this together. Consider the kind of health care system we would design for our future selves if we had the choice and could not know what family we’d be born into. It would include healthcare available to everyone regardless of social class or income, with priority for surviving childbirth and childhood, treatment of curable and remediable illness, assurance of relief for those who suffer, and practical support for family caregivers and community resources.

Even if our societal resources are infinite, all of us will still die. All of us are profoundly interdependent and interrelated. All of us need our families to help care for us when our turn comes, and all of us rely on societal infrastructure and resources to help us when we are in need, protect our families from financial ruin imposed by illness, and assure us an equal shot at a long and healthy life.

Palliative care . . . recognizes that serious illness and the suffering that accompanies it is a universal human condition, affecting every one of us. It strives to redress the fragmentation and discontinuities of the health care system, recognizing that the patient and the family still need care when they leave the hospital or the doctor's office. It recognizes that families are the mainstay of the ill and that families need information, guidance, and support to help them fulfill their responsibilities. Palliative care wins trust because it begins and ends with what patients and families say they want and need: relief from pain and other symptom distress; kind and respectful treatment; information necessary to retain control over decisions; help for families; and an opportunity to strengthen relationships with others, seeking meaning through human connection "as deep calls to deep in the roar of waters" (Psalms 42:7)" (Meier, 2010, pg. 59)

In the first paragraph Meier gives us a vision of palliative care – of diversity, fairness, equity, and togetherness – in life as well as death. In the second she highlights the universality of serious illness in the human condition, the propinquity of the family to the ill, the fragmentation and discontinuities of health care systems, and the need for

continuing care “when they leave the hospital”. Meier complements her vision with a statement of the day-to-day mission of palliative care: what it does, who it does it for, and how it is done.

Meier iterates a promising shift in healthcare care policy from a focus on diseases to an emphasis on the patients and families whom the diseases affect. Patients leave the acute-care hospital and return home. The ‘home’ is a suitable platform for healthcare policy reform.

[2.3.] The Medical Home

Healthcare policy reform has led to the emergence of a patient-centered medical home model of care (Knapp, et al., 2012, p. 644). The story of a ‘medical home’ for children in the US may go back as far as 1935 when the Social Security Legislation Act called for the Maternal and Child Health Title V Programs to “locate, diagnose, and treat crippled children” (Anon., 2013). The mandate was to find a place (or home) in the health care system for ‘crippled’ children – children that were previously neglected, orphaned or abandoned by the health care system. The concept of the medical home was formally introduced by the American Academy of Pediatrics (AAP) in 1967 to promote one central source for a child’s record. (Council on Pediatric Practice, 1967, p. 77) A centralized source for the record was especially important to children with chronic illnesses with stacked co-morbidities who received care from several specialists (Sia, et al., 2004, p. 1473). In 1992 the concept was expanded to a medical home for the child’s care:

The American Academy of Pediatrics (AAP) believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them. These characteristics define the “medical home.” In contrast to care provided in a medical home, care provided through emergency departments, walk-in clinics, and other urgent-care facilities, though sometimes necessary, is more costly and often less effective (American Academy of Pediatrics, 1992, p. 774).

This definition of the medical home embraces accessibility, continuity, compassion, familiarity, and coordinated management. By 2004 the concept had matured and was the major thrust of child health policy reform in the US.

The need for an ongoing source of health care—ideally a medical home—for all children has been identified as a priority for child health policy reform at the national and local level. The US Department of Health and Human Services’ *Healthy People 2010* goals and objectives state that “all children with special health care needs will receive regular ongoing comprehensive care within a medical home” and multiple federal programs require that all children have access to an ongoing source of health care. In addition, the Future of Pediatric Education II goals and objectives state: “Pediatric medical education at all levels must be based on the health needs of children in the context of

the family and community” and “all children should receive primary care services through a consistent ‘medical home.’” Over the next decade, with the collaboration of families, insurers, employers, government, medical educators, and other components of the health care system, the quality of life can be improved for all children through the care provided in a medical home (Anon., 2011).

But then again, what does a ‘primary care medical home’ really mean? Concepts and principles need to be applied and then their outcomes evaluated as iterated by this author:

The primary care medical home provides a care model for both well children and those with special health care needs that expands primary care services beyond those provided in the examination room by individual providers to include systemic services such as patient registries, explicit care planning and care coordination, planned co-management with specialists, patient advocacy, and patient education. There is an immediate need for large-scale, practice-based studies of the outcomes for children and youth, providers, and the health care system when such improvements in primary care are implemented. (Cooley, 2004, p. 689)

Parenthetically, tools are now available to evaluate outcomes of a pediatric medical home (Malouin & Merten, 2010).

Alas, implementation of the primary care medical home is not without problems. The average adult primary care physician in the US is responsible for a panel¹² of 2300 patients (Robert Graham Center, 2008, p. 24) (Willard & Bodenheimer, 2012, p. 10) (Reid & Trescott, 2012), and their workload is projected to increase by 29% in 2025 (Colwill, et al., 2008, p. 233). Only 2% of medical graduates are choosing primary care, and a shortage of 44,000 adult primary care physicians is projected in the US for 2025 (Colwill, et al., 2008, p. 236). The future prospects for implementing the adult primary care medical home model seem limited. The prospects for pediatric medical home, however, are more promising. Using US Census Bureau statistics and the National Ambulatory Medical Care Survey, the supply and demand for children's generalist care will be balanced in 2025 (Colwill, et al., 2008, p. 236). Since the supply of generalist pediatricians is projected to be adequate in the future (2025), the concept of a medical home for children seems here to stay.

[2.4] PPC and the Medical Home

In baseball and cricket, 'home' is marked by the home plate where the batter bats and scores are made. In an internet website, home page is the opening, index page. The home office of a corporation is the headquarters. For an elderly person moving into a home means moving to a place which can provide assistance with daily living. For the homesick college student, home is where s/he belongs. To CHILLD or CHILTD a medical home means having a space where they can feel they belong, where they are fully

¹² A patient panel in the context of the medical home is defined as the list of patients who are assigned to a specific primary care physician

understood and appreciated, where they know their caregivers and are known by them, and where everyone is on their side – just like at home. For the professional caregiver, PPC in the medical home is not easy to apply in a general pediatric practice as pointed out in this review:

Pediatric palliative care, a comprehensive, family-centered approach, is now widely recognized as an essential component of care. A crucial element of this approach is to provide consistent, seamless care, regardless of where the child is being treated. Having a medically fragile child on a medical home patient panel may be potentially overwhelming, stretching the limits of the primary care office practice; however, with preparation, networking with other providers, and staff education and coaching, primary care providers have the potential to experience the unique and rewarding opportunity that comes with helping to maximize quality-of-life for such patients and their families. (Tripathi, et al., 2012, p. 112)

Tripathi et al. refer to PPC as “an essential component of care” – but just one part of the care plan. My rhetorical question is “Which part of the care of CHILLD or CHILTD is PPC?” Most children with life-threatening and life-limiting illnesses are not “medically fragile” in the sense that they require frequent acute interventions as a child with recent onset diabetes or viral pneumonia. However, many cannot communicate, are not ambulatory, and have multiple co-morbidities. Moreover, the child with severe cerebral palsy will not look like the other children in the waiting room, and the child with muscular dystrophy in his wheel chair might feel estranged from the other children waiting to be seen. “Consistent, seamless care regardless of where the child is being

treated” is the catchphrase but nothing like home. Knapp et al. (2012) envisions PPC and the medical home as an ‘integration’ model:

In the proposed integration model, the expertise of health care professionals would be more effectively utilized and managed, resulting in improved and expanded pediatric palliative care services. Patients and families would have interactions with members of their palliative care and primary care teams. Thus if the child’s trajectory indicates that end-of-life care is needed, the health care providers taking over at this difficult point of care will be known to the child and family. The transition of care from the primary care team to the palliative care team would be seamless, thereby improving care of the patient, avoiding unnecessary admissions, and avoiding expenditures of resources that are too often implemented by a health care system focused on cure. (Knapp, et al., 2012, p. 644)

Their broad, commanding statement is, however, only conjecture. There is no evidence to suggest the expertise of health care professions would be better utilized or managed. Interaction with members of two separate teams does not translate into familiarity, trust, or confidence. There is no reason to think that the “transition of care” will be seamless. If the care baton is passed smoothly, what happens to bond between the passing team and the family? Is the bond of caring for the patient broken? What will palliative care provide that is not being provided by primary care? Will only PPC be responsible for avoiding unnecessary admissions and needless expenditures of resources?

Homer et al. (2008) reviewed 1268 titles and abstracts and selected 33 articles that reported outcome evidence for the medical home¹³.

None of the studies examined the medical home in its entirety. Although tempered by weak designs, inconsistent definitions, poorly delineated medical home attributes, and inconsistent outcome measures, the preponderance of evidence supported a positive relationship between the medical home and desired outcomes, such as better health status, timeliness of care, family centeredness, and improved family functioning (Homer, et al., 2008, p. 922).

The review provides only “moderate support” for the hypothesis that the medical home concept improved health-related outcomes for children with special health care needs.

The study by Palfrey et al. (Palfrey, et al., 2004, p. 1507) is worth looking at more closely because of its relevance to the Discussion. The data came from six primary care pediatric practices. This is a study of children with special health care needs (CSHCN): 60% had >five qualifying diagnoses¹⁴; 41% were dependent on medical technology¹⁵, and 47% were considered ‘severe’ by their physicians (Palfrey, et al., 2004, p. 1507).

The intervention increased parental satisfaction with pediatric primary care, but more

¹³ Inclusion criteria specified that studies need to be quantitative, focused on populations of children with special health care needs (CSHCN) aged zero to 18 years of age residing in the United States, published between 1986 and November 2006 in a peer-reviewed journal that included abstracts, written in English, and based on primary or secondary data analysis.

¹⁴ 1) Mental disorders (*International Classification of Diseases, Ninth Revision* [ICD-9] values 290-319); 2) diseases of nervous system/sense organs (ICD-9 values 320-389); 3) congenital anomalies (ICD-9 values 740-759); 4) conditions originating in perinatal period (ICD-9 values 760-779); and 5) symptoms, signs, ill-defined conditions, and organ-specific conditions (ICD-9 values 780-799, 001-289, 390-739, 800-999, and V42.7).

¹⁵ Medical technology included gastrostomy, tracheostomy, continuous positive airway pressure, oxygen by mask, ventilator, and mechanical hospital bed

importantly, parents of the most severely affected children were the most satisfied. CSHCN include children with life-threatening or life-limiting diseases (CHILLD and CHILTD). As of the date of their publication (2004), all six practices have been able to continue the intervention without the financial support of the study grant. The intervention was implemented by pediatric nurse practitioners (PNP). One small but telling detail is that the PNP at one practice has been replaced by a social worker – telling in that it emphasizes the important although often neglected role of the social worker. This small study was not controlled or randomized, and my interpretation is that the ‘intervention’ was a nursing model of enhanced care coordination rather than a comprehensive medical home model. The American Academy of Pediatrics defined the characteristics of a “medical home”:

. . . accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them (American Academy of Pediatrics, 1992, p. 774).

[2.5.] Pediatric Palliative Care in Different Parts of the World

To put the findings of this study in perspective, CHILLD and CHILTD care in other countries merits review. Grinyer has emphasized the necessity for studies in different countries to show that the needs of their children are met (Grinyer, 2012, p. 168). The

task of describing PPC in different parts of the world has been undertaken by the International Observatory on End of Life Care (Lynch, et al., 2009) (Wright & Clark, 2006) and the European Association of Palliative Care (Centeno, et al., 2007) (Centeno, et al., 2013). Knapp et al. (2009) have highlighted innovative programs in Australia, South Africa, the UK, and the USA (Knapp, et al., 2009). 'Innovative' may not be synonymous with 'successful' but these programs provide a substantive basis for comparison with Brasov. In response to the potential criticism that comparing PPC in a developing country with PPC in developed countries is unfair or inappropriate, programs in Poland and Hungary were added.

[2.5.1] Australia

Very Special Kids (VSK) was founded in 1985 as a support organization for CHILLD and CHILTD: bereavement support, family activities, camps, and counseling. A registry of the families that attended the activities, camps, and counseling and bereavement sessions defined the population that would benefit from PPC. While working with these families, the need for in-patient hospice care became evident. The VSK House in Melbourne was Australia's first pediatric hospice. VSK House was established in 1996 for respite, transition¹⁶, and terminal care¹⁷. This eight-bed unit serves 820 families in the Victoria community – one third of those families are bereaved. It is staffed by pediatric nurses and aides; general practitioners who are experienced with CHILLD and CHILTD visit daily and are on-call. Referrals come from the community: parents, hospital staff,

¹⁶ 'Transition' is presumed to mean assisting in making the transition from hospital to home, but it has also when used in the context of transitioning from pediatric to adult services.

¹⁷ "The hospice facility is used predominantly for respite care but a small number of children receive terminal care there each year" (Hynson & Drake, 2012, p. 385).

and community providers. This is clearly a 'grass-roots' organization that was founded by the community to address the needs of the community. The referral process is open and designed to merge the curative and palliative tracks, but there is no pediatric homecare service in Melbourne. Forty regional palliative care teams provide home care to adults in the state of Victoria, where Melbourne is the capital, but they lack experience with children. As a reflection of its community groundedness, VSK is heavily dependent on a network of trained volunteers for family support. Continuity of care also seems dependent on the time and commitment of the volunteers. Only 20% of healthcare funding comes from the government; the remainder is from philanthropic sources (Knapp, et al., 2009, pp. 132-133) (Hynson & Drake, 2012, pp. 384-385).

The Royal Children's Hospital (RCH) in Melbourne provides high-level subspecialty care to most CHILLD and CHILTD, and hospital-in-the-home programs are available for short-term respite care. However, eligibility for these programs is very restricted. Despite the fact that most of the children who are served by VSK are also seen at the RCH, the links between the two institutions have traditionally been weak (Hynson & Drake, 2012, p. 387).

Duplication of services and poor communication led to the creation of the Victoria Pediatric Palliative Care Program (VPPCP), an association of pediatric health care professionals that function as intermediary between RCH, the Pediatric Program at Southern Health (also in Melbourne), and VSK. The multi-disciplinary VPPCP functions under the auspices of RCH as a consultation-liaison team, providing planning, coordination, and advice. With no resources to provide direct patient care (Hynson &

Drake, 2012, p. 388), VPPCP risks creating more crisscrossing passages in the labyrinth of care.

The diversity and complexity of services available to CHILLD is exemplified by the case example of Billy, an eight year-old boy with adrenoleukodystrophy: a general pediatrician, a general practitioner, pediatric pulmonologist, pediatric neurologist, pediatric gastroenterologist, pediatric orthopedist, social worker, physiotherapist, occupational therapists (home and school), case manager to organize pediatric home respite, VSK for out-of-home respite, adult palliative care team (for palliative care nursing, counseling, and music therapy), and a pediatric palliative care program which provides access to services and resources, help with decision-making, and management of symptoms as well as emotional, psychological, and social issues (Hynson & Drake, 2012, p. 386).

That being said and with Grinyer's admonition that the needs of families must be addressed and studied, it is worth noting what exactly Australian parents want for their children. In a project commissioned by the Australian government to "identify a model of care that would best meet the needs of CHILLD, CHILTD, and their families", the parents wanted

. . . an integrated, user-friendly, co-operative, interdisciplinary, flexible, compassionate service, not a fragmented, labyrinthine collection of services that did not "speak to each other". (Hynson & Drake, 2012, p. 383)

Perhaps the authors use Billy merely to showcase the wealth of resources available to CHILLD, but his care certainly has the potential to be a “fragmented, labyrinthine collection of services that do not speak to each other”. The lack of pediatric home care further confounds the collaborative model created by VSK, RCH, and CPCCP and falls short of a comprehensive paradigm of care for these children. The palliative care of orphaned CHILLD and CHILTD as well as those from the indigenous populations of Torres Strait Islanders and Aboriginal Australians has not been documented.

[2.5.2] South Africa

In contrast to the myriad of services available to Billy in Australia, the needs of a nine year-old orphan (Mahanuwa¹⁸) in South Africa with advanced acquired immune deficiency syndrome (AIDS) were met more succinctly with a home and a place to die at Sunflower House (Voets, 2012). Nearly half (41%) of the population in Africa are children, and 60% of those live in poverty (Harding, et al., 2010, p. 16) (Marston, et al., 2012, p. 34). Of the children in the world living with human immunodeficiency virus (HIV), nine out of ten live in sub-Saharan Africa¹⁹ (Harding, et al., 2010). As a result of

¹⁸ Mahanuwa translates into ‘unwanted’ in the Sesotho language; she was born with HIV, developed advanced AIDS, and died at age nine.

¹⁹ Sub-Saharan or ‘Black’ Africa includes the following countries and covers 3,500,000 square miles:

AIDS, 15 million children have been orphaned in this vast part of the continent (Harding, et al., 2010, p. 11).

The Sunflower House of St. Nicholas Children’s Hospice near Bloemfontein, South Africa, was opened in 1998 as a place for children with advanced HIV/AIDS to die and their caregivers to be supported. Before anti-retroviral therapy (ART) became available, seven children died each month in the 20-bed unit (Knapp, et al., 2009, p. 133). With the advent of ART, serving the needs of these children became ever more complicated by their sheer numbers (1.3 million HIV-infected persons under the age of 25 in 2007), unemployment, severe poverty, and infected children orphaned by HIV/AIDS. To help meet these needs, St. Nicholas Children’s Hospice added a home care program and then in the year 2000 developed three community day-care centers in poor, settlement areas (Marston, et al., 2012, p. 30). The strength of the program comes from the community: caregivers are trained and supervised by professional nurses. By 2007 the program has also expanded to include diagnoses other than HIV/AIDS (Marston, et al.,

Angola	Côte d'Ivoire	Madagascar	Seychelles
Benin	Djibouti	Malawi	Sierra Leone
Botswana	Equatorial Guinea	Mali	Somalia
Burkina Faso	Eritrea	Mauritania	South Africa
Burundi	Ethiopia	Mauritius	Sudan
Cameroon	Gabon	Mozambique	Swaziland
Cape Verde	The Gambia	Namibia	Tanzania
Central African Republic	Ghana	Niger	Togo
Chad	Guinea	Nigeria	Uganda
Comoros	Guinea-Bissau	Réunion	Western Sahara
Congo (Brazzaville)	Kenya	Rwanda	Zambia
Congo (Democratic Republic)	Lesotho	Sao Tome and Principe	Zimbabwe
	Liberia	Senegal	

2012, p. 31). The watchword of Sunflower House is “No child dies alone” (Wrin, 2012); indeed, “Every child counts” (Morris-Travers, 2012) (Marston, et al., 2012, p. 38).

St. Nicholas Children’s Hospice qualifies as a comprehensive PPC service delivery model because it provides an in-patient service, homecare, and day care (Marston, et al., 2012, p. 36). However, little is known and documented about the details of how service is provided in any of these venues or how they are interconnected; moreover, there is a paucity of physician involvement (Harding, et al., 2010, p. 11) (Marston, et al., 2012, p. 31). Sunflower House is on the grounds of a district hospital and may suffer the double stigma of a hospice (house of death) and a repository of untouchables (AIDS). Despite a national and international outpouring of aid, funding for PPC has yet to come from the government although a National Strategic Plan for HIV, AIDS, TB and Malaria and a National Cancer Control Policy includes provision for adult palliative care (Marston, et al., 2012, p. 35).

[2.5.3.] United Kingdom

PPC in the UK became part of the revolution in the care of dying persons that was started in London by Dame Cicely Saunders (Clark, 2005, pp. 1-14). Early development of PPC depended on in-hospital PPC consultation and free-standing pediatric hospices. No review of pediatric palliative care in the UK would be complete without mention of Sister Frances Dominica Ritchie. Sister Dominica founded Helen House, the first pediatric hospices in the UK.²⁰ (Anon., 1988) The need to reduce costs and improve

²⁰ Sister Dominica was named UK Woman of the Year in 2006 for her selfless commitment to pediatric palliative care

quality of care has moved PPC more in the direction of homecare and daycare services (Lowson, 2007). PPC at Great Ormond Street Hospital (GOSH) exemplifies the kind of networking involved in caring for CHILLD in the UK (Knapp, 2009). GOSH's clinical team of three physicians and five nurses provides in-hospital consultation for symptom management and is contracted to serve five London hospices. GOSH also provides specialist PPC to Life Force, a London community-based pediatric palliative care program that provides "hospice at home": symptom management, respite, and bereavement counseling (Anon., 2012). Life Force has alliances with community children's nurses, school nurses, district nurses, and specialist outreach nurses (for example, neurology, respiratory medicine, and oncology) (Baba & Hain, 2012, p. 279) but only provides services Monday through Friday, nine AM to five PM (Anon., 2012). Moreover, a "hospice at home" which covers only weekdays – no nights and no weekends – cannot realistically be called home care. Even the community teams, whom PPC specialists from GOSH support, fail to meet families' wishes for access 24 hours each day, seven days every week (Craft & Killen, 2007, p. 25).

"Our Children's Home Care Team currently provide a 24 hour on-call support service for end of life care for children and young people at home on an ad hoc basis. Staff provide this service as a 'goodwill' gesture, and as a result of this, the existing workload of the community team is either delayed or managed in some other way while providing 'end of life' care. There is no additional funding to provide for this end of life service, meaning that other patient visits are cancelled and only emergency visits provided." (Craft & Killen, 2007, p. 26)

The value of this volunteered 'goodwill' service is articulated by a parent:

"The only reason I survive Friday to Monday is having the doctor's mobile number." (Craft & Killen, 2007, p. 27)

"Having the doctor's mobile number" is understandably comforting but does not suffice for managing intractable symptoms or a child's death at the home. Children don't die during office hours, and life-threatening crises occur at all hours of the day. In spite of the families' wish to have the child at home, children still die in the hospital (Baba & Hain, 2012, p. 279). In the UK 19% of children birth-19 (excluding neonates) died at home; 4% died in hospice; and 74% died in hospital (Cochrane, et al., 2007, p. 3). Until an infrastructure that will support a 24/7 response system for home care is in place, the venue for crisis management and end of life care will remain the acute hospital. Davies (2010) continues to stress the inequities in the provision of Community Children's Nursing (which includes PPC) in the UK and calls for "a wholesale change in the working culture of paediatric (palliative care) services" (Davies, 2010, p. 5). Her call will resound in Chapter 6 (see **[6.4.3.2] Compassion** and **[6.9] Future research**).

PPC in Australia and the UK seems top-heavy – stacked high with expertise, education, and services. But without a broad base of pediatric nursing support, the programs are likely to tip over and spill its contents with any sharp change of course or gust of a crisis. The profusion of services in urban UK and Australia contrast sharply with the paucity of pediatric home care and lack of other services in rural areas in both

countries. The need for networking, coordination, and cooperation is common to both countries. I would only intone the requests of parents in Australia for:

. . . an integrated, user-friendly, co-operative, interdisciplinary, flexible, compassionate service, not a fragmented, labyrinthine collection of services that did not “speak to each other”. (Hynson & Drake, 2012, p. 383)

On the other hand, PPC in South Africa is bottom-heavy. A strong base of volunteers trained by nurses is deeply embedded in the community and provide the bulk of basic hands-on CHILLD and CHILTD (including orphaned CHILLD and CHILTD) care. Rock steady and immovable, South Africa PPC needs physician input to meet the expanding needs of their children.

[2.5.4] United States of America: Florida

The US has a privileged healthcare system that spends more per capita on healthcare than any other nation in the world but ranks 13th in patient satisfaction.²¹ PPC is disguised in multiple, duplicate layers of benefits designed for specific diagnoses and conditions (for example cerebral palsy, cystic fibrosis, and spina bifida). The major obstacle to the advancement of PPC in the US has been the lack of a reimbursement mechanism; regulations for government reimbursement for adult hospice were written to embrace the last six months of life and required physician certification. (Knapp, et al., 2008, p. 1212) Since children don’t die so predictably and could seldom be certified for the benefit, the government eventually waived the six-month benefit period for

²¹ Perhaps reimbursement and funding are not the defining principles of good healthcare.

children. But PPC has continued to struggle with eligibility criteria, physician resistance to referral, identifying eligible children, and rural isolation. Such struggles are exemplified by Florida's *Partners in Care: Together for Kids*, a pilot 'model' program that provides home PPC and the promise of care continuity. The program is considered at the cutting edge of innovation – the first program to provide PPC beginning at the time of diagnosis. The children were identified for enrollment in the model program by nurse care coordinators of the Children's Medical Services Network (CMSN), the state of Florida's program for children with special needs. Once a child was considered eligible, the CMSN nurse coordinator was responsible for obtaining the consent of the child's primary physician to refer the child as having a potentially life-threatening condition. Then the nurse was required to obtain the consent of the family before referring to a hospice. The hospice, nurse coordinator, and family then developed a plan of care upon which all participants signed off. The primary physician was copied but not involved in formulation of the plan of care. Reimbursement to the hospices comes from the Agency for Health Care Administration, which authorizes the hospice waiver. A key to the success of the program is the CMSN nurse coordinators – their energy, experience, education, and networking skills varied at different test sites in the state of Florida. Ongoing education, language-appropriate materials, and diagnostic screening tools improved enrollment. Moreover, prior to a child being assigned to a CMSN nurse coordinator, new cases enrolled in the state program are pre-screened and flagged. Duplication of effort amongst the service partners – hospice and CMSN – is reduced by careful auditing, computerized tracking systems, and provider collaboration. The

logistical complexity of administering and coordinating this model of care may limit application in other countries. However, there are elements that have global appeal: early intervention rather than at the very end of life (as crisis intervention), reduced duplication of effort, a family-based plan of care, and 24/7 hour service (Sumner, 2006). There are also unseemly elements that are globally recognized: physician-dominated referral process (approval needed), limited access, and no apparent provision for orphaned CHILLD.

[2.5.5] Poland

Early proponents of palliative care from Belarus, Bulgaria, the Czech Republic, Hungary, Latvia, Lithuania, Poland, Romania, and Slovakia gathered annually in Poznan, Poland. During the Ninth Palliative Medicine Advanced Course, the Poznan Declaration (Anon., 1998) was signed which outlined the goals of the group. At their tenth meeting in 1999, the Eastern and Central Europe Palliative Care Task Force (ECEPT) was created to implement the goals and create standards of care (Knapp, et al., 2012, p. 256). These two events played a pivotal role in the development and success of Brasov PPC (see

[6.6.4.1] Transversality).

Pediatric palliative care in Warsaw, Poland, was designated as one of five beacons of palliative care in Eastern and Central Europe (Anon., n.d., pp. 177-194). Brasov was also selected as a beacon. The selection criteria are relevant to this review: 1) significant contribution to the historical development of hospice and palliative care in that nation, 2) involvement of individuals of "national/international repute", 3) the existence of a center for education and training, and 4) evidence of influence on health

policy as it relates to palliative care (Clark & Wright, 2003, p. 177). Individuals of “national/international repute” are supported by the many workers in pediatric palliative care that have dedicated their lives to caring for CHILLD but stand in their shadows. One such individual is Jolanta Grabowska-Markowska. In the shadow of Polish adult palliative care pioneer Professor Jacek Luczak, she managed a hospice residence (“stationary hospice”) for the terminally ill adults, school-age children, and teenagers with cancer in Poznan (western Poland) in 1990. In 1994 she took a similar position in Myslowice (southern Poland) at Hospice Cordis (Hospicjum Cordis, 2012). In 1998 the Children’s House of Divine Guardian Angels was created at Hospice Cordis. The children’s hospice consisted of three beds on the second floor (but no elevator) above the six beds of the adult hospice. A new combined facility in neighboring Katowice was completed in 2012 (Hospicjum Cordis, 2012). Meanwhile, Jolanta Grabowska-Markowska was granted an MD in 1999, in 2002 became certified as a pediatrician and in 2003 as a palliative care specialist (Hospicjum Cordis, 2012). The paradigm of care at Children’s House of Divine Guardian Angels has not been documented for comparison with Brasov; the criteria for admission as well as the involvement of homecare and daycare are not available on their website. There is only the hint of orphaned CHILLD care. My point in bringing this relatively small children’s hospice to the readers’ attention is the value of a comparison with Brasov to future research which would complement this study.

Stationary or inpatient pediatric palliative and hospice care is the exception in Poland. The preferred model of care is in the home “which best meets the needs of the dying

child” (Karwacki, 2012, p. 262).²² Warsaw in east-central Poland became home to the first specialist home care hospice for children in Poland in 1994 – the Warsaw Hospice for Children (WHC). WHC was founded by Tomasz Dangel, a pediatric anesthesiologist who was disillusioned with the care of children with cancer in acute hospitals. The service has been expanded to include children with non-oncological diseases. In contrast to Brasov, the program has been duplicated in 15 other locations within Poland.

After the initial flush of success, WHC has painted itself into a corner. The program was initially financed by the National Health Fund (NHF). In 1999 the WHC published “Polish Standards in Pediatric Palliative Care”, but the standards have never been implemented by the Ministry of Health which administers the NHF. Instead, the Ministry of Health provides

. . . a guaranteed and reimbursable service [for] children until the end of 17th year of age, suffering from a life-limiting condition at terminal stage mentioned by name in a detailed list contained in the Decree, with an expected death within 90 days. (Karwacki, 2012, p. 264)²³

Only a few Polish PPC hospices can provide a model which integrates continuing care of the underlying disease (for example, phrenic nerve palsy, cystic fibrosis, and spina

²² However, only 36% of children dying under the care of Polish PPC hospices die at home. (Karwacki, 2012, p. 263)

²³ The ‘service’ is defined with minimum standards: 1) 24 hours/day, 365 days/year availability of interdisciplinary care team, 2) one pediatrician per 20 children, 3) one nurse trained in PPC or PC per 12 patients, visiting them at least twice weekly, 4) a social worker, 5) a psychologist for every 24 children, and 6) a physiotherapist for every 30 children. (Karwacki, 2012, p. 264)

bifida) and its multi-organ effects but do so without government reimbursement. In most children's hospices, especially those supported by Dr. Dangel and WHC, the parents must sign a release to withdraw from active treatment of the underlying disease (Karwacki, 2012, p. 263). Not surprisingly, this requirement is strongly supported by the Ministry of Health. Reimbursement policy has come to define the Polish standard of PPC. Although this policy may reflect Dr. Dangel's background experience with CHILTD with cancer, it is no wonder that the dominant emotion of parents of CHILLD and CHILTD in Poland is helplessness. (Dangel, et al., 2006, p. 105) It is relevant to this study that helplessness surfaces in the palliative care literature in the same context as powerlessness (Kissane, et al., 2001, p. 12), (Milberg, et al., 2004, p. 120) as will be argued in **[2.8.2] Powerlessness and helplessness** and **[6.5]**

The medical home model: a standard for PPC success.

[2.5.6] Hungary

At Bethesda Children's Hospital in Budapest, Hungary, three rooms (a total of six beds) in a pediatric oncology ward were allocated to PPC in 1995. The director of the hospice was a general pediatrician, and most of the nurses were trained in pediatric oncology and palliative care.

In 1999 Bethesda Children's Hospice co-hosted the first European pediatric palliative care conference with Warsaw Hospice for Children. After this propitious beginning, the beds have been absorbed back into the oncology ward.²⁴

²⁴ Personal communication with Delia Birtar, MD, Hospice Casa Sperantei, Brasov, Romania

On May 19, 2010, “the ‘first’ Hungarian children’s hospice, Dori House, was officially opened” (Anon., 2010), but there are no further details published or to be found on the Internet. According to the report of Centeno et al. (2013), there are two pediatric inpatient hospices (nine beds) in Hungary; both hospices opened in 2011 (Centeno, et al., 2013, p. 149). No other details were provided.

The question now is, can Brasov or any of these innovative PPC programs meet the challenges of the 21st century?

[2.6.] 21st Century Challenges for PPC (Liben, et al., 2008)

Liben et al. (2008) evaluated the progress that had been made in PPC since the landmark report of the Institute of Medicine in 2003 (Field & Behrman, 2003). The paper was co-authored by Liben from Canada, Papadatou from Greece, and Wolfe from the US. The significance of this review is in the authority of its international authorship and the timeliness of its content. Their definition of PPC is a clear change in the swing of the pendulum from cancer to include other severe, chronic life-limiting illnesses:

“PPC is focused on ensuring the best possible quality of life for children whose illness makes it likely that they will not live to become adults . . . recognizing the need to improve access for the many children worldwide that lack basic medical care, we contend that all children facing the possibility of death would benefit from the application of basic, low-cost principles of PPC (Liben, et al., 2008, p. 852).”

This simple, low-key statement has global appeal and contrasts sharply with the rather ambitious manifesto of the London-based Association for Children's Palliative Care (ACT) which was updated in the same year (ACT, 2008):

- Every life-limited baby, child, young person and their family in the UK deserves an individualized 'package' of care and support 24/7
- That they have the choice of where care is delivered
- That there be a seamless transition from child to adult palliative care
- That universal emotional and bereavement support for extended family (diagnosis to death) be available
- That they have the choice of place of death
- That there is sustainable funding

ACT set the bar for PPC, but presented a vision which is unobtainable in the UK and, for that matter, in any other culture or country. The ACT manifesto was more the agenda of an advocacy group rather than a statement that could be applied purposefully. The merger between ACT and Children's Hospices UK to Together for Short Lives in 2011 produced more substantive objectives:

- The right information from the moment of diagnosis so they can make choices about the care they receive

- Easy access to services so that they can spend more time together
- The best quality care
- Reliable support now and throughout their journey (Anon., n.d.)

The challenges presented by Liben, Papadatou, and Wolfe (2008) are similarly straightforward and grounded:

1. Understand the needs of the children
2. Provide care that responds adequately to suffering
3. Advance strategies that support caregivers and health-care providers alike
4. Develop an approach that is appropriate across different communities

I will discuss each of these challenges in turn and bring them up to date in the literature.

[2.6.1.] Understanding the needs of children with life-limiting conditions and their families

Using concept mapping methodology, Donnelly et al. (2005) offer an “empirically-based conceptual model of the needs of children with life-limiting conditions”. The concept map has 74 need statements that are clustered in seven groups: pain, decision-making, medical system access and quality, dignity and respect, family-oriented care, spirituality, and psychosocial issues. The authors liken concept mapping to astronomy: the ‘need’ items which are brainstormed by professional caregivers are like stars, and the clusters of stars are like constellations. Indeed, imaging constellations requires a vivid imagination. Twenty-five pediatric experts searched for stars through the

methodological telescope: nurses (6), social workers (6), physicians (4), "public health professionals" (4), psychologists (3), educators (1), and chaplains (1). Once the needs were identified, the experts invited some of their colleagues to join in rating the needs by importance and feasibility. Another social worker, a nurse, two physicians, an educator, and two more pastoral care providers joined the group for a total of 32 raters. Each statement of need was rated 1-5 for importance (1= not very important to 5=extremely important) and 1-5 for feasibility (1= not feasible to 5= already being done). The pain cluster was the most important (4.9) followed by decision making (4.3), medical system access and quality, dignity and respect, family oriented care, and spiritual concerns clusters (all at 4.1); finally the psychosocial cluster came in at 4.0. Similarly feasibility in the groups ranged from 4.1 (pain) to 3.4 (medical access and quality). (Donnelley, et al., 2005, p. 264)

This study has conceptual limitations. An "empirically-based conceptual model" is a contradiction of terms, especially if *empirical* is interpreted as derived from experience or observation and *conceptual* as developed from an idea or from the mind. The needs of Donnelley et al.'s study are not seen through the eyes of the children or their families but rather through the eyes of 'experts' in the field. Psychosocial concepts such as "love, fun, laughter for release, and access to child-friendly Web sites" come from the professional caregiver rather than the child and family. Similarly, the spiritual item "to create a personal legacy" seems hardly relevant to a child. "Dignity and respect" is comprehensible to the retired railroad worker with advanced lung cancer²⁵, but what

²⁵ The study was modeled on prior work with an adult population.

does it mean to a severely impaired child with metachromatic leukodystrophy or cerebral palsy? Bereavement and the management of symptoms other than pain are also not included in the model. This study also has serious practical limitations. Not surprisingly all the professionally brain-stormed needs were rated as either 'very important' or 'extremely important', and the feasibility of satisfying these needs were rated 'feasible' or 'very feasible'. The study has not been validated and the results are not only unconvincing but also lack practical application. I am left with the authors' 'beliefs' (as contrasted to 'results' or 'findings') which are iterated at the conclusion of their Discussion:

There is no question that enhancing quality of life is a goal of palliative care.

Ultimately, the definition of quality of life for children with life-limiting or life-threatening conditions is a personal one for the individual child and the family.

(Donnelley, et al., 2005, p. 266)

Huang et al. share the aforementioned authors' belief about enhancing quality of life but fall short of providing detailed 'needs'. Instead, they focus on measuring outcome in terms of health-related quality of life (HRQOL) (Huang, et al., 2010, p. 176).

Unfortunately, the standard instrument (Pediatric Quality of Life 4.0) proved invalid for measuring HRQOL in this population (Huang, et al., 2010, p. 180).

Is it too ordinary to say that these children and their families simply want a 'good death' or more to the point, a good life: a humane care system that people can trust to serve them well as they live and die, even if their needs and beliefs call for departures from routine practices or idealized expectations? (Field M. & Cassell C., 1997; p. 24) (Field

M. & Behrman R., 2003, p. 40) The poetry of a gifted 12 year-old who died at the age of 14 with dysautonomic mitochondrial myopathy in the company of PPC gives some perspective (Stepanek, 2001, p.14).

When still in my life of now
When I swing,
I feel happy
And excited, and peaceful,
And yet,
I feel a little lonely
About the time that
Will come, when I will not be
Able to swing anymore,
And so, for now,
When I swing,
I move back and forth
In the everywhere
And the Nowhere
That is the understanding
Of an echo.

Indeed, the term 'good death' is too ordinary; a good life to the very end is more to the point. Without over-interpreting Stepanek's poetry, he expresses a need for acceptance,

participation, and involvement. His existential poetry also speaks to me . . . for the very neurologically impaired CHILLD.

When I swing,
I move back and forth
In the everywhere
And the Nowhere

To be born with or acquire a life-limiting disease should not be a death sentence waited out on death row. Indeed, as a 12 year-old suffering with HIV commented "I want to grow up until I die" (Ferreira, 2010, p. 22).

Chris Feudtner tries to sum up the literature on the needs of children with life-limiting illness to date:

"The perception of quality of life of impaired patients has an entire spectrum and needs to be investigated or researched and certainly cannot be presumed. We don't really know how parents prefer to make medical decisions for CHILLD – or the reasons and values underlying those preferences" (Feudtner, 2010, p.588)

Perhaps the perception of quality by impaired patients and their families is not so complex, and perhaps a paradigm which turns on parents' individual preferences would be too muddling.

The European Association of Palliative Care (EAPC) Taskforce for Palliative Care in Children asserts that CHILLD across Europe have similar but not the same needs.

The needs of children and families living with life-limiting and life-threatening illness are similar across Europe. Meeting these needs requires a comprehensive and integrative approach from a skilled multidisciplinary team. (EAPC Pediatric Taskforce, 2007, p. 7)

Their recommendations can be pared down and summarized to symptom management, emotional support, social access to other children, and spiritual care appropriate to their cultural and religious background.

Grinyer has provided in-depth individual accounts of what it is like to provide care to a dying child and emphasizes the need to statistically map the expressed needs and concerns of children and families across countries (Grinyer, 2012, p. 168).

The second challenge put forth by Liben et al. was to provide care that is appropriate to the suffering.

[2.6.2.] Adequate Care for Suffering

Suffering in children, especially in infants and the neurologically impaired CHILLD is poorly understood (Liben, et al., 2008). At the outset, 'suffering' must be carefully defined. Is suffering the emotional dimension of pain, or is it the dyspnea, nausea, and other distressing symptoms? Or does it take on an entirely existential meaning – a threat to our being. Eric Cassel's definition of suffering as an experience which results from a threat to any part of an individual's personhood is hardly pertinent in the context of CHILLD (Cassel, 1991, p. 46). Viktor Frankl, a psychiatrist and survivor of the

holocaust, asserted that lack of meaning must accompany physical discomfort and deprivation to cause suffering (Frankl, 1984). Did the children with AIDS dying in Romanian orphanages really suffer – never knowing attachment or loss? Perhaps they have only known deprivation and physical discomfort and have no emotional platform from which to suffer. What is their 'personhood'? Ira Byock points out that the major religions view suffering as having a purpose: suffering is a way to rise above the imperfections of human existence (Byock, 1994, pp. 8-12). Tell that to a child who is struggling to breathe. Are we so overwhelmed by our own suffering in the presence of death or sense of hopelessness, meaninglessness, and despair in what we see and hear from our patients that we fail to provide simple symptom management? If the child is indifferent – not knowing death as good or bad, is that child free of suffering? Since we can't preserve hope or transform hope for young children, do we build an image or promise of a future to live for . . . or to die for? Or is quiet darkness welcome relief from the bright lights that blind them and noise around them that makes them stiffen and jerk – a quiet, dark place that is not here? Psychologist Sourkes suggests otherwise:

"This is not dark work. The reality may be black or dark grey, but the kids aren't. They're adorable." (Chester, 1998)

From interviews with bereaved parents (interviewed on the average 3 years after the death of the child) in the US, Wolfe et al. spoke of another reality for children dying of cancer: 89% of children experienced significant symptoms (pain, dyspnea, fatigue, and loss of appetite most commonly) (Wolfe, et al., 2000 , p. 326). What was even more

revealing was that only 27% of children with pain and 16% of those with dyspnea were satisfactorily treated. This was, indeed, a wake-up call for pediatric palliative care.

To determine if their own Dana-Farber Cancer Institute had risen to the challenge, (Wolfe, et al., 2008, p. 1717) interviewed a more recent second cohort of bereaved parents (1997-2004 vs. 1990-1997). The response rate of those contacted was 71% (the referring oncologist disallowed contact of 10%) – similar to the response rate in the original cohort. They found less suffering in the last month of life – a 19% decrease in pain, 21% decrease in dyspnea, and 19% for anxiety (Wolfe, et al., 2008, p. 1721). As care became more preemptive, that is to say, when PPC was introduced earlier in the course of illness, fewer children were dying in the intensive care unit and fewer children were having more things done *to* them rather than *for* them. Eight-seven percent (vs. 80% in the earlier study) of deaths were attributed to progressive disease rather than complications of treatment. There was even the suggestion that outcomes were improved for children who died of treatment complications. It should be emphasized that this study was limited to CHILTD and that these rather compelling results are based upon a parental survey and a time series, single-site design rather than a more convincing multi-institutional cluster randomized trial.

The challenge of responding adequately to suffering of CHILLD and CHILTD is also being met internationally. In a study from Germany that surveyed bereaved parents of children who died of cancer (also co-authored by Wolfe), the most distressing symptoms were fatigue, loss of appetite, pain, and dyspnea (Heckler, et al., 2008, p. 166). All symptoms were treated successfully except for anxiety and loss of appetite. Is

loss of appetite more distressing to the parent who loves and nurtures their child with a spoon? Who owns the anxiety? How much of it is shared? In a similar study that Wolfe helped organize in Australia, 84% of the children with cancer had suffered one or more symptoms in the last month of life – most commonly pain. Of those with pain, 47% were treated successfully (Heath, et al., 2010, p. 71). Parents were interviewed on an average of four years after their child's death, and the deaths occurred between 1998 and 2004. Though the data seem 'old', there is a clear measure of improvement. The proviso is that more of the children in the Australian study died at home (61% vs. 44% in US) which might expose them to fewer treatment-related symptoms that might otherwise prove intractable. An important limitation in all of the aforementioned studies needs to be iterated: the children all died of cancer.

The existential suffering that a family endures in the presence of a child dying from cancer is universally recognized and documented, (Postovsky & Arush, 2008, p. 75) (Mack, et al., 2009, p. 519), but little is known about the suffering of the family of a child with chronic, life-limiting illnesses. Neurodegenerative diseases make up the majority of the children admitted to Helen House in the UK, and the medical model of suffering (distressing symptoms combined with loss of meaning and purpose) fails to adequately describe the experience of the children and professional caregivers. Their experience may not be "dark work", but most of the children had no means of communication and they die more slowly and more unpredictably than those with cancer (Hunt & Burne, 1995, p. 22).

[2.6.3.] Advance strategies that support caregivers and health-care providers

The Footprintssm Model (Toce & Collins, 2003, p. 998) was designed specifically for professional caregivers in the US with funding from the Robert Wood Johnson Foundation. In contrast, the 'Pennsylvania model' (Hawley, 2010, p. 61) was created by bereaved parents many of whom are also medical professionals. Both models emphasize advocacy for children and education for parents, caregivers, and professional providers. Helping Hands-Healing Hearts (HHHH), the Pittsburgh Pediatric Palliative Care Collaboration (PPPCC), and the Liam Lawson Foundation for Pediatric Palliative Care joined in a state-sponsored task force to improve PPC. The PPC Task Force made a number of recommendations: 1) convert the large volume of published evidence of best practice to action or practical application; this includes establishing evidence-based standards of practice upon which to base specialty certification and program accreditation²⁶; 2) educate public, government officials, caregivers, and professionals; 3) develop a system for sibling support; 4) provide information regarding PPC at the time of diagnosis to facilitate decision-making: information should be forthright, transparent, unbiased, and ethical; and 5) improve access by coordinating community resources (Anon., 2008). The Pennsylvania Children's Hospice and Palliative Care Coalition emerged from the Task Force with the mission to educate health care professionals, to empower parents and caretakers to educate themselves, to provide advocacy for PPC, and to develop a resource guide of PPC services, including a guide for physicians.

²⁶ Standards of care for pediatric palliative care have recently published by the National Hospice and Palliative Care Organization in the US and in Europe.

In California Lori Butterworth co-founded the Children's Hospice and Palliative Care Coalition (CHPCC), and currently serves as Co-Executive Director along with Devon Dabbs. Together Lori and Devon have spearheaded healthcare policy initiatives including the enactment of the Nick Snow Children's Hospice and Palliative Care Act of 2006. This landmark legislation creates an entirely new hospice and palliative care benefit for children in California. In 2007, Lori and Devon formed an alliance between CHPCC, the National Hospice and Palliative Care Organization, and National Hospice Foundation to develop "Partnering for Children," a national public engagement campaign which includes resources and tools to raise national awareness about the unique needs of children with life-threatening conditions. These strategies which were modeled in resource-rich US (the States of Missouri, Pennsylvania, and California) are very context dependent.

Great Ormond Street Hospital, in partnership with Liverpool Children's Hospital, supports a free phone helpline – Child Death Helpline – which is staffed by bereaved parents (bereaved a minimum of 3½ years) and supervised by PPC staff. In 1995 the helpline registered 1,600 calls; in 2006 the number had grown to 3,400 – a unique service meeting a well-defined need (Knapp, et al., 2009, p. 135).

Modern-day internet resources such as blogging and Facebook have promise, but according to 2012 internet usage statistics, only 34% of the world's population has computer access (Miniwatts Marketing Group, 2012).

One of the most troubling issues for healthcare providers involved with dying patients is 'burnout' (Todaro-Franceschi, 2013, p. 82). Compassion burnout or fatigue has a

number causes. To begin with, medical education has historically been very accomplished at culling compassion out of the curriculum (Pence, 1983, p. 191), (Shea & Lionis, 2010, p. 1679). Shea & Lionis (2010) underscore the decrease in compassion in UK National Health Service. They suggest that the decline is a product of the training that doctors and nurses receive “which may emphasize scientific values while placing little focus on the emotional wellbeing of the patient”. The compassion that young people bring to their professions is ‘taught out’ of them during their training through a process of ‘brutalization’ (Shea & Lionis, 2010, p. 1679). Not surprisingly UK Prime Minister David Cameron recently stated that “lack of compassion in the NHS (National Health Service) is the biggest problem we have” (Borland & Groves, 2012). A promising development is the current effort underway in the UK to create a culture of compassionate care:

The actions set out in this vision and strategy, which have been developed with you, will change the way we work, transform the care of our patients and ensure we deliver a culture of compassionate care (Cummings & Bennett, 2012, p. 6).

Secondary traumatic stress disorder or death overload (Todaro-Franceschi, 2013, p. 82) is another cause of compassion burnout but is more common in adult palliative care where death is a more frequent occurrence than in PPC. Mental exhaustion associated with futile care is a recurring issue in critical care units (Meltzer & Huckabay, 2004, p. 202) (Vincent, 1999, p. 1626) but is not in the purview of this study. Needless-to-say, the involvement of palliative care reduces the incidence of futile care (Temel, et al., 2010, p. 733). The last cause of compassion fatigue that I would like to draw attention

to is the insensitivity or callousness that comes from working with overly dependent families – families who ask for more than the healthcare system can reasonably provide.

[2.6.5.] An Inclusive Approach: An Approach that is Appropriate across Different Communities

Access, informed decision-making, care coordination, and continuity of care are the recurring themes in each of the innovative approaches to PPC outlined by Knapp et al. (2009). These themes echo the recommendations of the Institute of Medicine in the US (Field & Behrman, 2003). However, how are these concepts to be applied “across different communities”? The report by Knapp et al. (Knapp, et al., 2009, pp. 132-6) lacks some practical details. Are the programs ‘successful’? What counts as success? Is it the sheer will power and dedication of the caregivers that carry the program? How burdensome is the ‘paper trail’ which includes the forms necessary to establish eligibility, the records submitted to verify services for reimbursement, and the data necessary for auditing? Are caregivers overwhelmed by forging this trail of paper? Electronic record-keeping is a boon to care coordination and providing continuity of care, and it is quickly becoming the standard of practice in the developed world. Moreover, the internet has tremendous potential in providing access and in making available information for informed decision-making in PPC (Knapp, 2010, p. 66). How threatening are electronic records to privacy and personal freedom in developing and undeveloped countries? Information has considerable nefarious potential to reinforce

oppressive power. And is it enough of a threat to slow the progress of PPC in developing countries like Romania?

The EAPC (European Association for Palliative Care) Task for Palliative Care in Children has recommended a universal healthcare model for PPC:

A homecare service network supported by specialized teams together with temporary residential alternatives offer the most effective, efficient, and viable palliative care solution for children and their families (EAPC Task Force for Palliative Care in Children, 2009, p. 40).

The homecare network is reinforced by specialized consult teams, respite for parental caregivers, and inpatient management of symptom overload. However, 'network' and 'specialized teams' ring hollow and convey an uncertain, faceless accountability.

A social issue that is common to every community in which an innovative PPC program might be applied is the care of orphaned CHILLD and CHILTD. Some background for the care of orphans in Romania is pertinent to the findings of this study.

[2.7] The orphan problem

For me the term 'orphan' carries the perception of a child left behind in the 'bush'²⁷, bereft of family – 'unwanted' and under-valued by a poorly developed society for which survival is the priority. Institutionalization is still the most common fate for orphaned

²⁷ 'Bush' refers to the stark terms of survival in the wild

children throughout the world (Smyke, et al., 2007, p. 210). My frame of reference for an orphanage is the Milton Hershey Industrial School – which was established in 1910 by the American candy-maker Milton S. Hershey in Hershey, Pennsylvania, for male children who were deprived of a mother and/or father. The term 'Industrial School' was used because 'orphanage' gave the perception of large number of homeless children kept under less than desirable – even shameful – conditions. Even 'industrial' was deleted from the name in 1951 as the term had become synonymous with reform school or a prison for felonious children. A name has some truth value, and the school did not wish to be perceived as less than benevolent. Eligibility requirements for the Milton Hershey School have changed to stay in step with social reforms. The School was racially integrated in 1968 and girls were admitted in 1977. What is more, parental death is no longer required; the family unit need only be disrupted (usually by divorce or spousal abandonment). Each child is housed in one of many homes with surrogate parents and other 'orphans' as siblings. Medical care is provided on site and a more sophisticated state-of-the-art hospital is close by. Access to organized individual and team sports is provided. Over a period of years, the children are trained to practice a trade or prepared for college. The Hershey 'orphanage' is a model for institutions dedicated to the care of orphans. No one could argue the magnitude of Hershey's achievement. However, Hershey's school has failed to serve a significant population of unwanted and abandoned children. The School does not provide for the 'other' orphans who are unwanted – that is to say, children who are mentally disturbed or physically

disabled, children with untreated hydrocephalus, and children with other chronic life-limiting illnesses.

The purpose of extolling the virtues of Milton Hershey School (MHS) is not to provide a basis for comparison with the orphanages in Romania but rather to set a standard for the care of abandoned and unwanted children. Hospice Casa Sperantei also cares for 'orphaned' children. Hershey's 'unwanted' children are embraced, nurtured, educated, and prepared for an independent future. Children with life-limiting illnesses are often unwanted and abandoned and deserve the same considerations. Recognition of this standard segues to the 'orphan problem' in Romania and how the care of unwanted and abandoned children plays such an important role in enabling the success of PPC.

Orphan care in Romania has a long and ignoble history. But unlike Hershey, Ceausescu provided a solution for all unwanted and abandoned children. The Roma children were envisioned as a 'Robot Work Force', and the non-Roma as the key to developing Ceausescu's 'Master Race' (Hunt, 1990, p. 28) (Hancock, 1997, p. 6). Such an egomaniacal vision is consistent with Ceausescu's narcissism, but I would put these 'facts' about orphan care in the category of allegations because they are so fantastic that they could easily be interpreted as being conjured up with journalistic zeal. The references above certainly lack the scholarly rigor associated with peer-reviewed journals. Hunt's photographic documentary was published in the New York Times, and Hancock is a Romani activist. However, they did capture a point in time. In contrast, Morrison's work (Morrison, 2004, pp. 168-182) was thorough and methodical. The first paragraph of her Methods section in a peer-reviewed journal makes my point:

The research was conducted in May of 1991 in Hirlau, located in the province of Moldavia, Romania. With one research assistant and two Romanian interpreters, data collected consisted of eight key informant interviews, fifty-nine in-depth interviews, an additional seventy-two survey questionnaires, and twelve case studies. Several site visits to local factories and schools were also conducted. Key informants included international volunteers and local employees working in the orphanages, a priest, schoolteachers, and several Romanian researchers and social service employees. The in-depth interviews and surveys were based on questionnaires covering topics on family life, caretaking of children, employment and income, attitudes toward the disabled and the orphanages, knowledge and attitudes regarding birth control, safer sex and HIV/AIDS, and opinions of the Ceausescu regime and the immediate post-communist political situation. The sample included factory workers, employees of the orphanages, chambermaids, town officials, schoolteachers, librarians, saleswomen, and farm workers. All adult-age categories were represented with slightly more females than males. Ninety-five percent of the respondents were Romanian Orthodox. The case studies were based on disabled family members who were kept at home rather than institutionalized. Issues concerning caretaking, financial constraints, availability of medical and social services, people's perceived etiology of the disability, and family support were explored. (Morrison, 2004, p. 169)

According to Morrison, (2004) 'irrecuperables', those with life-limiting illnesses, were placed in a separate orphanage to be neglected until death. Some of the healthier and

better-looking children were adopted out with the adoption fees paid to the government. Instead of being embraced, the children were left at the orphanages. Instead of being nurtured the children were overseen by a few untrained staff with scarce resources. Instead of being educated they were indoctrinated in Communist propaganda. And, finally, instead of being prepared for independence, they faced an all too uncertain future (Morrison, 2004, p. 179).

Ceausescu's larger narcissistic vision was to consolidate his power at home and to enhance his prestige in the West by becoming a debt-free, world export power through industrialization. A general plan had been instituted in 1948 to meet the high labor needs of such an economy (Kligman, 1998, p. 21); an essential part of the plan was to incorporate women into the labor market. Abortion was criminalized in 1948 (Article 482 of Romanian Penal Code) ostensibly as an effort to stimulate the low birth rate that followed the Second World War. Unfortunately, since modern means of contraception were not available to the majority of women in Romania, abortion was the only sure way to avoid unwanted children, but illegal abortion was associated with considerable morbidity and mortality. The birth rate continued to fall, and in the rhetorical guise of a "humane" concern for women's health and in a more blatant effort to encourage the full participation of women in the workforce, abortion was legalized in 1957. Nevertheless, the birth rate continued to fall until Ceausescu came to full power in 1965. In 1966 with Council of the State's Decree 770 (Kligman, 1998, pp. 52-55), abortion was again outlawed for women less than 45 years of age who had not yet had 4 children with only a few, strictly enforced exceptions. What was unique about this 'decree' was in its detail

– the depth to which the State invaded women’s lives. The immediate effect of Decree 770 was a dramatic surge in the birth rate, but as women found ways to circumvent the law, the rate again began to fall despite increasing political and economic repression (Morrison, 2004, p. 170). Workers were given the bare minimum to survive in terms of food, heat, and electricity. More children only stressed what limited resources were available. In a day-to-day existence whose priorities were bread, electricity, and heat, birth control was available only to the well-to-do (Kligman, 1998, p. 65).

Poor and middle income families simply registered their newborns with the authorities and then dropped them off at an orphanage. The situation was even direr for the destitute Roma (Morrison, 2004, p. 171).

A frequent visitor to Romania, Perolls had the impression that the social climate was deteriorating:

By '75 things were really tightening politically and so we had a guide for that visit. I went with a Swedish friend actually and we were watched all the time and very much herded around together just to see the main tourist sites

(Perolls, 2001)

Both inadequate and poorly-trained staff, as well as ever-dwindling resources at the orphanages, set the stage for the next act in the tragedy: the AIDS epidemic and the well-publicized deaths of thousands of orphans and abandoned children. The set on the stage also included medical negligence, medical incompetence, and a political cover up. Perolls learned of the cover-up from a pediatric hospitalist to whom he was introduced

by a friend. She was caring for HIV-positive children that were in the final stages of AIDS. In his interview with Clark in 2001, Perolls alluded to the cover-up:

. . . she was getting a lot of children brought into the ward that were HIV positive, and that problem had been totally pushed under the carpet. Up until then they weren't really allowed to speak about it, even though they actually knew this virus existed, they weren't allowed to acknowledge it in Romania. So she was getting those children brought in, some not particularly ill but others in fairly advanced stages of the illness. And the friend that I knew asked me if I could get her any training in the UK. (Perolls, 2001)

A brief summary of the origins of this epidemic will provide context for the care of orphaned and abandoned children that is engrained in PPC. The decree came down that the death of any child in the care of a physician under the age of one year would be investigated. The fear of legal investigation resulted in two practices that were contradicted by available medical evidence: 1) the outcome of malnourished newborns would improve with the 'tonic' of blood injected intramuscularly; 2) antibiotics given intramuscularly or intravenously were more effective than when given by mouth; antibiotics were given indiscriminately to treat fever and catarrh.

The unscreened blood that was given to children included HIV-infected blood from the port cities on the Black Sea which exposed Romania to the outside world. To exponentially compound the exposure, contaminated needles used for injections of blood and antibiotics were re-used without sterilization (Morrison, 2004, p. 171).

While this was happening behind closed doors, Ceausescu raised the number of children per family to 5 in 1985 (Kligman, 1998, p. 68). Romanians were pushed to a breaking point. Perolls provides an eye-witness account in his 2001 interview:

And on New year's Eve (of 1989), we arrived on New Year's Eve there was a 13-course gala buffet in the hotel, which is a traditional Romanian celebration, and I think we coped with about three or four courses and then I began to realise that this was, you know, all the communist officials partying the night away, while in Brasov in the town everyone was starving and we'd seen as we'd arrived queues for bread at four o'clock in the morning, the place was an absolute shambles. And it was just, you know, we just couldn't, you know, really stay there any longer at this meal, because it just seemed all wrong. And the following day we went back down to Brasov and I introduced Caroline to the friends I'd met here and, you know, they told us that life was almost impossible, they didn't know where the next, you know, food was coming from. They'd hardly got any heating, the water was intermittent, and life was just terrible really. And just after that was the time when, you know, the Berlin Wall had fallen and gradually countries were opening up. But Romania was a different situation and Ceausescu seemed to have a very tight grip on the country . . . people had heard what had been going on in Timisoara with one of the Hungarian priests being locked up and people being shot on the street. And that is when people started revolting. (Perolls, 2001)

The Revolution of 1989 opened Romania and its orphanages to the outside world and to pediatric palliative care. The care of these unwanted and abandoned children was a starting point for PPC in Romania and has a significant impact on the findings of this study. The plight of another marginal group, the Roma or gypsies, is another social issue that significantly impacts a discussion of the findings. The 'Roma problem' will be introduced separately as part of the findings.

Marginal populations, Ceausescu's 'Master Race', and the State's invasion of women's lives all bear the footprints of power. The Revolution of 1989 changed the face but not the structure (or dining habits) of the power elite (Siani-Davies, 2005, pp. 261-271). A social theory of power gives some background for a discussion of the study's findings.

[2.8.] Power

"Power is everywhere and there is no freedom from or reasoning independent of it" (Lukes, 2005, p. 12). Indeed, since power relations pervade the findings of this thesis, I begin by presenting a theoretical framework for the analysis of these power relations.

[2.8.1.] Power relationships

The parties in a basic power relationship are the principal, who is dominant, and the subaltern, who is acquiescent and accepting of the principal's domination in a certain context or on a particular agenda (Scott, 2004, p. 3). A simple example is the Romanian House of Health Insurance (the principal) determines the compensation for the services that Hospice Casa Sperantei (HCS) (the subaltern) provides. According to Lukes, power relations can be analyzed in three dimensions. (Lukes, 2005, p. 1) In the first

dimension: the more empowered principal can make the less empowered subaltern do something that is not necessarily in subaltern's best interests; for example, the House of Insurance (HHI) reimburses only a fraction of the real costs of care. The second dimension comes into play when the principal reinforces the power imbalance by manipulating the agenda (the list of items subject to the power relationship) in favor of its own the interests. Some of the agenda items are 'organized out' of contention by the power holder (Gaventa, 1980, p. 255). In the example of HHI and HCS, compensation for home care services is not on the agenda and thus not reimbursable. If HCS was entirely dependent on government payment, they would be forced to abandon home care. Thus, the wants and beliefs of the powerless are shaped by the process.

Power is hardened or consolidated in Lukes' third dimension. In the third dimension, the power imbalance is secured and even galvanized by subverting the interests of the less empowered to correspond to those who hold the power. Lukes uses the term 'false consciousness' for the subaltern's internalization of the principal's norm or interests in his third dimension. They are 'false' because the subaltern has subconsciously accepted a norm that is not true to their beliefs. I agree with Gaventa that consciousness is not something that can be imposed and that the term 'false consensus' is more fitting (Gaventa, 1980, p. 29). PPC in Poland labors under a false consensus. Warsaw Hospice for Children (WHC) never implemented their own Polish Standards of PPC in deference to the reimbursable standards or criteria set by Ministry of Health (**see [2.5.5]** **Poland**).The government ignored the true consensus created by WHC and set its own standards so high that only a very limited number of providers can meet them. What is

more, eligibility is restricted only to the last three months of life . . . and parents must sign a release to withdraw treatment of any underlying disease. This false consensus is certainly in the financial interests of the government but does not serve the care needs of CHILLD or CHILTD.

[2.8.2] Powerlessness and helplessness

The issue of helplessness has been introduced earlier in **2.5.5 Poland**. Lukes' theory assumes some degree of agency on the part of the subaltern – some albeit small measure of independence inherent in the relationship with the principal. His theory cannot be applied to the homeless, the untouchable caste in India, the untouchables of leprosy, the Romani, unwanted orphans – especially those born Romani or with life-limiting diseases (CHILLD) – and to some extent all of CHILLD and CHILTD. Such abject powerlessness is present but seldom accounted for. A hint of its significance is provided by parents of CHILLD and CHILTD in Poland whose dominant emotion was helplessness (Dangel, et al., 2006, p. 105). Helplessness is an apt description of the emotion of parents who feel overwhelmed by their child's illness, but powerlessness is more appropriate for the children who have no parents or who have been abandoned by their families. This study's research process and methods account for these children; the factors that contribute to the success of Brasov PPC include them; and in the Discussion the theory of power equity gives a credible explanation.

[2.8.3] An unsteady balance

Setting aside the inequities of the powerless groups introduced above, the agents of power, whether they are the principal or the subaltern, act within structurally determined limits in an unsteady balance; and, within those limits, the subaltern has some autonomy or alternative choices. (Scott, 2004, p. 3) Therein lays the potential for imbalance, resistance, and an active struggle to overcome power inequity. In order to create cohesion and unity amongst the relatively powerless shipyard workers, Lech Walesa popularized the term 'solidarity' in his rise to political power in Communist Poland. The Independent Self-Governing Trade Union which was named Solidarity was formed in 1980, and in 1989 Solidarity won a majority in the first free elections and formed the first non-communist government in the Soviet bloc. In that same year, the Berlin Wall, which was emblematic of the power disparity that existed in the Soviet bloc, was torn down, and a new government was formed in Romania. The Solidarity movement swept through Eastern Europe as a transformative social force, and in an eddy of this movement, HCS/PPC spawned. The data in this study will show that this same solidarity and equitable balance of power are critical to the success of PPC in Brasov. That being said, is this idea or concept nothing more than a power shift – rather than a movement to create social reform? The social mandate of solidarity and its relation to PPC will become more evident in my discussion of the findings. The data will also help clarify or give voice to solidarity. Ahmed gives more background substance to the concept:

Solidarity does not assume that our struggles are the same struggles, or that our pain is the same pain, or that our hope is for the same future. Solidarity involves commitment and work, as well as the recognition that even if we do not have the same feelings, or the same lives, or the same bodies, we do live on common ground. (Ahmed, 2004, p. 189)

[2.8.4.] Solidarity: a moral compass for power

Solidarity provides a moral compass for social relations. We share the same struggles, pain, and hope, and in the care of CHILLD/CHILTD we are bound together by respect for human life and for one another. We are different and yet ". . . we do live on common ground".

Not to detract from the sense of intimacy and purpose that is associated with solidarity, Walesa's agency and Ahmed's definition also underscore the necessity for outreach and diversity ". . . we do live on common ground".

On the occasion of the announcement in Geneva of the creation of an International Committee against Piracy, Foucault asserted that solidarity carries an element of international citizenship:

"There exists an international citizenship that has its rights and its duties, and that obliges one to speak out against every abuse of power, whoever its author, and whoever its victims. After all, we are all members of the community of the governed, and thereby obliged to show mutual solidarity." (Carter, 2001, p. 226)

[2.8.5.] International citizenship

Indeed, HCS/PPC is partner to a larger struggle against authority that comes with international citizenship: the struggle against the deeply entrenched influence of the medical profession, the deep-rooted power structure of the government bureaucracy, and the omnipresence of an untouchable power elite. Foucault has examined the shared characteristics of such enduring anti-authority struggles. (Foucault, 1994, p. 328) He proposed that they have 6 things in common: 1) "transversality", 2) target the effects of power rather than the power elite, 3) look to deal with the immediate problem and don't expect to find a solution, 4) oppose efforts to separate the individual from the society that nurtures him/her, 5) contest the privileges of knowledge – against secrecy and mystifying representations of the "regime of knowledge", 6) resist efforts to control "who we are" – a struggle for the right of self-determination.

[2.9.] SUMMARY OF MAJOR POINTS

By way of summary, a few points bear emphasis.

[2.9.1] Definition

A definition of palliative care provides a backdrop upon which the findings will be silhouetted.

Palliative care . . . recognizes that serious illness and the suffering that accompanies it is a universal human condition, affecting every one of us. It strives to redress the fragmentation and discontinuities of the health care system, recognizing that the patient and the family still need care

when they leave the hospital or the doctor's office. It recognizes that families are the mainstay of the ill and that families need information, guidance, and support to help them fulfill their responsibilities. Palliative care wins trust because it begins and ends with what patients and families say they want and need: relief from pain and other symptom distress; kind and respectful treatment; information necessary to retain control over decisions; help for families; and an opportunity to strengthen relationships with others, seeking meaning through human connection "as deep calls to deep in the roar of waters" (Psalms 42:7)" (Meier, 2010, pg. 59)

It provides insights to the human condition that are universal: the centrality of the family who bears the final responsibility of caring for children, the sense of helplessness in the face of serious illness, and the importance of social relationships in sustaining life in the family after death of the child. The child and family need relief from symptoms, respite from the day-to-day wearing presence of illness, help in accessing a fragmented and sometimes broken healthcare system, and solidarity, a common voice that speaks to this universal human condition. It is noteworthy that there is no mention of death or vague reference to quality of life but rather recognition of the need for help.

[2.9.2.] Pediatric palliative care in different parts of the world

Pediatric palliative care was reviewed in different parts of the world to give perspective to the findings. PPC programs in 4 countries were selected because they have previously been described as innovative. Two other countries were added because they

are situated closer geographically and culturally to Romania and have been previously described as palliative care 'beacons' in Eastern and Central Europe. Thus the review includes programs from 3 developing countries and 3 developed countries.

All of the paradigms reviewed lack a broad base of pediatric nursing support and decisive care coordination. None of the programs have been able to shed the public specter of death: Very Special Kids House in Melbourne Australia provides terminal care for children with cancer; St. Nicolas Children's Hospice in South Africa is where end stage AIDS children go to die; in Poland the parents must 'sign off' on the death of their child before being admitted to Warsaw Children's Hospice. Bethesda Children's Hospital in Budapest no longer has a hospice; the beds have been absorbed back into the oncology ward. Death is especially unwelcome on a children's oncology ward.

PPC in developed countries

PPC in developed countries offer multidisciplinary care and a wealth of services to all children with life-limiting diseases: symptom management, respite, physical therapy, music therapy, occupational therapy for school, spiritual counseling, etc. However, duplication of services, remote access, and poor communication are all too common. What is more, care is at risk for being driven and directed by austere government reimbursement policy. What the government reimburses may be a far cry from what the child and family needs, but it can become the standard of care.

PPC in developing countries

In developing countries, care tends to focus on the children who have the most pressing needs: children dying of cancer (Poland and Hungary) and HIV/AIDS (South Africa). Fragile infrastructures in these countries cannot manage the entire population at need; crisis management is quite different from continuing care for children with severe chronic illnesses. And as international philanthropic support 'moves on' to other countries in need, developing countries become dependent on in-country philanthropy and minimalist government funding.

Limited access and availability

Access and availability is limited by time and space. In the UK, PPC is limited to the days of the week and hours of the daylight – no weekends and nights. In Poland government-reimbursed PPC is limited to the last 3 months of life (and only for a list diagnoses so decreed). In South Africa and Australia, PPC is limited by geographic distance.

PPC for orphans and marginal populations (for examples, Roma in Romania, Hungary, and Poland and Torre Strait Islanders and Aborigines in Australia) is not well documented in any of the countries reviewed. The suffering of CHILLD, orphaned CHILLD, and estranged marginal populations are inexorably linked in the universal human condition.

[2.9.3] Current challenges to PPC

The 21st century challenges to PPC are addressed as follows. A change in the working or organizational culture of PPC would be needed to meet these challenges.

Needs of children and families

The needs of children – once they are relieved of all-consuming symptoms such as pain, shortness of breath, and nausea – are to be like or grow up like other children, to have contact with other children and people, and to escape the 4 walls of their illness. Helplessness is by far the most common emotion expressed by parents in Poland and may well be an emotion shared by parents in other countries but never surveyed. For parents, access to the health care system and help with the care of their child are paramount. How do both parents deal with the illness? How will they manage financially? What about the other children in the family? How do they get to their appointments? Is the marriage at risk? Has the illness created a spiritual crisis? They also need emotional support and value respite or “time off”.

Adequate care

The challenge of providing adequate care for suffering of CHILLD is daunting especially since many of the children cannot communicate. If the child suffers pain, facial expressions, muscle tone, or pulse rate can guide management. Similarly, if the child is short of breath, there are physical signs that help improve care. There is also a heavy existential burden of caring for a severely impaired child.

Supporting caregivers and providers

A number of strategies have been advanced to support caregivers and health-care providers that include educating health care professionals, empowering parents and caretakers to educate themselves, advocacy for PPC, and establishing worldwide standards of care.

An inclusive approach

The EAPC Task for Palliative Care in Children has recommended an inclusive approach that can be used across different communities. The clinical core is a homecare network that is reinforced by specialized consult teams, respite for parental caregivers, and inpatient management of symptom overload.

The liberal use of such buzzwords as 'network', 'specialized', 'teams', and 'alternatives' are like sharp heels sounding on a barren, tiled floor. Homecare is obviously important but is not the key to an all-inclusive, comprehensive approach and certainly lacks relevance to orphaned and Roma CHILLD.

Social power

Finally, a theoretical framework of power relations is presented in preparation for the discussion of the findings.

This chapter has provided the necessary background to have an informed and insightful discussion of the findings of this study. This review of the literature situates the study in

the field of pediatric palliative care and sets the stage for the research questions at play.

Brasov PPC can now be understood and appreciated as compared to other innovative PPC programs in the developed and developing world. The challenges which have been posed set the bar for defining success and redefining PPC. The needs of children and their families must be understood. Care ought to address their suffering. Mechanisms must be in place to support caregivers and healthcare providers. Finally, success ought to be inclusive, rather than selective. The task set forth by this review is to find out what works in Brasov, that is to say, define the paradigm of care. What are more important to the literature and to the discipline of PPC are the social structures and causal mechanisms that underlie the success of Brasov. Then and only then can we posit its application elsewhere in another setting or culture.

To assure methodological rigor for such an ambitious undertaking, the next chapter a transparent articulation of the research methodology which underlies the research methods.

Chapter 3. METHODOLOGY

The goals of this chapter are three-fold: to render the disciplinary origin of my work transparent, to situate this study within the traditions of qualitative research, and to provide justification for the methods chosen to collect and analyze the data that answer the research questions. The central research question is what are the factors that enabled the success of Brasov PPC? The corollary questions are 1) what works in Brasov; that is to say, what is the paradigm of care; 2) why does it work (social structures and causal mechanisms); and 3) would it work elsewhere?

[3.1] Disciplinary origin

The methodology of this thesis is strongly rooted in the humanity of medicine. Although the testing of new drugs and new treatment procedures may require a rigorous scientific approach, quantitative methodology does not do justice to the complexity humankind. This study offers a qualitative but no less methodologically demanding alternative to how and why we care for one another. Caring for people and children in particular, is far from an exact science, and the results are not always predictable. I did not anticipate a career involving research when I entered medical school; I hoped to be a country doctor and part of a small community. My odyssey began aspiring to the human, social side of medicine, but I was drawn to the close correlation between anatomy and physiology in the neurosciences and the apparent exactness of quantitative research. However, my evolving disillusionment with the precision of neurosurgery and my realization that quantitative methodology did not adequately fathom the human condition parallels a paradigm shift from quantitative to qualitative

methods in other basic disciplines and applied fields over the past several decades (Miles & Huberman, 1994, p. 1). My journey brought me full circle back to the human side of medicine and qualitative methodology. A review of this odyssey will provide some insight into my credibility as an investigator and the plausibility of this work.

My career in medicine is rooted in and nurtured by a primary educational system that favored and promoted the biological and physical sciences. But when asked why I wished to attend medical school, I told the interviewer that I wanted to become a country doctor (small town general practitioner) or a medical missionary. He replied sardonically, "Other than your religious zealotry, why else do you want to become a doctor?" Perhaps he wanted to see more interest in the science of medicine, rather than my emphasis on its social and spiritual dimensions, or perhaps he recognized my naiveté and was looking for a more substantive or 'quantitative' response. Needless to say, the daunting complexity of the basic sciences in the first 2 years in medical school seemed incompatible with the simple humanistic vision of being both a family physician and a valued member of a community or practicing outreach medicine in Southeast Asia. How could I know it all as a generalist? On the other hand, how could I justify specializing only on the heart, lungs, or the brain? Cole & Carlin (2009) give perspective to my anecdotal experience:

During the past 40 years, we have become all too familiar with the dehumanisation of modern medicine: new technologies have altered the relationship between doctor and patient; specialised physicians know more and more about less and less; doctors treat diseases rather than people; medical

schools teach the science but ignore the art of medicine; medical technology has outpaced moral understanding; and hospitals have become cold, impersonal mazes. (Cole & Carlin, 2009, p. 1414)

But in the end, specializing was quite simply easier, and I was fascinated by the logic and reason of neurological surgery: form and function, structure and agency, disease and pathophysiology, and, finally, precision surgery. In retrospect, my choice of a career in academic pediatric neurosurgery was flawed in 3 important respects: paucity of humanness, lack of precision, and disappointing research methodology.

My training began in general neurosurgery and included adults and children. My social and spiritual sensibilities were blunted by the physical rigor of training²⁸. The calloused mockery of patients by my senior fellow residents in training was a depressing form of psychological abuse. My peers counted and talked to patients but did not listen or converse with them. On morning hospital rounds, I vividly remember presenting a patient's social circumstances that I passionately believed were important to the management of the case only to be rudely interrupted with "Get to the case!" My reaction to their insensitivity and cold-heartedness might be explained by sleep deprivation, burnout, and/or chronic fatigue. Maslach has described burnout as an "erosion of the human soul":

It represents an erosion in values, dignity, spirit, and will – an erosion of the human soul." (Maslach & Leiter, 1997, p. 17)

²⁸ 120+-hour work weeks were a badge of honor for nodding marionettes; every-other-night on call with no respite after a busy night on call to the next day.

The lack of humanness was also a major challenge to my sense of being and purpose. My biggest fear was that in this process of becoming a neurosurgeon my values and ideals would be rung out of me. Looking back, I took no less than 10 years to recover from the 'brutalization'²⁹ of my training and regain my sense of humanity.

As for the microscopic precision that seems inherent in neurological form/function, structure/agency, and disease/pathophysiology, I watched a neurosurgeon make a lesion (destroy an anatomic locus in the brain) in order to study its functional effects in a monkey; he used anatomical maps and a sophisticated stereotaxic apparatus to zero in on the target. You can imagine my consternation when, at the last moment, he 'eye-balled' the 3-dimensional set-up and said, "It just doesn't look right!" He then made an adjustment free-hand and advanced the needle.

My experience with clinical quantitative research methodology was also disappointing. One example stands out. My clinical experience suggested that the radiation used to cure malignant tumors of the brain in children (e.g. medulloblastoma) had a devastating effect on their neurological development. To show that radiation was an imperfect cure, variability must be controlled and reduced; moreover, the variables must be measurable. Height, body mass, and intelligence are all measurable. So my 'hypothesis' was that children who received radiation for medulloblastoma early in life and survived more than 10 years were short, overweight, and below average in intelligence. This sardonic hypothesis was an early indication of my cynicism. I only

²⁹ 'Brutalization' is a term used to describe the process in the UK which discounts the emotional wellbeing of the patient and instead emphasizes the science of medicine and nursing. (Shea & Lionis, 2010, p. 1679).

confirmed the obvious but learned nothing about the survivors themselves – about the fear of recurrence, the need for ongoing support, the emotional legacy, questions of personal identity, “long-term life plans”, and fertility. (Grinyer, 2009, pp. 31-167) These quantitative studies purposely excluded complicating factors and extenuating circumstances.

This professional odyssey would hardly be complete without some physical suffering on the part of the physician-investigator to heighten the sensitivity of his analysis. Fox opines that “the compassionate engagement in the suffering of our fellowman” is lacking in the medical profession. (Fox, 1986, p. 553) The physician who has suffered from a life-threatening illness of his own may be more sensitive to and perceptive of the suffering of patients living with life-threatening illnesses. I developed an idiopathic cardiomyopathy when I was 42 years old which progressed to cardiac arrest 8 years later. I was placed on an external heart assist pump until a ‘matched’ transplanted heart became available. Three months later I received a heart, but my 8-year experience as a patient only intensified: steroid-induced psychosis, myopathy, bone thinning/fractures, and weight gain. Postoperative contact with the cardiac surgeon was minimal (thumbs up, arm pump), and the personal contact with one of several medical cardiologists was limited to watching him write a requisite note (to justify reimbursement) in my chart at the nursing desk.

When I returned to the practice of pediatric neurosurgery, I was more sensitive to patients’ families who had unrealistic expectations about the success of treatment, and I was more acutely aware of my limitations as an academic pediatric neurosurgeon and

the vagaries of a revenue-driven healthcare system. I had come to a tipping point.³⁰ In an article discussing the suffering of physicians, Cole & Carlin (2009) address the issue poignantly:

Physicians in many developed countries live and work in a technocentric, dehumanised, and financially driven environment often within a broken and unjust system of health care. Those who work in academic health centres face institutional strains caused by the marketplace restructuring of health care, a shrinking safety net, more indigent patients to care for, and increasing competition for research funding. Their counterparts in developing countries often work under conditions that are shaped by inadequate resources, a shortage of health workers, and weak health-care systems. In different settings worldwide, therefore, physicians may work under conditions that increasingly prevent them from living up to their highest ideals (Cole & Carlin, 2009, p. 1414).

I ended my career in neurosurgery, and began a new career in palliative medicine. My life had come full circle from the humanistic aspirations of my youth, to a fascination with the science of medicine/surgery and the quantitative tradition of research, and back around to give a qualitative voice to the most human and intimate aspects of medicine. My odyssey has led to some conclusions about the nature of reality and truth which bear on methodology and help situate this study within the traditions of qualitative research.

³⁰ This term has been popularized by Malcolm Gladwell and will be expanded upon.

[3.2] About reality and truth

For each of us there is a reality – a level of acceptance of what is, what can be known, and what can be achieved with what we know – whether we are carpenters, plumbers, cowboys, doctors, petroleum engineers, or anthropologists. We may be drawn by curiosity, the thrill of the hunt, and/or the wonder of new discovery, but then so often we are driven by the desire to prosper (for example, home, family, transportation, food), to be remunerated (for example, salary/grant), and to achieve the next higher position of authority (for example, assistant to associate professor or to be self-employed). Our view of the world around us is thus biased by our desires, the wishes of those who remunerate us, and the next higher order of authority. In an attempt to investigate or research the true nature of things impartially, without bias or prejudice, investigators adhere to methodical, normative, widely accepted, traditional approaches (see below) within each field of research (for example, health care, public health, anthropology, sociology, psychology, communication); the results aim to meet a high standard or quality of understanding that is credible, valid, and true. Our pursuit of reality hopefully gives rise to truth.

Now that the disciplinary origin of this thesis has been clarified and some reflections on reality and truth are taken into consideration, I will situate this study within the traditions of qualitative research.

[3.3] Traditions of qualitative research

I will put my ontological stance – my stand on *what is* real and can be known – in perspective by reviewing the 2 broad, historic, ontological positions that have been outlined by Ritchie and Lewis: idealism and realism (Ritchie & Lewis, 2003, p. 16). I will then defend and clarify my epistemological position – how ‘what is’ can be known in the context the 4 broad epistemological approaches presented by Grbich (Grbich, 2007, pp. 1-12).³¹

The simplicity and limitations of this presentation hardly do justice to the many nuances and carefully etched variants of these approaches. Taylor and Bogdan (1998) emphasize this point:

Even a cursory review of the qualitative research literature over the past 25 years yields an incredible number of new theories and theoretical perspectives: a sociology of the absurd, reflexive sociology, poststructuralism, postfoundationalism, dramaturgy, labeling theory, critical ethnography, critical realism, emerging relational constructionism, analytic ethnography, interpretative biography, cultural theory, standpoint research, feminist empiricism, deconstructionism, ethnic modeling, critical hermeneutics, resistance postmodernism, and so on (Taylor & Bogdan, 1998, p. 22).

[3.3.1] Ontology: idealism

For the idealist, reality can only be known and understood through the human mind.

What has meaning and is therefore real, is socially constructed and does not exist

³¹ Hirschheim (1995) defines epistemology as: “The nature of human knowledge and understanding that can possibly be acquired through different types of inquiry and alternative methods of investigation” (Hirschheim, et al., 1995, p. 20).

beyond our perception. The properties of objects owe their existence at least in part to being perceived (Michaels & Carello, 1981, p. 86). The idealist moves away from seeking truth to construing meaning (Grbich, 2007, p. 10). Relativism, a variant of idealism agrees that reality is a social construction, but denies that there are shared meanings or a collective mind; social constructions are all relative – to the particular context, culture, and time. The extreme relativism of Derrida's deconstructionism drifts towards nihilism and a leveled rubble of unshared meanings (Bernstein, 1991, p. 172).

[3.3.2] Ontology: realism

For the realist, external reality is separate from and independent of his/her beliefs. There is a clear distinction between this external reality or the way the world is and the beliefs and understanding of it. Commonsense or direct realists perceive a world of material objects that are known to be true through direct experience; and the objects exist even when they are not being perceived. The existence of the real world does not depend on being experienced (Michaels & Carello, 1981, p. 86). Claims to knowledge are justified because the world is perceived directly, as it is. This as-it-is social world is complex and is to be found in detailed descriptions of social events and processes without reference to underlying causal theory. This commonsense reality is captured by bringing all the individual interpretations together – a rich social reality. The diversity of interpretations and experiences reflects the diversity and complexity of the external reality. The aim is to produce as complete a picture as possible to "capture" the external reality (Ritchie & Lewis, 2003, p. 19).

In contrast to the commonsense realists, transcendental realists acknowledge underlying causal mechanisms in a 3-layered ontology: empiric, actual, and real. These 3 layers together make up an absolute reality – not ‘pure’ reality in the sense of unadulterated, undeniable, ultimate, or refined but absolute in the sense standing above all else, not partial or relative and not to be doubted (Lawson, 1997, p. 21). In an interview with Norris, Bhaskar further clarifies absolute truth:

So truth at this higher level just is reality, and it is the reality that grounds or accounts for the mundane realities that we invoke in the absolute conception of truth, and it is that absolute conception of truth that backs our epistemological or social conception of truth (Bhaskar, 1999).

Concrete, physical ‘at hand’ objects which are observable, palpable, and/or countable are real at an *empirical* level, just as they appear. Another real part of our social world – the *actual* – is made up of human events, and experiences that go beyond appearance. Deep to this layer of reality, yet another layer of truth can be found – a preexisting, stratum of social structures (social relations) and causal mechanisms. The social structures and mechanisms themselves are multi-layered and stratified and require human agency to actuate. Nonetheless, they have causal power and are part of our being and the true nature of the world. However, these preexisting, largely invisible structures and mechanisms cannot be deduced from or reduced to the effects that they cause. But the researcher can facilitate their emergence and make explanatory claims about them. Miles and Huberman (1994) are more succinct:

Our aim is to register and “transcend” these processes by building theories to account for a real world that is both bounded and perceptually laden, and to test these theories in our various disciplines. (Miles & Huberman, 1994, p. 4)

The 3-layered ontology of transcendental realism is much like the layers of the common avocado. The avocado, less commonly known as the alligator pear, is a fruit that tastes like a vegetable. Most people know it by its typical green-black, alligator-like, knobby ‘skin’ or peel – its empirical reality. It is what you see in the market. Beneath the peel is the actual or fleshy part of the fruit – the actual reality – what is to be sliced and eaten. As the knife cuts deeper, it meets the core or seed – the real – is encountered. The seed can be planted to create another tree and more fruit. Both the peel and the edible part of the fruit have their origin in the seed, but there is no one part or strand of the seed that can account for the eaten fruit or its covering. The overlapping and interconnected biological and biochemical mechanisms within the seed are far too complex to be deduced from the actual fruit, and although the fruit can be pared down to the seed, it cannot be ‘reduced’ to it. The alligator peel contains the actual fruit which contains or immediately surrounds the seed which is the ‘end’ reality which contains enduring mechanisms such as productivity, reproduction and sustainability . . . but all together the peel, the fruit, and the seed constitute the “alligator pear”.

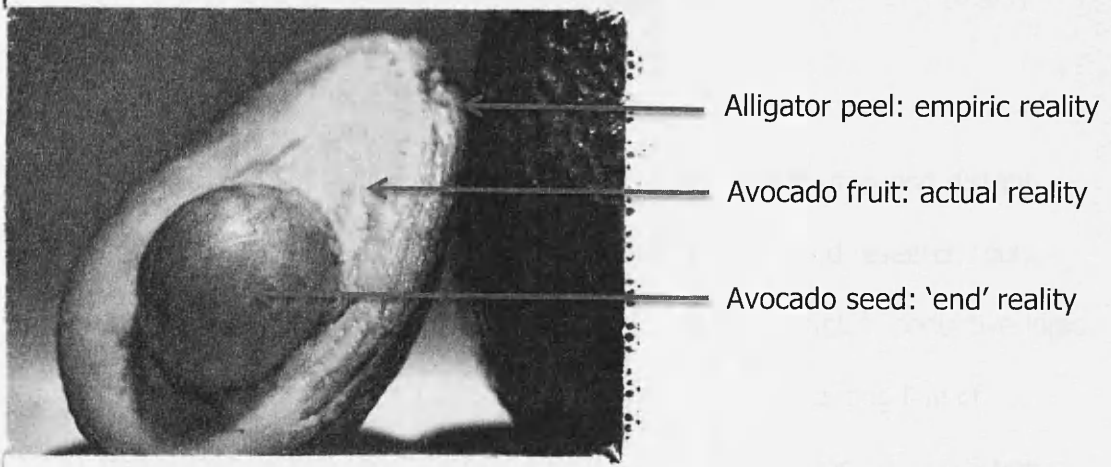


Figure 3.1 Alligator pear: 3-layered ontology of transcendental realism

Commonsense realists might catalogue the many different recipes that call for avocado but discard the seed as inedible whereas the transcendental realists would savor the fruit and look to the seed for causal explanation and replanting.

Bhaskar (2009) asserts that knowledge exists *about* real, concrete objects in an intransitive dimension. The world is not solely “as it is for us” as mediated by social institutions and human-perceived concepts. This real world is also “in-itself”, and we can come to know it (Bhaskar, 2009).

Having settled on a complex multi-leveled reality, how can this reality come to be known or faithfully rendered? Grbich describes 4 broad epistemological approaches: positivism, critical emancipation, constructionism, and postmodernism (Grbich, 2007, pp. 1-12).

[3.3.3] Epistemology: Positivism/empiricism

For the positivist, truth is objective. Knowledge is acquired by a neutral and distant researcher utilizing reason, logic, and a range of carefully pre-tested research tools.

Dominant features are observation and experience, scientific principles, deductive logic, laws of nature, logical determinism (one thing leads to another in a long line of causation), hypothesis testing, and statistical analysis. The objectives are prediction, universality of findings, and generalizability. This epistemology is most characteristic of quantitative research. According to Grbich (2007), the limitations of this approach are: 1) 'objectivity' is easily dulled by researcher bias; 2) knowledge is limited to the sense experiences of observation and experience (or experiment) and disregard such thought processes as intuition, reflexivity, abstract thinking, cognitive restructuring, and thinking outside the box; 3) the positivist's world view is static and fails to encompass the complexity of phenomena (Grbich, 2007, p. 5).

[3.3.4] Epistemology: Critical emancipatory positions

Emancipatory positions in social research were assumed in order to counter the societal fragmentation of the 1960's and 1970's in which reality was imposed by the dominant social powers in exploitive social and political systems (Grbich, 2007, p. 7). Knowledge and ways of knowing were manipulated to serve those in power. 'Critical' researchers challenge or are critical of the reality imposed on the powerless. They seek out and engage the powerless to document the inequality and bring about transformative,

emancipatory change. According to Grbich (2007), this approach has three distinctive limitations: 1) someone decides who needs to be emancipated; 2) someone has all the correct answers; and 3) research may promote social transformation, but it is disingenuous to think of a closeted researcher as a social reformer. Such critical stances are taken by grounded theorists, ethnomethodologists, and ethnographers. The methods they commonly use are interviews, observation, field notes, 'thick' contextualized descriptions, discourse analysis, and discourse deconstruction (Grbich, 2007, p. 7). There are certainly less powerful groups of participants in this study (for examples Roma, Roma women in particular, nurses, children with life-limiting diseases [CHILLD], children with life-threatening diseases [CHILTD], and CHILLD/CHILTD families), but the purpose or goal of this study is not to bring about transformative change in Romania but rather to understand the social mechanisms underlying the success of PPC in Brasov.

[3.3.5] Epistemology: Constructionism/interpretism

For the constructionist/interpretist, social reality is fluid, changing, and embedded. Knowledge is created by the joint or collaborative effort of the research participants and the researcher. The researcher draws near and engages the participants rather than standing clear at a distance, supposing independence and objectivity. Subjectivity and intersubjectivity (construction through interaction with others) are embraced. The constructionist/interpretist stance is taken by grounded theorists, ethno-methodologists, ethnographers, and feminists who use interviews, observations, field notes, 'thick'

descriptions, discourse analyses, and discourse deconstructions to collect and analyze data. (Grbich, 2007, pp. 8-9)

The major limitations of using this approach to answer my research question are: 1) important underlying structures and processes would not be taken into account; 2) intersubjectivity – getting inside the participants' minds – is problematic and leads to superficial individual understandings and an inadequate account of underlying social structures (Grbich, 2007, p. 9); and 3) the thorny issue of intersubjectivity is compounded by the capriciousness of the interpreter effect (Bowling, 2005, p. 209) (see **[4.3.2] Poor quality translation and transcription**) and the potential for only shallow conversations with Romanians who have learned English as a second language.

[3.3.6] Epistemology: Postmodernism

Postmodernism is a reaction to the strict objectivity and purposive simplicity of 'modernistic' positivism. The postmodernist takes a more sweeping, though cluttered view of the world:

Postmodernism views the world as complex and chaotic and reality as multiply constructed and transitional – unable to be explained solely by grand narratives or metanarratives³² (Grbich, 2007, p. 9).

Meaning replaces knowledge as the end game for research. Reality is socially constructed, and the meaning can be exposed by disruption (dissection), multiplicity of

³²Examples of grand narratives are Marxism and Buddhism which make universal claims to truth.

forms, and deconstructive challenge. There are no pretensions of abstract theory, universality, or generalizability. We can only know what is within the narrow scope of our experience. Objectivity is replaced by reflexive subjectivity and transparency. The researcher exposes his biases and prejudices to make his interpretations transparent and uses her/his experiences to help justify them. Positivism's insistence on the validity and reliability of the findings are replaced by transparency in postmodernism.

Transcendental realists (TR) adopt the postmodernistic epistemological tradition with 4 significant provisos. First of all, in order to avoid the collapse of knowledge into nihilism by deconstructive methods, TR looks for underlying structures (social relations) and processes. Secondly, a place for objectivity is reserved at the empirical and actual levels of reality in TR. Thirdly, in contrast to mainstream postmodernism, theoretical explanatory propositions emerge from mechanisms, processes and structures which provide information for policy makers. Lastly, even though TR rejects grand narratives, their ontology facilitates rather than limits theoretical explanations (Grbich, 2007, p. 11).

In summary, my work takes its disciplinary origin from the most human and intimate aspects of medicine and finds a resonant voice in the postmodern tradition of qualitative research. The next chapter will detail the research process and methods used to collect and analyze the data which will provide an answer to the research question.

Chapter 4. RESEARCH PROCESS and METHODS

This chapter describes the research process and methods used in this study. Before moving on to the sources of data, data collection, and data analysis, two important issues warrant attention, namely epistemological integrity and gatekeeping.

[4.1] Epistemological integrity

The methods are informed by the study's methodology which unpacks the nature of social reality. The multi-layered reality of transcendental realism was introduced in the previous chapter (see [3.3.2] **Ontology: realism**) and consists of an objective external dimension (observable, palpable objects), a layer of human events and experiences, and a pre-existing underlying stratum of social relations and causal mechanisms. All 3 layers together make up the reality of being and the true nature of the world in which we ask the research question (What factors enabled the success of pediatric palliative care in Brasov, Romania?). A multi-dimensional approach with data from several sources is called for to gain as full and complete a picture as possible (Fielding & Fielding, 1986, p. 28) (Ritchie, 2003, p. 44). Such triangulation of the data not only allows impressions to be substantiated or rejected but also offers a clearer understanding of the people and the social setting (Taylor & Bogdan, 1998, p. 80). These are the methodological connections that sustain the epistemological integrity³³ of this study (King & Horrocks, 2010, p. 8).

³³ Marshall & Rossman define epistemological integrity as "the logical and compelling connections between the genre, the overall strategy, the research questions, the design, and the methods (King & Horrocks, 2010, p. 8)."

[4.2] Gatekeeping

Gatekeeping in healthcare research is the process of allowing or denying the researcher access to the research site or to the research participants and can be a formidable barrier to conducting research (Lee, 2005, p. 36) (Ewing, et al., 2004, p. 452). Much to my chagrin, gatekeeping had a major impact on the research process and methods. If I had recognized the importance of gatekeeping and identified the gatekeepers beforehand, the beginning of the research process would have been less arduous and wearing. What I failed to address adequately was gatekeeping at the organizational level and at both the medical and nursing professional levels. In the 2009 exploratory visit, Daniela³⁴ provided a travel itinerary and contact sources which would give me an overview of pediatric palliative care in Romania. But when I returned in 2010, I was not prepared for Daniela's resistance to my research plan and her need to shelter and protect the privacy of the children and her staff. Shortly after my return, Daniela expressed displeasure that I had not written up and published the findings of the exploratory visit and dismissed my explanation that the trip was only exploratory and that I had not yet obtained ethical approval to conduct research in 2009. Although I had sent her copies of the Lancaster Ethics Committee Application and the Fulbright resume, both of which detailed the research plan and she had signed off on the Fulbright application and had submitted a letter of support for the application, I failed to recognize that this busy professional could not read every word that I wrote. And it was her habit to make decisions based on face-to-face communication. Daniela was

³⁴ Daniela is the Medical Director of HCS and the contact person who was identified by Professor Clark.

emphatic that the research study would not proceed until I had gained the full support of her pediatric nursing staff. The Director of Nursing, who was a pediatric nurse, was not supportive and curtly stated that the nursing staff were too busy to participate. I had interviewed her in 2009 during the exploratory field trip, and she was the only individual who subsequently refused permission to use her original interview in the current (2010-2011), ethically-approved research study. I resorted to seeking out and speaking directly to the nursing staff in the inpatient unit, but the language barrier was insurmountable. In a chance exchange of pleasantries with the supervisor of the Children's Day Care Center, I learned that she spoke excellent English. She confirmed that the nursing staff had limited English language skills with the exception of the head nurse of the pediatric homecare team. After I explained what I hoped to accomplish, she volunteered to present the project to the pediatric staff at their weekly staff meeting. The staff expressed support for the study, and the head pediatrician took my case to Daniela.³⁵ With prompting from head pediatrician, Daniela agreed to meet with me. After I reviewed the study structure, we went together to the inpatient unit to meet with the nurses, and the pediatric social worker. The major issues of communication were resolved: everyone was 'on the same page', and my primary interpreters or 'connectors' would be the supervisor of the Children's Day Care Center (who learned her excellent English by watching American TV and while employed as a nanny in Switzerland for six months) and head outpatient nurse (who also had an embedded English experience). All of the interviews with the staff were conducted in English with

³⁵ My academic advisors at Lancaster University had also sensed an impasse and lobbied Daniela on my behalf.

the exception of the pediatric social worker who seemed to understand the conversation as well as if not better than head outpatient nurse, our interpreter.

The principal sources of data for this study are interviews, ethnographic observations in the field, and archived documents.

[4.3.1] Data sources: interviews

Since this study accepts that the human events, experiences, and interactions which make up the reality of our being are socially constructed, conversation is a suitable source of data. Conversation does not just simply convey or pass on knowledge but in the postmodernistic epistemological tradition also creates or constitutes knowledge (Grbich, 2007, p. 10). According to Charmaz (2006) interviews are essentially directed conversations (Charmaz, 2006, p. 25). Even though qualitative interviews are a prominent source of data in qualitative research, the assumption that accurate, meaningful information will emerge from or be generated by interview respondents is naïve (King & Horrocks, 2010, p. 17). For the interviews I adopted a reflexive approach commonly used in grounded theory (Anon., n.d., p. 25) (Grbich, 2007, p. 11). That is to say the original semi-structured format for the interviews was continuously adapted to redefine dead-end topics and to accommodate new issues that were raised with the intent of keeping the data grounded in the participants – in what was happening on the ground. Charmaz emphasizes this point:

. . . researchers need to be constantly reflexive about the nature of their questions and whether they work for the specific participants . . . (Charmaz, 2006, p. 32).

Miles and Huberman (1994) emphasize the value of this reflexive process in guarding against "bias-ridden judgments and pre-existing beliefs of rotten scientists" (Miles & Huberman, 1994, p. 262). For example, I had the preconceived notion that 'spiritual calling' or strong religious background was a factor contributing to the success of Brasov PPC. When I visited Hospice Emanuel Oradea during the exploratory field trip to Romania, my belief was informed by a strong spiritual presence and a solid link to the Baptist Church (a church service was included in the itinerary).³⁶ However, during that same exploratory trip a pediatrician associated with Children in Distress in Bucharest flatly stated that her interest in the children had nothing to do with spiritual calling or religious faith. For the most part since the topic of 'spiritual calling' brought only quizzical, ambivalent, or yes/no responses, I deemed it a dead-end topic – a self-deluding result of my tunnel vision. The prompt "Do you consider your work a 'calling'?" was changed to "What brought you here?" Then the conceptual categories of 'working together' and a 'different approach' emerged and were explored as social processes and fleshed out in subsequent interviews (some participants were interviewed more than once).

³⁶ The Hospice Emanuel Oradea website states that its "mission is to provide, in the spirit of Christian love, an optimal quality of life"

In another example, the R2, website designer/publicist, touched upon 'image' while describing their website as one of his responsibilities (descriptive category of 'roles and responsibilities'). His comment touched a responsive chord: developing a satisfactory definition and image of PPC for polite conversation or for fund-raising was, in my mind, an important unsolved problem. By encouraging him to expand on the concept, the interview took an unanticipated but very productive turn into the conflict resolution, team work, and image building that went into the marathon poster image.³⁷ Image building became what Miles and Huberman refer to as a pattern category (Miles & Huberman, 1994, p. 57), a higher-level inferential or explanatory analytic category. Questions that might bring out more about 'image' were included in the Interview Topic Guide for subsequent interviews and contributed to the evolution of several factors that contribute to the success of Brasov PPC. Charmaz's insight is incisive:

Any competent interviewer shapes questions to obtain rich material and, simultaneously, avoids imposing preconceived concepts on it. Keeping the questions open-ended helps enormously. When participants use terms from the lexicon of their experience, such as 'good days' and 'bad days,' the interviewer can ask for more detail (Charmaz, 2006, p. 33).

In this study, the credibility of interview data was challenged in several ways:

- 1) researcher inexperience, 2) poor quality translation and/or transcription, and
- 3) language selectivity and exclusivity.

³⁷ The marathon poster was emblematic of a very successful hospice fundraiser.

[4.3.1] Data sources: interviews – researcher inexperience

I presumed that I would be a good interviewer because I was practiced at interviewing patients and taking medical histories, but in fact I was a middling interviewer, prepping the interviewee for the 'right' answer . . . not encouraging the interviewee to expand or expound. Payne is quick to point out that this fallacy.

Research interviews are different from clinical interviews because they are not intended to lead to clinical interventions or diagnosis . . . researchers need to learn how to explore topics using probes to elicit full accounts. (Payne, 2007, p. 146)

As I re-read the early transcriptions, I wished that I had said "Can you tell me more about that?" Instead the interview often stalled, and I shuffled on to the next semi-structured topic. I talked too much and didn't listen well enough. My lack of confidence and the desire to be well-received gave way to sycophantic prefaces to my questions: for example, when I interviewed M1 (Director of Development), I said "I think something very special is happening here; can you tell me what role you play"? When I interviewed the respondents in 2010, I asked more open questions without preamble which fostered more spontaneous and genuine responses. Charmaz iterates this point eloquently:

An interviewer's questions and interviewing style share the context, frame, and content of the study. Subsequently a naïve researcher may inadvertently force interview data into preconceived categories. Not only can asking the wrong

questions result in forcing the data, but also how interviewers pose, emphasize, and pace their questions can force the data. Such questions may also impose the researcher's concepts, concerns, and discourse upon the research participant's experiences in their own language (Charmaz, 2006, p. 32).

[4.3.1] Data sources: interviews – poor quality translation and transcription

The importance of language in transnational research cannot be overemphasized. My interpreter during the 2009 exploratory trip had limited translation skills, and transcription was a difficult and time-consuming process for her. When I had the 2009 tapes re-transcribed by a professional transcriber in 2010, it became clear that my questions and the interviewees' responses had not been accurately translated and transcribed. Other authors have acknowledged an interpreter effect or bias as a source of error in using interview data. (Bowling, 2005, p. 209) (Jentsch, 1998, p. 275) The interpreter may filter and influence data in another way. If the interpreter is known to the respondent, her/his response may be colored by normative expectations and/or tempered by what the interviewee is willing to share in the presence of the interpreter. To avoid the interpreter effect, I chose to mostly interview English-speaking caregivers and support personnel.

[4.3.1] Data sources: interviews – language selection and exclusion

Most Romanian physicians speak English, but many nurses and support staff do not. In choosing to interview only English-speaking staff (with one exception), I risked creating a major flaw in the design. If I selected the more highly educated members of the staff

(e.g. administrative, development, and fundraising) for the study, I would at the same time exclude the less highly educated, support-oriented staff (for example, housekeeping, kitchen, drivers, nurse's aides, and volunteers)³⁸. The exclusion of support staff only accentuates a potential power disparity. It is conceivable that a different version of success might emerge from the staff who spoke only Romanian and who in fact may have more insight 'on the ground'³⁹. In an effort to minimize this flaw, a number of support staff who did speak English is included in the sample. However, many of the nurses and support personnel who spoke English had learned English through an au pair experience or work experience in the US or UK⁴⁰ and brought with them a more worldly experience. The level of sophistication⁴¹ of those support people who were interviewed was equivalent to the non-support elite staff. For example, I interviewed a support staff person who would fit into the category of 'secretary' or administrative assistant to the chief executive officer, but she is the confidante of many other support people as well as being the mother of a child that died in the care of Hospice Casa Sperantei (HCS). Before being recruited to HCS she was an English interpreter for a truck-manufacturing company in Brasov. R, the one support person interviewed who spoke very little English, is uniquely positioned in the lobby of the hospice where she receives all visitors and greets all staff as they enter. T could have been assigned to translate for the interview, but to minimize the potential for an

³⁸ Housekeeping and kitchen workers are even required by law to wear distinctive blue uniforms.

³⁹ "On the ground" is a military metaphor referring to the action on the field of battle versus the strategic planning in the "war room".

⁴⁰ For examples, O1 spent 6 months in Switzerland as an au pair; R2 worked for a waste removal company in England for several summers; and C worked in England as an au pair.

⁴¹ The Encarta Dictionary defines 'sophistication': a combination of worldly wisdom, self-confidence, and refinement in a person.

'insider' interpreter effect, I used R's daughter as the interpreter. This may produce a more intimate interpreter effect but the transcription contained no discernible instances of the daughter re-interpreting the mother's responses. R was able to provide valuable insight into the internal social dynamics of Hospice Casa Sperantei (HCS), which she may not have confided in the presence of T (home care nurse).⁴²

These two exceptional support persons may not be representative of the majority of support staff. However, in all my days at HCS I witnessed only healthy working relationships and mutual respect between the support and the professional staff, and I believe they shared the same commitment to and compassion for the children.

When I interviewed children or parents, T or O1 (children's day care supervisor) served as interpreter. It is only natural that families would be complimentary of the hospice services because they are dependent on the nurses for access. Any potential interpreter effect on the part of T and O1 was muted by complementary ethnographic observations.⁴³

⁴² In Findings, page 71, Rozi spoke of "rude and harsh" interpersonal conflicts . . . and also spoke of a process of resolution.

⁴³ In Findings, Page 12, I describe the tearful response of the Roma mother of G1 which I initially thought was exaggerated for my benefit and to engender favor with the nurse interpreter. After discussing her response with T and C and incorporating my own observations I was able to conclude that her response was genuine.

[4.3.2] Data sources: ethnographic observations

At first glance, unstructured ethnographic observations⁴⁴ seem unobtrusive: no intervention is plied, and the researcher is but a 'fly on the wall'. Mulhall (2003) has pointed out that when making unstructured observations, the researcher cannot totally separate himself for the 'researched' (Mulhall, 2003, p. 307). Moreover, I am hardly a 'fly' (tall, small-eyed American with a distinctly un-Romanian beard). That being said, the children largely ignored me and seemed to go on about their usual routines. For example, 'H' is a blind, severely mentally and physically impaired child who nevertheless explores his environment by bumping into surrounding objects with his wheelchair. He 'found' me sitting on a couch in the inpatient unit but quickly moved on in his endless search. A, an intelligent 17 year-old boy with muscular dystrophy is another good example of the negligible impact that my presence made:

I was sitting on the couch near the entrance to the day care center and greeted Andrei as he was about to wheeled in – I greeted him repeatedly by name with ever increasing volume, but he didn't notice me until the aide pushing him brought me to his attention. He promptly smiled and said "Hello".

A's world was illuminated by PPC, and I was just a dim shadow – a virtual fly on the wall – in his world. Nevertheless, the 'observer effect' has a variable influence on

⁴⁴ Unstructured observations are characteristic of qualitative research and are made by an observer who has no preconceived notion of what he will see. In contrast, the structured observation made in quantitative research are taken from an observation schedule which is based on predetermined taxonomies (Mulhall, 2003, p. 306)

participant behavior⁴⁵ which has been pointed out by several authors (Holloway & Wheeler, 2009, p. 49) (Berg, 2004, p. 196). I trust that this effect was minimized as I immersed myself in the setting and became part of it (Mays & Pope, 1995, p. 110). Unstructured observations were made that are consistent with the postmodernistic epistemological position. As I pointed out in the methodology chapter (**[3.3.6] Epistemology: Postmodernism**) the strict objectivity of modernistic positivism is for the most part replaced by reflexive subjectivity and transparency. In the postmodern tradition of transcendental realism, however, a place for objective observations is reserved for the empirical and actual layers of reality. Unstructured observations provide insight into social interactions, gather in the influence of the physical environment, and capture both process and context (Mulhall, 2003, p. 307). Nevertheless, the approximate objectivity of my observations is affected by my subjective reflexivity as discussed in **[6.2] Theoretical foundation, methods, and methodological problems**. In the spirit of transparency, I have supported my findings with extensive quotes from field notes and interviews.

[4.3.3] Data sources: archived documents

Access to 2 unpublished documents from the archives of the International Observatory for End-of-Life Care was granted by Professor David Clark: interviews by Professor Clark with Graham Perolls (2001) and with Daniela Mosoiu (2002). HCS annual reports from 2002-2010 were also made available by M1, the Director of Development.

⁴⁵ This effect is most profound in action research

[4.4] Data collection and analysis

The purpose of this section is to convey solid qualitative grounds for how the data were gathered (Charmaz, 2006, p. 1). Much the same reflexive approach used in conducting interviews was taken in collecting and analyzing the data (see **[4.3.1] Data sources: interviews**). Gathering and analyzing data were parallel, complementary processes rather than serial processes taken in order. That is to say, the data were not collected and then analyzed but rather analyzed as they were being gathered. An advantage of this iterative, reflexive approach was to explore unanticipated circumstances that would have an impact on the factors of success. I did not anticipate, for example, the enormous social welfare burden of orphan care and the Roma population. The guide for subsequent interviews included prompts about Roma children which disclosed a whole new dimension to PPC success. My growing interest in the care of Roma CHILLD and CHILTD led my homecare nursing hosts to include an entire day of home visits in a Roma village. Without the ongoing processes of data collection, reflection, and analysis (Taylor & Bogdan, 1998, p. 141) I may have missed a significant dimension to their success and the critical insight that PPC did more than just provide care to Roma children but also empowered Roma families.

In preparation for data collection, a list of generic descriptive categories that might lead to success was put together. Another advantage to simultaneously gathering and analyzing data is to 'thicken' or broaden the data and not limit the scope of the data to the original descriptive categories (Charmaz, 2006, p. 46) (Taylor & Bogdan, 1998, p. 140). The list was expanded after studying transcripts from the first wave of

interviews. To deal with what was destined to become an imponderable mass of data, the data were repeatedly reduced, stacked, and collated.

To further clarify and make transparent the data collection and analysis process, some comments about data logistics are helpful. Abbreviated notes were made in the car between home visits and in the inpatient unit while making rounds with the staff or 'hanging out'⁴⁶ on the couch next to the nurses' station. I also saved notes from daycare field trips which were jotted down in short hand on small pieces of paper and stuffed in my coat pocket in an attempt to avoid being obtrusive and to minimize the observer effect. My 'job' for the field trips was to push wheel chairs and open doors. At the conclusion of every field trip from the day care unit and when we returned from a day's home visits, a formal set of field observations were word processed into an ethnographic journal and saved in two duplicate digital files. In accordance with standard practice (King & Horrocks, 2010, p. 45) (Stockdale, 2002, p. 38) audio-tapes of the interviews were also saved in two separate files and copied electronically to the transcriptionist. The field notes and transcribed interviews were studied over and over again; excerpts that corresponded to a category were referenced (to the original document), recorded on a card, and 'stacked' in that category. Similarly, thoughts and concepts which surfaced during this reflexive process were saved on cards and were submitted to the same process of filtering and sorting that facilitated identification of similar phrases, themes and patterns. Higher level themes emerged from the alignment of the categorized data. To rule out spurious relationships (Miles & Huberman, 1994, p.

⁴⁶ "Deep hanging out" is a term used by anthropologist Clifford Geertz for prolonged presence in a culture to make ethnographic observations (Geertz, 2000, p. 110)

272) and to check for representativeness (Miles & Huberman, 1994, p. 263), the inferential and explanatory themes which emerged were interrogated by further data collection, sorting, 'clustering'⁴⁷, and analysis. Data were collected until this iterative process expended itself at the point of theoretical saturation.

Categories are 'saturated' when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories (Charmaz, 2006, p. 113).

To model or approximate this complex process, I have modified Miles and Huberman's interactive schema to better represent the continuous, rolling evolution of the analysis (see Fig. 4.1).

⁴⁷ Miles and Huberman (1994) define 'clustering' as the process of inductively forming and iteratively sorting categories (Miles & Huberman, 1994, p. 249)

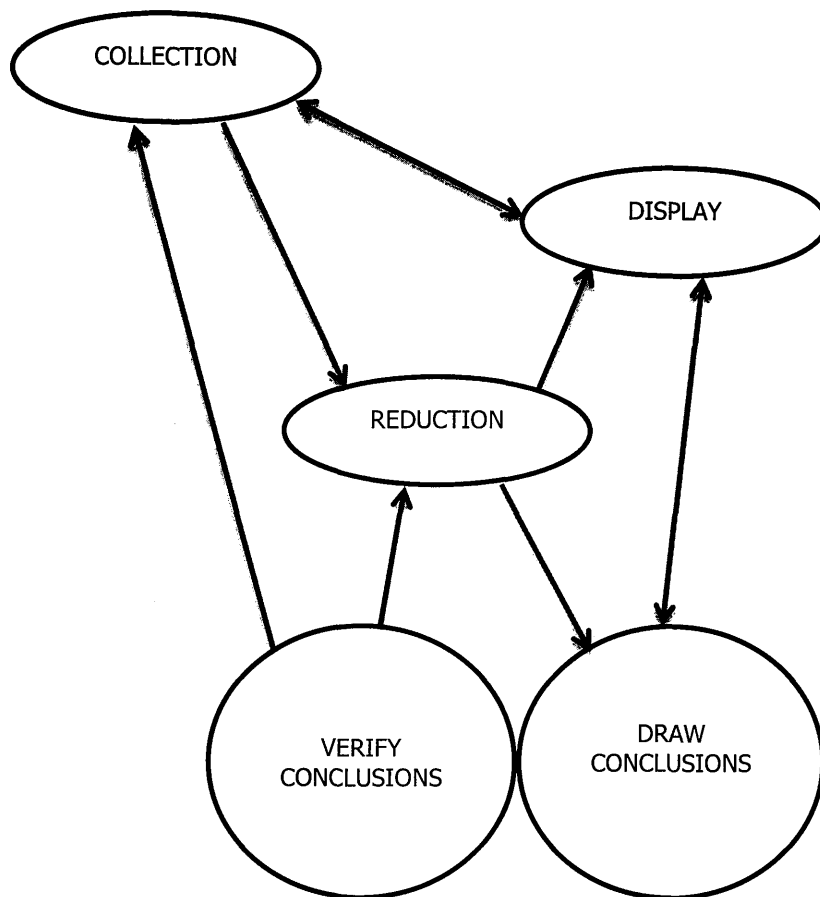


Figure 4.1 Interactive model of data collection and analysis: modified from Miles & Huberman (Miles & Huberman, 1994, p. 12)

Miles and Huberman's original schema has a one-way connection from "collection" to "display"; I find it more useful to consider a reciprocal connection. Data displayed in a table may prompt the addition or collection of more data to make the display more meaningful. Similarly, the original depiction of "conclusions: drawing/verifying" as a single component has been modified to a more tentative and separate "drawing" and "verifying" components. (Miles & Huberman, 1994, p. 12)

This review of the research process and methods segues to the results or findings of the research study. At the beginning of the next chapter, I will present a geographic breakdown of the interviews and ethnographic observations from which the findings are derived. Suffice to say, the duration of the time spent in the field is my best estimate.

Chapter 5. FINDINGS

Figure 5.1. Professional caregiver interviews by city in Romania



City	Nurses	Physicians	Social workers	Administrative support
Brasov	4	2	2	9
Tirgu Mures		3		
Cluj-Napoca		2		
Oradea	2		1	1
Timisoara	2	3		
Bucharest	3	2	1	1
Pitesti	1	1		2

Figure 5.2. Home visits: Roma vs. non-Roma interviews with location of Hospice (H) Casa Speranței. Each visit lasted about one hour.



I spent eight months in Romania, 102 days of which I spent in Arcus, a small village 40 minutes north and east of Brașov. The remainder of the time was spent in Brașov at the hospice (inpatient unit and day care center) and walking back and forth from the hospice to my room near Poiana, Brașov. Twice each day I walked through a busy, ever-changing market quarter replete with musicians, vendors, beggars, and hundreds of people – a rich ethnographic milieu. Four days of formal, recorded ethnographic observations were made in the hospice inpatient unit; four days were spent with in the day care center; and four days were spent in home visits. I spent the days in Arcus working on a family horse farm in the company of a child with a life-limiting illness, a Roma farm worker and his two boys, nine non-Roma village workers, and a host of fellow equestrians. The experience provided a treasure trove of ethnographic

observations which were largely committed to memory and only selectively to written record.

The principal findings of this study are factors that enabled the success of pediatric palliative care (PPC) in Brasov:

1. An unique paradigm of PPC [5.3],
2. An undying image: "Children don't die here" [5.4],
3. Compassion for abandoned and unwanted children [5.5],
4. Solidarity [5.6], and
5. An equitable balance of power [5.7]

To place these findings in context, I will first substantiate the financial stability of Hospice Casa Sperantei (5.1). Another issue which bears heavily on these findings is the Roma 'problem' (5.2). My observations in the field bear on both issues.

[5.1] Financial stability

Brasov is the only beacon of care with a pediatric palliative care unit and, according to M1 and D2 provides service to more than 140 children and families in the Brasov municipality at no cost. In a review of patient records and their annual reports, Hospice Casa Sperantei has operated in the black since 2005, the third year after the doors were opened. This is a fair measure of stability especially in light of an underfunded healthcare system and widespread government corruption discussed in the Review of Literature. Nevertheless, the percentage contribution to the budget from the government House of Insurance grew from 0.1% in 2003 to 28% in 2009. In the same

time frame, contributions from the founding non-government organization in England diminished from 62% to 16% (Anon., 2003, 2004, 2005, 2007, 2008, 2009, 2010). PPC in Brasov has also managed to weather the global recession and the debt crisis in Romania. Health sector wages were cut 25% in 2010 as a condition of the International Monetary Fund's management of the crisis. (Holt, 2010) (World Bank, 2005) The only casualty has been a teacher who provided an educational program for children who attended the day care unit; she took another job and was not replaced.

[5.2] The Roma 'Problem'

The financial robustness of PPC/HCS is extraordinary in light of the fact that half of their children are Roma. Roma or gypsies⁴⁸ are ranked at the bottom of the socioeconomic scale throughout Europe – partly by lifestyle choice and partly the product of ten centuries of persecution for their enduring uniqueness. A discussion of their history, culture, persecution, and uniqueness is not within the scope of this thesis. However, the “gypsy problem or question” (Hancock, 2002, p. 40) (Fonseca, 1995, p. 7) or “gypsy nuisance” (Fraser, 1995, p. 248) cannot be ignored. My observations in the field shed some light on the challenges of caring for this marginal population.

I bear witness to the deep prejudice that Romanians and Hungarians⁴⁹ have towards the Roma as vagrants, pickpockets, and thugs – a prejudice derived from fictitious, irrational stereotypes that is part of central and east European society (Crowe, 1995, pp. 32-33). When discussing the Roma culture with C1 (Romanian/Hungarian

⁴⁸ I use the terms 'gypsy' and 'Roma' interchangeably.

⁴⁹ The population of the village of Arkos, which I frequented on the weekends, is nearly all Hungarian.

interpreter and transcriptionist), I mentioned that George Soros (Hungarian multi-billionaire) and his Open Society Fund (a great supporter of palliative care) champions the Roma cause. She promptly quipped, "I'll bet he has never lived near them!" T (PPC home care nurse) spoke of her fear of physical assault and concern for theft when entering Roma villages; hospice workers never enter the villages alone, despite the fact that no one has ever been accosted or threatened. At the orientation for Fulbright Scholars in Bucharest, a representative from the US embassy warned of 'gypsy pickpockets'; however, I attended two orientations at different times of the year, and different representatives from the embassy related the same 'personal' experience: a family of gypsies swarmed over them on their way to the office from the parking lot; they 'picked' empty all the compartments of his and her briefcases. This was ostensibly a cautionary tale⁵⁰. Nonetheless, I carried my wallet in my breast pocket instead of my hip pocket. As C1 and I entered a train station where gypsy children tend to congregate she asked, "Where is your wallet?" She nodded approval when I patted my breast pocket. While traveling the country with O2 (research assistant to D3), she pointed out a group of gypsies along the way – "They are the ones with dark skin, and they are no good!" This dimension of the prejudice might be traced back to the Indian origin of the Roma and to their incorrect association with the hated Moslem Turks who ruled the Balkans in the 15th and 16th centuries (Crowe, 1997, p. 179).

⁵⁰ Cautionary tales are written for children to warn them of worldly dangers: the first chapter of Fonseca's published account of the gypsies is titled "Out of the Mouth of Papusza: A Cautionary Tale" (Fonseca, 1995, p. 3). The cautionary tale of Papusza exemplifies the three essential parts of a cautionary tale: 1) the taboo or prohibition: settlement of gypsies wandering; 2) the narrative of the forbidden act: Papusza's poetry was interpreted as favoring settlement; 3) the violator's unpleasant fate: Papusza was ostracized by her own people

The Roma whom I saw with my own eyes appeared to be professional beggars, opportunists, and scavengers, but I also saw hard-working gypsies. I remember a mother with baby in arms sitting on the sidewalk with two other children lying on her lap with pleading eyes and languid postures; they were begging from passersby including a group of well-dressed students. As the students ignored them and sauntered on by, one of the children jumped up and mimicked the students' gait with an affected saunter – much to the delight of her mother. I remember a Roma boy and girl jumping into a city bus and dropping to their knees to sing a plaintive song then work the bus with outstretched cupped palms and practiced, beseeching eye contact; at the next bus stop they jumped off and were seen comparing their 'take'. I saw older Roma women in train stations sorting through garbage bins and in the village square selling tiny bundles of wild flowers. Early Friday morning before the garbage truck came to collect the weekly refuse, young gypsy men and women roamed up the long narrow street where I lived to scavenge through trash bins . . . stripping wires from a discarded TV left at the curbside. Every day I saw resolute gypsy men pulling small carts piled with metal scraps that they had salvaged. In a Roma village, a man was pulling a large cart that would normally be pulled by a horse or two. On weekends I worked at a farm where B1, a gypsy 'farmhand', came to work in the winter on a stripped-down bicycle which had no air in the tires and which had nylon baling string holding the tires on the wheel rims; a newer 'mountain bike' had been given to him by his employer, but B1 took all the 'fancy parts' off the bike and left them in the corner of the barn. He and his family of six live in a one-room shack that had previously sheltered goats. The shelter is

moved from the farm to the foothills of the surrounding mountains where the cows were pastured during the spring and summer. Part of his job was to shepherd the cows two miles in and out of the farmyard morning and night for milking. Three of his children were old enough to help with the cows – very focused and intent (also polite and friendly) prodding the cows forward with their wooden staves. He was at the farm early every morning to milk cows, feed pigs, bring in firewood, and muck out the milking room and horse stables – not the usual profile of the shiftless, conniving gypsy or gypsy criminality (Osztolykan, 2011) (Fonseca, 1995, p. 217). What stands out to me is that Roma can be easily identified by their darker skin (and the bright, flowered dresses of Roma women) and their small stature; they are poor, and they are separate and apart⁵¹. The real Roma problem is that they are an indigent, marginalized population with poor access to health care which itself is woefully inadequate. This brief presentation of Brasov PPC financial stability and the Roma problem complements the principal findings which follow: the unique paradigm of care [5.3], the non-dying image [5.4], compassion for abandoned and unwanted children [5.5], solidarity [5.6], and an equitable balance of power [5.7]. That is to say, a generous philanthropic endowment did not enable the success of Brasov PPC, but rather the findings were complemented by a strong financial position. That is not to say, a solution for the Roma problem can be supposed from these findings. This study shows that the Brasov success is all the more remarkable because the recipients of care include children from four marginal populations: the poor, orphans, CHILLD, and CHILTD. A disproportionately high number

⁵¹ Gypsies were usually located in clusters, colonies, or shanty towns. The one gypsy family that lived in Arkos lived on the edge of the village, separate from other houses.

of each group is Roma. The findings that follow show how this marginal Roma population is engaged, enabled, and contained.

[5.3] Unique paradigm of pediatric palliative care

A number of aspects of the Brasov paradigm make it one of a kind and worthy of attention because the physical layout facilitates the delivery of comprehensive care, including outpatient, inpatient, home care, and day care. Symptom management, respite, and education are all blended into the paradigm.

[5.3.1] Physical layout

The physical location and layout of HCS/PPC is a key element in its uniqueness.

Children's Hospice Casa Sperantei is positioned in the center of the Brasov community: down the street from a major ambulance depot, across the street from a funeral parlor, not far from Transylvania University, and just in front of a hospital that specializes in pulmonology and another 'acute hospital' dedicated to urology. It is so central that disoriented travelers often stop at the HCS reception desk for directions. Its central physical location is emblematic of its role in the community. HCS is embedded in the community – not detached, removed, and isolated on its fringe.

The children's inpatient unit (Unit) is the central hub of PPC. It is not an acute care unit, a place to die, a terminal residence, a nursing home, or a chronic care facility. It offers only temporary lodging for travelers on their life's journey – rest, recuperation, and rejuvenation – which is consistent with the Latin, French, and Old Slavic etymological roots of 'hospice'. The Unit has a total of seven beds in two patient rooms, a treatment

room, bathing room, toilet, kitchen, dining room, nurse's station, and the Head Pediatrician's office. The home care nurses come and go through the Unit on their way to home visits. The Children's Day Care Center (CDCC) is separated from the Unit by French doors and has an exit to a patio. The following description of the CDCC is taken from my field notes:

The CDCC is a large (about 30'X30') space with no artificial lights turned on – but well lit by four side-by-side windows, each measuring about four and one-half by three feet – one of which was open. Six computer stations line one wall with an additional large screen for the video games. The opposite wall has an assortment of games, books, and 'stuff'. The wall separating the Center from the inpatient unit is glassed. An octagonal layout of tables creates a circle with the children and staff facing one another. It is a room of colour with clusters of orange, purple and white balloons hanging from the ceiling. (Johnson, Field notes, April 26, 2011)

[5.3.2] Paradigm of Care

CHILLD and CHILTD care in Romania is based in the home and managed by periodic home visits by nurse, social worker, and physician. Each year every child is also routinely admitted to the seven-bed PPC Unit for a one- or two-week interval for respite and maintenance care. That is to say, seven children are admitted on Monday and discharged on Friday. Another group is admitted the following Monday. In addition the CDCC brings together those children who can communicate with one another for daily group activities and lunch. All children are transported by a specially-equipped van.

[5.3.2] Paradigm of Care: Homecare

Homecare is provided to all patients; the home visits are made by nurses, social workers, and physicians, but the bulk of communication is done by phone. I accompanied a nurse and a social worker on a round of home visits. While a front-seat passenger, C received and made several calls to families and other social workers on our way to see M2, our first patient.

M2 is a 19 year-old girl with epidermolysis bulosa (blistering skin disease that causes contracture deformities of fingers, knees, elbows; fused fingers and toes; contractures of esophagus and inability to swallow; restricted mobility). When I asked her what she liked about the hospice, M2 said, "The people . . . friends . . . T (her homecare hospice nurse)".

What M2 was really talking about was companionship and camaraderie. Her mother's response to her 'experience' with the hospice was

"These are good people who care and listen . . . and I can call them anytime with a problem".

I am confident that symptom management, resource availability, and respite are important to M2's mother, but she chooses instead to name access, shared problem solving, and solidarity.

According to T, M2's natural mother died when she was five years old, and she was abandoned to the basement of an orphanage for mentally ill children. The severity and rare nature of her illness attracted the attention of physicians at the pediatric hospital in

Brasov where another child with epidermolysis bulosa was being evaluated and treated. During her hospitalization she was introduced to a Casa Sperantei nurse whose sister was a Brasov PPC nurse. To preempt her return to an orphanage, M2 was also introduced to an affluent family who eventually adopted her in an enduring partnership with Brasov PPC. Together, they have endured the vagaries of the dysfunctional Romanian healthcare system, which is vividly described by this excerpt from my field notes:

The mother excuses the Romanian doctors "because they are so busy" and yet her experience in the "private clinic" with the same "busy" surgeon was unsatisfactory: "I wanted to talk about her feeding – about dilating her scarred and constricted esophagus and putting in a feeding gastrostomy – and he wanted to talk about her hands! And then they didn't even have a gastrostomy 'kit'!" An attempt was made to dilate her esophagus in Bucharest but failed because of the lack of pediatric instrumentation. They went to Germany for the care that they needed – to the tune of 5000 Euros (surgery and five-day hospitalization).

G1 was the focus of our second visit of the day. She and her impoverished Roma family were in the process of being evicted from their one-room home when we visited. The eviction was demanded by her ex-mother-in-law. G1 is 15 years-old and maximally disabled from viral encephalitis that she contracted at seven years of age; she does not walk, talk, see, or hear but rather lies inert on a bed that she shares with her mother and four year-old sister. When I asked her mother what the hospice meant to her, she

responded by saying, "Everything . . . I cannot express well enough how much it means to me." Then she began to cry and smile at the same time . . . with the four year-old climbing up into her lap and trying to comfort her by snuggling and stroking her chin. She went on to talk about the hospice Christmas party where all the children received gifts, even the siblings. It was a year that the hospice presents were the only gifts that they received. "They care about all the children!" The mother's emotional but clichéd response could fit the pervasive cultural stereotype of the Roma: a professional beggar and scavenger who is scrapping out an existence for her daughters, son, and husband. Whether it is crying as a cue to evoke sadness or laughing as a prompt for joy, she might do whatever the occasion requires or whatever she thinks the audience expects. However, the comments of the social worker and nurse who accompanied me and my own observations in the field put any question the mother's sincerity or genuineness to rest. The social worker had the following to say:

She appreciates what we do for her. True, sometimes she tries to manipulate. But we have been working with them (Roma) for five years, and I know who tries to do such a thing, and who truly respects us for what we do. Even though they cry, I treat them in an equal way.

In the same interview the nurse-interpreter added:

Even though she manipulates, we don't let her do more than that. The feelings are her own. It doesn't mean that they are Romani and don't need support. They express their feelings in their own way. She is the type of person who often feels

she deserves more than what she is given, but C (social worker) explains how much we can do, and where our limits are.

What I saw with my own eyes was the respect that the gypsy women accorded the hospice workers – the welcoming gestures and the quick responses to requests for records and photo documents. The solidarity between G1's mother, C, and T was evident as we stopped along the way (after our first visit with Madalina and her family) to give a ride home to G1's mother and her other, four year-old daughter; they had taken the bus into the city to have the child's vision evaluated earlier that morning. They bantered about the impending eviction, the requirements for renewing the certificate of disability, and the need for a wheelchair. Hospice services are free of charge, but there was no sense of vertical charity which the philanthropist condescends to give and the recipient humbly receives without question – there was a sense of working together to improve quality of life for this child. Their solidarity is an unequivocal measure of success for pediatric palliative care. C and T enabled G1's mother to apply for 'social' housing, for a wheelchair for transporting the child, for a free bus pass, and for a government child care stipend⁵². The family is entitled to these services, but the application process is complicated and requires notarization from several government agencies. Poor families who rely on public transportation (which they may not be able to afford) must somehow acquire the necessary application forms, take time away from care-giving (in this case, the mother left G1 home alone) or work,

⁵² A child must qualify for a significant degree of disability to eligible for a child care stipend; documentation of the degree of disability includes evidence of birth, a physician's evaluation, and photographs demonstrating the disability.

and then wait interminably in a queue – hopefully in the correct queue. What is more, most Roma in Brasov cannot read or write to complete the applications.

My own anecdotal experience in obtaining a residence permit in Brasov provides an example of the bureaucratic obduracy. To obtain a permit to reside in Brasov more than three months, a physician's certificate of good health, documentation of employment, evidence of residence, and a passport are needed. After waiting in the wrong queue for an hour, then in another queue for 45 minutes, I was told that my Fulbright Scholarship contract was not sufficient evidence for employment; an original letter from the American Embassy would be necessary. C (in her role as a social worker) told me about an alternative: I simply needed evidence on my passport that I had left Romania – however briefly – to start another permit-free three months. Her advice is a good example of the bureaucratic know-how that is necessary to negotiate the social welfare. Another small example of 'working together' horizontally instead of vertically is the 'side conversation' that C had with the father of another Roma child as we climbing back into the car to leave. The father had left the house when we entered and was standing in the road amongst a group of men and children that had been attracted by our arrival in the Roma village. Sensing that he was distancing himself from the care of the child and knowing that the mother would not leave the child for a prolonged period, C made it very clear to him that in the event that the clerk at the House of Insurance refused to take the wheelchair application from her, it would be his obligation to hand it in to the clerk. In that same interview, I questioned C and T about the role of the husband in the family:

DJ: How often is the husband involved in the care of the child?

C: Not too involved. We usually try to make them do more.

DJ: Why are they not involved?

T: Their mentality. But several reasons: some of them work and say they don't have time, leaving in the morning, coming back in the evening, very tired.

C: True, but in the Roma community there are some that aren't working. They prefer to stay home and do nothing. It is a big problem. There is no support for the wife, and most times the woman, being more emotional, bears more of the burden, and is most of the times more involved. But there is another aspect. Ninety per cent of the people who care for the children are women. They choose this as they think men earn more money through the work they do. Not always, but most times this is what happens.

Advocating for these families does not mean giving food and resources but rather enabling to obtain services. In the Roma community, one crisis follows another as is evident for the mother of this child diagnosed with Hodgkin's lymphoma:

The purpose of the visit is 'social': six of the mother's seven daughters have been placed in an orphanage ("orphanage – but not those big ones we used to have with hundreds of children") because the father abuses the mother and the children. The abuse was discovered or exposed by the children's hospital where one of the daughters was taken with frost-bitten feet after staying out in the winter snow cold with her mother after she (the mother) had been beaten,

slashed across the face with a knife, and thrown out of the house. The prosecution of the father has been ongoing for three years; meanwhile there is no restraining order to keep him out of the home. The home belongs to the husband's grandmother, and the wife has no place to go. Assuming the father will be convicted, she will likewise be homeless. Application for social placement is being made so that the mother can get all her children back and have a place to live. The (application for) mother's allowance for caring for her disabled child must be renewed every year. The entire application process must be repeated, not just undated.

In addition to advocacy and working together to meet the needs of the family and children, homecare fosters self-sufficiency through education. For example, M2's mother had learned through PPC that the priority for her continuing care was not surgical release of her scarred hands but rather nutrition; since her esophagus was scarred and immobile, she could not eat. A feeding gastrostomy or jejunostomy would allow her to receive nutrition. Her mother and sister were also taught how to change dressings on M2's painful wounds caused by relatively minor bumps and bruises. G1's mother learned the basics of hygiene and exercises to limit contractures. Hygiene is a major public health challenge in the Roma community as T attests:

Lack of hygiene is a big issue for the Roma . . . and for us as nurses. We got permission from the mayor to use the town hall to provide classes on hygiene for the Roma community. A social worker and I gave many talks, but we didn't see

any changes in the homes we visited. We kept giving talks, and the women would talk amongst themselves. Very slowly we are seeing change.

This is the substance of success. The common themes for both these poor and well-to-do families and children are advocacy, access, shared problem solving, solidarity and education. T and C are advocates for their patients with more than verbal support; they provide feet on the ground and wheels on the road. They provide access to medical care at home and access to their entitlements in the socialist bureaucracy. Both families had a share in solving problems, and both families worked together with T and C to improve the quality of life for their children. One striking difference between the two families was that M2's family is seldom in crisis. C's remark that the Roma families are always in crisis is apposite. M2's family is embedded in a supportive society, and the G1's hangs on the fringe.

Education to encourage self-sufficiency, particularly in regards to hygiene, continues in the inpatient care unit.

[5.3.2] Paradigm of Care: Inpatient Care

Through routinely scheduled admissions, the inpatient unit provides respite for families, symptom management, caregiver and child education, and reevaluation.

Some examples are in order to show the common pattern of these admissions, the uniqueness of each child, and the emphasis on quality of life.

A new patient has been admitted – a peanut-sized three year-old Roma boy with cystic fibrosis. Peanut was abandoned by his poor family and his many siblings

and spends his time between the hospice and the acute pediatric hospital. He comes to hospice for "stimulation"; he was last here about a month ago. His respiratory rate is increased but he is not dyspneic and did not cough during the period of observation. He is not plaintive, does not cry, and has learned that he only has to stretch both arms upward to be picked up and cuddled. The aides and nurses jostle him to get him to smile which he does like a low-watt light bulb. One of the aides has taught him to point to his nose, mouth, and ears when she points to hers. He gets it right most of the time but always needs the visual prompt. Perhaps he is deaf from aminoglycoside antibiotics or repeated ear infections; he is just developmentally delayed or dulled by his illness. One of the nurses plopped him down in front of me in a children's walker. We looked at one another a little while – I smiled; he didn't. He kept looking around for the nurse that had just left him. An aide finally picked him up and sat him on the octagonal banister and gave him her best animated Jim Carrey smile.

In addition to respite for the pediatric hospital staff, the nurses and aides at Brasov PPC are providing stimulation to improve his quality of life. He appears again in the ethnographic observations below as the boy "with an indifferent sourness to his expression".

I walked into the first patient room with J to the malodor of a really dirty diaper. There were three candidates, but the most likely sat dead center in the room with an indifferent sourness to his expression. J said (in her broken English), "He doesn't look as good as before." I indicated with broken English that he was

probably the culprit, and she promptly called for the aide. As the aide took him to his room (by frog-walking him between her legs), J donned rubber gloves and began checking the other children in the room. The boy was walking like a strung puppet with the same indifference (since you can't pull strings for facial expression). The aide was giggling, cajoling, and generally seemed to be trying to make the upcoming diaper change a rich, stimulating, and joyful experience.

This child is an exception to the usual paradigm of care or culture in acute hospitals; orphaned CHILLD are usually discharged to residential homes (modern-day orphanages). Occasionally such children are 'adopted' by the nursing staff and even taken home on weekends. Orphaned CHILLD in residential homes are also routinely scheduled for admission to the Unit:

In chatting with the physician covering for the PPC pediatrician this morning, I discovered that both orphaned children are taking their turn in the routine admission schedule to be admitted with the explicit intent to improve their quality of life. The child with spina bifida has a urinary tract infection that is being treated at the orphanage, and the PPC unit nurses inserted a catheter to eliminate the reservoir of infection to improve treatment. The child with quadriparesis and intractable multi-focal seizures is being fed by a nasogastric tube at the orphanage; she is also receiving a number of anti-epileptic drugs (prescribed by a neurologist and verified by adequate serum levels) through the tube. Her nasogastric tube was changed just after she was admitted to the unit.

Her only spontaneous movements are seizures. Extremities are bone-thin and cool but not mottled. Her face is small, almost sparrow-shaped.

In some small measure the quality of life of both of these patients was improved by providing satisfactory management of the urinary tract infection and by changing the position of the naso-gastric tube to make it less likely that the tube will erode the nostril, turbinates, or esophagus – and to avoid a certain degree of discomfort. The services that were provided to these children fall into the categories of routine re-evaluation, maintenance, and symptom management.

This snapshot of what goes on in the care of these patients is given further qualitative resolution by this excerpt from my field notes.

The second bed lodges a 13 year-old boy also with microcephaly and cerebral palsy, but he also has controlled epilepsy. He turns expectantly to sound, motion, or people and smiles whole-mouthedly. His palate is arched high; his gums are hypertrophic; and his teeth appear as little stumps in a clear-cut forest. He has the appearance of a baby bird waiting to be fed – with his head extended and his mouth opened unusually wide. His face, arms, and legs are sun-burned from the weekend. “Some parents just don’t have good sense”, said a young staff nurse. Last week he developed urinary retention and an infection associated with phimosis⁵³, so part of the inpatient management is stretching the foreskin over the glans. Of course his sunburn will be treated gently with lotion. He is fed by

⁵³ Stricture of the foreskin of the penis.

mouth with a syringe. Half of each small syringe-full is pumped back out of the corner of his mouth – to be swept back in by the attentive nurse.

In another room a mother and child were there for a routine admission to focus on the child's dry skin and limited range of joint motion.

The second bed is occupied by a ten year-old Roma child and her mother. The child has an unidentified genetic disorder characterized by severe developmental delay, dextrocardia⁵⁴, and ichthyosis⁵⁵. The Roma village that they live in includes about 1000 people; several cases of congenital heart disease, cystic fibrosis, and Down's syndrome also come from that village. The child is dressed colorfully in multiple layers. Red and white cotton balls adorn her braided hair. Her mother presents herself in a flowered red dressing gown with her hair back in a pony tail (tied by colorful curly strings); she wears no make-up. She is attentive and respectful. All of their belongings are well-organized at the bedside. The child's skin will be treated with more lotions, and she will receive some kinetotherapy.

During this routine admission the child's quality of life was improved by symptom management and by educating the mother in skin care and hands-on exercises.

The loving care of the nurses is also in this mix and is exemplified by this excerpt from my notes:

These three nurses are somehow my favorites. The head nurse, almost always wears red in some part of her apparel and always has a small bandanna around

⁵⁴ Heart is in the right side instead of the left side of the chest cavity.

⁵⁵ Severe dry skin which restricts the mobility of her extremities

her neck; she has one darkened tooth in her smile. Her movements are graceful, and her conversation is quiet and measured. C2 is the public face of the unit: a kind, 'open' face with listening eyes; she could be nurse to a queen. And then there is J: light blue smock and pants, straight shoulder-length hair, two pairs of low-fashion spectacles, and gray-green eyes that seem almost mischievous. I watch her standing off to the side watching the children in the day care center laughing and smiling; I see her at the bedside with the pediatrician more intense and inquiring; I watch her don rubber gloves, crouching to stalk a child with a loaded diaper like a lioness about to pounce on her prey (for the child's comic benefit of course).

These nurses are real people who are committed to the care of these children.

The inpatient unit provides common ground for other travelers who happen by – such as this young mother who came for a physician's signature on an application for government services ('degree of disability'):

An attractive mother in her late 20s or early 30s 'strolled' her child through the unit today, poking her head through the door of the large patient room to say "hello" to the nurses and aides. Her child is three-ish with a twisted, ghoulish face, screeching, and arms outstretched and wind-milling. Her legs were flexed at the hip and extended at the knee giving the appearance of an 'unruly' doll stuffed into the stroller. The physician gave her the hand-written medical report which is one part of the 'degree of disability' application. One of the nurses disappeared with her into the elevator in the back of the room and returned

about 15 minutes later. She came for a signature . . . to a safe place . . . where she and her child were welcomed and reminded that they were not alone. The mother and child are travelers on their life journey together.

[5.3.2] Paradigm of Care: Day Care

Children who are sufficiently mobile attend day care; most of these children are wheelchair bound and transported by the hospice van from their homes to the CDCC. They arrive around ten AM and plan an outing together for the sunny days. After returning from their wheelchair excursion, they eat lunch together and then depart about two PM. Respite for the families and children is the stated mission of the CDCC.

I asked M3, a bright 17 year-old boy with muscular dystrophy what he liked about the Children's Day Care Center (CDCC), and he said, "Just be able to talk with my friends". Watching and listening to what goes on in the CDCC and the three-hour 'walks' in the city sheds more light on his simple statement. On any one particular day, four to seven children from different socio-economic backgrounds, degrees of disability, and levels of intelligence share a common ground. They work together to solve problems, make decisions, and gain access to the 'other' world. In an atmosphere of solidarity, they strive for the best quality of life – as this field note from an excursion shows:

C2 (age19), A (age 17), V1 (age 16), V2 (age 15), M4 (volunteer), an aide, O1, and myself were present on another fine day. C2 arrived first and was given a puzzle to piece together. He smiled at me, and I managed to find a piece or two. V2 was the last to arrive – with a flat expression on his face when he looked at

me. O1 tells me that he is 'shy' about new faces and does not invest in a relationship with volunteers who don't seem to be 'keepers' (i.e. stay very long). V2 has advanced muscular dystrophy: he can move his fingers slightly but they are non-functional. The kitchen aide fed him at lunch. He had a slight cough after lunch; his head tends to loll to the left side – worse at the end of our day. By O1's account he does not receive much attention at home. A younger brother is very active in sports and school, and an older sister is severely mentally and physically impaired – requiring complete care. Mother manages the home and is overwhelmed; father works and is seldom there. Weight loss has been dramatic in the last three months.

Everyone was smiling and/or laughing – O1 is ostensibly fond of all of them. All of the boys participated in the discussion of where we are to 'walk' today. During the discussion A used the top of the puzzle box to scratch his head and orbits . . . or just something with which to diddle.

Our excursion took us to an upscale four-story department store: we walked every aisle on every floor, moving from one floor to another via a three-wheelchair elevator. There were several book kiosks in the store; we would stop at each kiosk and look through some of the bigger pictured books. Three female clerks gave us polite smiles. The boys seem completely oblivious to passersby.

A was particularly curious and interested and asked questions about the merchandise non-stop. At one point he jokingly said, "Let's catch the escalator!" All the boys know their limits in terms of safety in the wheelchairs, and they will

often caution the 'driver' (especially if they are new) to back down curbs or to slow down. A knows the limits but shows no fear; he is very bright and can speak some English – wants to know and see as much as he can. As his disease has progressed, he has expressed no sense of doom, hopelessness, or anger. A likes to keep his fingernails long because it gives him a little more 'reach' and purchase with his fingers. He is very adept at moving a spoon or fork into a functioning position. 'Seeing' was the process rather than 'wanting'. And they were also 'doing' instead of watching (moving, through doors, up and down elevators).

There is a lot going on in the CDCC, and 'respite' hardly does it justice. When not occupied, the CDCC also serves as a consultation suite as I note in this field observation:

While I was sitting on the couch, waiting to interview C, the pediatric psychologist came through the unit followed by a young Roma family with two children. They sat in the CDCC with the psychologist and mother (with child patient) at the octagonal table and the father and other child on a couch in the corner. I peered through the window to see the father perched on the edge of the couch smiling and intent on the conversation.

Weekly staff or 'team' meetings also take place in the CDCC and are attended by the nurses from home and inpatient care, the two social workers, the psychologist, and the Director of Nursing. Care plans for the patients 'in the field' and those in the inpatient unit are discussed.

[5.3.3] One last 'point'

CHILLD care in Brasov began with homecare. Parents had access to care by simply opening the door to their home. M1 provides a little more insight:

I think, looking back now, I think it was wise to go first in the community, and then with the building, because probably, at the beginning we didn't think, think it that way, the only reason was then that we had a small amount of money, little staff, let's do as much as we can for most of the patients.

The construction of Hospice Casa Sperantei in Brasov, Romania was a response to the needs of the patient population, as M1 articulates in her 2009 interview:

Oh, well, it took us . . . actually it was exactly ten years after we set up the homecare services, that was in 2002, we were able to open this inpatient unit, but before opening at some point around 2000 or '99, we were pushing Graham⁵⁶ toward this idea about opening an inpatient unit. It was ok having the patients looked after at home, the children and so on, but there were times when we thought, either for symptom control for adults or to give parents a respite time, there was a need to have an inpatient unit as well. And also, to give other opportunities to these children, like having a day-center, trying to add something which was missing in the care of these children as they were just in their homes with their parents. So this is how we started with the idea of having a building with an inpatient unit.

⁵⁶ Graham Perolls was the founding philanthropist for Hospice Casa Sperantei

D2, the head pediatrician, added:

I think in Romania it is another type of care. It is care that is closer to the need of the patient and family and it is a relationship in which you are closer to family and patient. You try to respond to their needs more like a human being than a highly qualified specialist. You can see the complexity of their needs. Our satisfaction is being able to respond to most of that and helping them to cope.

Yes, now we offer services complete with day center and in-patient unit. We are able to cover all 140 patients. Some of them are very poorly (sick) . . . we only see them at home. Some of them come in. We have a minibus, and we can pick up those who have no other means of getting here. The day center was another input for care and quality of life of children, as most of them are severely disabled or suffer from life-limiting illnesses: they are not part of a group; they are not at school; and they are isolated at home.

In summary, the mission of PPC is to provide respite, ongoing maintenance care, symptom management, and a sense of belonging for children with life-limiting conditions and their families. M1 reminisced:

But, as I said looking back now, it was a good way because by the time we wanted to build something, the community knew so much about us in ten years that it was, even if they didn't contribute with money, they told the authorities that it's a good thing to happen. So we were given this piece of land right in the center of Brasov. The local authority, by the city hall and they gave us several options: somewhere out of the city, but they understood the idea that we don't want these

patients to feel like we are putting them away . . . that we don't want to touch them. We want families to be able to come and visit them, and this was an ideal place . . . right close to several medical units. I think we broke several others' plan, who wanted to see here a hotel or petrol station, but somehow, God was on our side, and we managed to get it here.

The construction of Children's Hospice Casa Sperantei was indeed a response to the needs of the patient population, but it was also an historic 'tipping point', the epidemiologic term in a viral epidemic for the moment in an epidemic when it dramatically escalates. Pediatric palliative care was a "word-of-mouth epidemic" that reached critical mass or a "tipping point" with the construction of HCS. (Gladwell, 2002, p. 56) The geographic location reaffirms an undying image; children are drawn into the heart of the community – "an ideal place" where they would be treated "more like a human being".

Anyone can refer a patient to PPC. In other words, HPS/PPC is not bound by a physician referral process to accrue patients. The only restriction to being admitted to Children's Hospice Casa Sperantei is that the illness must be life-limiting or life-threatening. With palliative care outside the walls of their power enclave, physician specialists in hospitals are no longer threatened by loss of hospital beds to PPC. The specialist comes to see the services as complementary, embraces them, and loses none of his or her 'power' in the process. Hospital-bound specialists need to move patients along to accommodate others who are waiting to be admitted, and to unburden themselves of those children

who are still sick but not benefiting from hospitalization. HCS offers alternatives as D2 points out:

The main reason is the good relationships that we have developed with the specialists at the children's hospital – that we provide good care for their children at home; we educate the families how to care for their own children. I frequently go to the children's hospital to give talks and organize discussions, and some of them come to our courses. I also go to give them feedback on their patients or pick up prescriptions for their patients. Pancreatic enzymes and anti-epileptics, for example, can only be prescribed by specialists.

The Roma orphan with cystic fibrosis, is a good example. He was referred by a pediatric pulmonary specialist. Instead of relegating him to a lonely death in an orphanage, He was entered into a 'time share' with HCS/PPC and the acute hospital. In return for respite (for the child as well as the hospital staff) and 'stimulation' at HCS, the hospital staff provides specialized management of his respiratory symptoms. M2 (a then five year-old girl with epidermolysis bulosa) was about to be discharged to an orphanage when a hospital nurse referred her to a pediatric hospice nurse. M2 was subsequently adopted by a very attentive family and is now, at 19 years of age, living at home. A cardiologist referred C4, a child with incurable (i.e. inoperable) congenital heart disease and spina bifida, for help in managing the child at home (i.e. educating the family on how to allow the child to sleep more comfortably, teaching the family how to manage salt and water intake to reduce pulmonary edema, and helping the child through dyspneic crises). In return the cardiologist agreed to hospitalize the child for 'treatable'

crises that can be managed with more specialized cardiologic care. Cosmin was referred shortly following his birth and is now 19 years old; he attends day care three times a week. G1, a 15 year-old Roma girl who was neurologically devastated by viral encephalitis, was referred by another Roma family.

However, not all children who are referred are accepted into the program. Such was the case with several children referred from the Roma community:

T: The hospice does get a lot of requests from the Roma community. Everyone knows everyone else's business and they talk. When someone is getting services, everyone wants it. We have specific eligibility criteria. For example, if the diagnosis is cerebral palsy, it has to be severe. Yes, we have criteria.

Their illnesses need to be truly life-threatening or life-ending. A cancer diagnosis need not be terminal or incurable to qualify for referral, but hospice services are discontinued six months after the child is declared 'cancer-free' (but can be reinstated in the event of recurrence), and the disease is no longer life-threatening.

The last requirement for referral is that the family must live in the physical proximity of Brasov. The inability to serve children beyond Brasov was lamented by D1 in this 2009 interview:

DJ: Is there something that we need to tell people out there, about what you do?

D1: You could talk to people here in Romania, so they will start more services like this because everything is not like us. A lady came today from Targu Mures

(several hours drive from Brasov) with her child, for example, who wanted to register her child here because there was no one to help her there; she was desperate. There are many children who have such needs in Romania that the State doesn't help.

The construction of HCS was more than putting bricks and mortar together; there were agents that facilitated the social change: mavens, connectors, and salesmen (Gladwell, 2002, p. 70). D3, the medical director, is a maven – a data bank of information, a teacher, and an information broker; she knows and shares all about palliative care; and she brokered information in this social transformation like the carrier of a virus in an epidemic. Her contacts multiply the message exponentially. In that sense she is also a 'connector' who provided the social glue – a consistent presence rather than a match that ignites with a short-lived flame. But the person who best exemplifies a connector is M1. The reader will recognize that I have referenced M1's interviews much more often than any other – she helps connect the pieces. She has "been there and done that" for HCS: founder, chauffeur, nurse's aide, executive director, and now Director of Development. The following is an excerpt from her 2009 interview:

For long time, I was the left hand of the nurse or for whatever was going on in the homecare when the only nurse was the English nurse working in Romania. So I got involved in several things, and then I was executive director for about eight years, and then, later as we developed on the national road (D3 and I are mostly involved), in advising and working with those who want to set up similar things in Romania. Not that we are doing that but we provide some sort of help. I wouldn't

call it consultancy, but anyway let them know how not to reinvent the wheel. She is the 'cake-in-hand' (it seems like she was always celebrating a birthday or anniversary with the HCS staff) social glue. Perolls described M1 and D3 as two of the Three Wise Women (or mavens) of HCS (the third woman was one of the founding nurses from the UK). The mavens did not give the impression that they were salespeople. The salespeople in social tipping points are characterized by their persuasive and sometimes overwhelming enthusiasm. O1 (director of CDCC) is just such a salesperson at HCS, as I noted in the field:

O1 is a tiny, vivacious, attractive young woman, and the boys seem to adore her. She is a bit of a light bulb in a darkened room; when the light is turned on there is excitement about the light. But then the light is taken for granted, and that's when companionship and friendship predominate.

Her bubbly enthusiasm is as socially infectious or contagious as a virus in a viral epidemic. O1 is one of Gladwell's "Little Things"⁵⁷ that make a big difference. R (the receptionist – the first person that greets the public) has a larger, more motherly physical appearance, but she is also one of those not-so-Little Things. C, the red-headed social worker whose warm and inclusive enthusiasm was undaunted by the unending crises amongst Roma families, rounds out Three Little Things who complement Perolls' Three Wise Women of HCS.⁵⁸ The ultimate salesman for this social

⁵⁷ The title of Gladwell's book is "Tipping Point: How Little Things Can Make a Big Difference". (Gladwell, 2002)

⁵⁸ The point begs to be made that nursing is a female-dominated profession and that there are no male social workers, nurses, physicians, or aides at Hospice Casa Sperantei. Similar comments about physical appearance of G2, R2, or the bus driver would not be necessary or appropriate because such descriptions

epidemic is Graham Perolls, the philanthropic founder. G2 (the CEO of HCS) alludes to his 'sell-everything' persuasiveness:

G2: Yes, something like that. I applied for the job, but not had my hopes up. I just told myself I would try. But I applied and in my mind I was hoping to get the job, just because I felt attracted to this new domain. I had the first interview with the president, Graham, which impressed me very deeply. Have you met him?

DJ: No, I have not met him. What impressed you about him?

G2: His dedication, his work. He is the man who first brought palliative care to Romania in 1992. He is a charming man.

The Brasov paradigm of care encompasses PPC in full measure: the mainstay homecare, a daycare 'commons'⁵⁹, and regularly scheduled inpatient surveillance and care. I have identified some of the mavens, connectors, and sales agents of change and success at HCS.

One unique aspect of this paradigm should be reemphasized: regularly inpatient admissions are scheduled to enrich quality of life. Children are not admitted to the inpatient unit just to die. To the contrary, the Brasov paradigm of pediatric palliative

would not enrich the readers' appreciation of the care setting – welcoming, enthusiastic, warmth, and inclusive. To put it another way, G2's casual, military bearing (clean-shaven, erect, squared posture with short hair but no tie or medals) and R1's disheveled, ill-shaven, harried appearance do not bear on care setting because they have no or very limiting contact with the children.

⁵⁹ A 'commons' or "what we share" is a way of epitomizing Brasov daycare: respite shared by the children and their professional caregivers.

care is an affirmation of life that is trumpeted by the second finding “Children don’t die here!”

[5.4] “Children don’t die here!”

I first heard this passionate exclamation in 2009 from the head nurse at St. Andrew’s Children’s Hospice in Pitesti, Romania. A hospice where people didn’t die struck me as rather odd and out of place – even oxymoronic. Was it another example of death denial, a point of professional pride, or just duplicitous Romanian rhetoric (Kligman, 1998, p. 13)? As the stream of qualitative data grew, the centrality and permanence of this statement stood out in the background like a large boulder in the stream – immovable and omnipresent. This finding didn’t suddenly bob to the surface but was so much a part of the setting as to hardly be noticed.

“Children don’t die here!” creates a non-dying or an un-dying image that is central to the success of Brasov PPC from three very different perspectives: 1) from the public’s perspective, 2) from the standpoint of the professional caregivers, and 3) from the viewpoint of the children and their families.

[5.4.1] Public perspective

First of all, an undying image is presented to the public by Hospice Casa Sperantei stationery, their logo, and the posters announcing fund-raising campaigns. The public donates their loose change into plastic containers at the cash registers of drug and grocery stores to sustain PPC; the public made land available for building the hospice; the public attends the concerts which support the children; the public supports the

runners in the Bucharest marathon that benefits the hospice; and it is the public that decides which philanthropy to contribute a mandatory 2% of their wages. The 'front man' for the public image is the HCS graphic designer and website manager R1. I asked him how the non-dying image was created:

R1: . . . our main goal was to create a website in such a way that people around here can use it and can update it. But in the same time obviously we had to work on the image so it has a nice lining, we can do prints on the same image and do web stuff, videos that don't look the same but are alike. So we created that line, we kept it for nearly two years now.

DJ: When you talk about an image, what do you mean?

R1: I'm talking about all the brand elements. We gave the logo a bit of a face lift; it was kind of oldish. The first one was made in 1997, and you can tell it is from '97. But at the same time when I got here Hospice didn't have any rules for image -- like green could be any green. The font could be any font; the size of the font could be any size; and there were no rules to help you make a proper material for the Hospice. So everyone who came around to help, they all did their own vision of it. Obviously after so many years it was a bit of a mess. We had to make it so that it had the same colors, the same fonts going on, same kind of layouts.

DJ: Tell me a little bit more about how you come to this vision. How do you create it? You need to reflect the character of the Hospice somehow or not that so much?

R1: I think we spent about maybe a month trying to understand how people see the Hospice as a charity place, and a medical place and a place where you need to do fundraising. We asked everyone to come in here and say what they think about the Hospice, and the main idea was that the Hospice is not a place where people die crying, but a place where people die smiling. We tried to make an image that is fresh with everything it has in it. If you go with a black and white picture with a green background that has a darker look. But if you combine it with a lot of white (color) and smiles, when you look at it makes you feel like it is not really a place where people die, but a place where people live happily for as long as they have.

An analysis of the HCS graphic images would be a fascinating addition to this discussion but is beyond the scope of the thesis. The importance of image to the public's perception is emphasized by R1:

But I think image is something that people can find interesting on a level that you don't really realize you are influenced. Like if you have an ad in a book, you read it, but also look at it, and that particular thing, when you look at it needs to give you some sort of as feeling.

He was particularly proud about the imaging that announced the Bucharest marathon fundraising campaign. There were no forlorn, pleading children peering out of the poster.

The first year we did it just to let people know we are there. We do have a marathon, please run it for us. This year it was a bit different. People wanted to have a bit more runners, and make some sort of a fundraising side as well. This year the image was different, the concept was different, everyone had to fundraise a certain amount of money to run. And basically we transformed everyone into fundraisers, which is quite good. People get to understand what it is like to get money for nothing. So that was it, we gave them a fund raising package and we taught them how to approach people, what the charity is for. But also, graphic and concept wise it was more of a different way to look at it. We had a concept where we wanted people to understand that anyone can run the marathon for us, whether they are professional runners, or people from a company, business owners, anyone can do it. So we created an image that didn't have anything to do with the patient. Sometimes they relate to that, but sometimes they don't. We had that before: "cancer, no, no, I don't want to hear about it". So we had this girl who in the poster is getting her fleece off, and underneath she has a running shirt. We used a girl instead of a guy, which was a bit of a discussion we had here. People said if we use a guy it wouldn't be so sexual. I said if we used a girl we could get both genders to look at it. The guys would look at it because it is a girl taking her top off on a big billboard. Not

taking everything off, but just a corner where you can see there is a running T-shirt underneath. The copy was made so that women would like it. Like the ones you would use at a fashion show. Like running is in fashion. So women would relate to that because it is fashion, guys would relate to that because it is fashion and it is a woman on the poster . . . we had billboards everywhere, we had videos everywhere, there was a building in Bucharest with the biggest screen in the south Eastern Europe, and we had that as well. It was quite amazing to see how many people you can reach with the cause, and to see how much they can give. And I have to admit, that day when the guy called me to say the billboards were up I had the feeling of an empty stomach, I didn't know if people would like it or not. I knew it was a good concept. It had an explosion on the website. Every material was meant to bring people on to the website. We had a special page, graphic wise it looked a bit different, the girl was there as well. But people actually liked it and came on the website like mad.

Normally the website receives about 3,000 'hits' each month. In the first month following the marathon 10,000 hits were made, and the next month 12,000. The hits are now simmering at about 6,500 per month. The slogan on the poster was "Just do something for the good of it!" This was not a plaintive call for mercy or salvation. It was a call to action. You don't need to come sit with us at the bedside; just come run with us! The slogan itself attracted the attention of women, and the woman showing the corner of her bare shoulder under the running shirt caught the eyes of men who then went on to read the slogan and the prospectus for the campaign.

Needless to say, the campaign was an unqualified success and highlights the value of this finding to maintaining a balanced budget and the success of PPC.

Keeping a favorable, non-dying public image is important in another important respect: to dispel the notion that palliative care is a form of passive euthanasia as mentioned in an interview with the psychologist I1:

Unfortunately the hardest fight in the beginning was in the professional society, not the community. There was little understanding of palliative care. And there were worries that this is a kind of passive euthanasia.

Passive euthanasia harkens back to the studied neglect of the 'irrecoverable' orphans (Morrison, 2004, p. 179). But the 'message' in the public image is that it is safe to bring children here because we are not here to allow them to die.

[5.4.2] Standpoint of the professional caregivers

From the second perspective – that of the professional inpatient caregivers – “Children don’t die here!” conveys more than an image: it personifies their workplace and permeates their every-day working life. This is not a somber place to work where they are reminded every day of impending death. Their job is not just to counsel the dying child and family but to also make every effort to improve quality of life. They believe that children prefer to die at home. Emergencies or the last stages of chronic illness are generally handled by the homecare team. Perhaps homecare professionals carry most of the emotional burden of dying – since most deaths occur at home – but I suspect the physical intimacy and emotional overlap of homecare, inpatient care, and day care at

HCS ensures some sharing of the burden. For the inpatient staff, there is a real difference between a visit and a 'stay'. A visit is like an encounter, and in a 'stay' the visitor brings the baggage of conflicting needs and wishes, as well as the partition of personal space.

The belief that children and their parents want to be home is iterated in this interview with D1:

DJ: are children staying here to die?

D1: we have had children in terminal stage, but the parents wanted them home, at home, so they died at home.

The preference for dying at home is touched upon by M1 who was the executive director of HCS in the beginning:

M1: Hmm. We had to adapt it, because, as you say, we thought we would get here children in very advanced, very severe stages, but since we, most of our children are in, with a pathology that evolves let's say, long term, meaning one to two years, we had to adapt to this. Since 2002 I don't think we have had more than three or four children who really died here in the unit. Because most parents would like them to be here for the terminal stages, but eventually want the child to be at home to die.

Since M1 does not present any 'data' or evidence for her last statement, her personal testimony qualifies best as a belief rather than a truth or near truth. The sentence fragment ". . . here for the terminal stages . . . but home to die" suggests at least some

ambivalence on the part of the parents. The model of care is heavily biased towards dying at home; a choice of dying at home or in HCS/PPC does not fit in the paradigm of care. And the stipulation for dying at home – even in the residential homes for orphans – instead of HCS/PPC is clearly spelled out.

The well-being of the staff is an important benefit of the non-dying, well-ordered organizational structure. They need not face grieving families or the same dying children day after day. There are no gut-wrenching decisions to be made about when enough is enough. No rehearsed, every-day discussions of the 'good death' are necessary. Eighty percent of the patient population is non-communicative with severe, life-long or life-threatening illnesses, and, according to D2, 18% come from residential homes for orphans; children are not brought here as faceless, near-lifeless bundles and left at the doorstep to die. The inpatient unit does not become a 'cold room'⁶⁰ or a virtual aerial toll house⁶¹. The staff need not feel directly responsible for the deaths; they continue to be carers rather than death watchers, funeral organizers, or just bystanders. Finally the staff has weekend respite for themselves and their families. The advantages to the inpatient staff of children dying at home instead of in the inpatient unit seem to outweigh any nodding preference of the family.

Is it a valid assumption that children and/or their parents prefer death at home? There is certainly a wealth of information suggesting that children in the UK want to die at

⁶⁰ The room in a hospice set aside for family and friends to view the body after death

⁶¹ 'Aerial toll house' reflects the toll-house teaching of the Eastern Orthodox Church: a house wherein a person's body can reside while "the soul leaves the body and is escorted to God by angels" through an aerial realm of demons (and literally through the open towers). The sins of the soul make up the toll to be exacted by the demons, and the angels gather together all the good deeds of the dearly departed to pay the toll.

home. (Goldman, et al., 1990, p. 642) In this oft-cited reference by Goldman et al. (1990), the children were cancer patients. Their findings were duplicated in a large population study of children with complex, chronic conditions. (Feudtner, et al., 2007, p. 2725) But can the same really be said in Romania? It certainly seems to be the case in this anecdote about a “dumb” child which was recounted by I1, the psychologist:

I1: There is awareness that we are not just a body. We feel the testimony that we are much more than that, and this is a lesson we can learn day by day. My greatest lessons were from stories of the children.

DJ: Can you give me an example?

I1: Not from here, as we didn't have too many dying children, but from Bucharest. I recall it with emotion. The child was close to the end, the parents were avoiding the subject, but the child wanted to know what is happening. And he started telling me about his dreams, and day by day getting ready to go. The way he told the dream, with white robe and stars on the robe, with such a light on his face, that it gave courage to the mother to be part of getting ready. These kinds of things happen. We had a child from a very poor family who spent his last years in hospitals. He couldn't talk, he was dumb. But he could express himself so well. And although he adapted well to having treatment here and at the hospital, when he felt his time was coming towards the end he wanted to be at home with his family. The child was an enlightened being in the family, and very quietly waited for the end. The staff was afraid of this child not being able to communicate, and how would they tell him what was happening. And this

child was mature enough to understand, and to express his wish to go home and get ready for the end. These are things we cannot understand. If we would have to go through such a situation we would get so excited, anxious, frustrated, and all kinds of emotional reactions. But children have the kind of maturity, and the real confidence that there is something above us.

DJ: Does that come from the outside, or do you think it comes from within the child.

I1: It is difficult to say at the parents of this little boy are very simple people, from a gypsy community. And I don't think they ever had religious education. And the other child I was telling you about, who saw himself going towards the light, the mother was in a crisis and denial, so I think it is much more. That is why I was saying that here we see we are much more than just a body.

That being said, a yet-to-be published study in the adult unit of HCS was done on the wishes of patients and families and related to me in an interview with the head nurse (R2):

DJ: Does everyone want to die at home?

R2: About 70% want to be at home, but only about 50% of families want them to die at home. What really happens is a mixture.

In actual practice and in contrast to the adult patients, children and their families are not really given a choice. So home it is.

Further doubt ought to be cast on the assumption that dying at home is the family's preference. Perhaps there was a time when death was more a part of everyday family life and was honored as such. But is this assumption shared by modern-day Romanians? C1 (interpreter) remembers as a child being present in her great grandparents' home when they were 'laid out' to be visited and honored by the neighbors and family. She still becomes anxious – at 27 years of age – even driving down the street where her great grandparents' house is located.

During the many weekends that I spent in a small village near Brasov, I watched the construction of a big, wooden, antediluvian structure in a meadow next to an old stone church. At both ends of the structure open towers topped with horned spirals rise up – an 'aerial toll house'. The house reflects the toll-house teaching of the Eastern Orthodox Church: a house wherein a person's body can reside while "the soul leaves the body and is escorted to God by angels" through an aerial realm of demons (and literally through the open towers). The sins of the soul make up the toll to be exacted by the demons, and the angels gather together all the good deeds of the dearly departed to pay the toll. A practical advantage to the modern Romanian reenactment of the toll-house doctrine is to get death out of the home. This may seem to be an almost random observation but it is one filamentous thread that suggests dying at home is not the default preference of all Romanians. Some may prefer to be escorted to God by angelic hospice workers.

Consider also the case of A (17 year-old boy with muscular dystrophy). In our interview, O1 (day care supervisor) outlines the conditions at home:

DJ: Tell me about some of your kids.

O1: I will start with A, who is the leader of the group. He is 17 and has muscular dystrophy. He is now at the stage where he only uses his hands, but gets tired very easily. But he has such a strong will that he won't give up. He told me that the worst thing to him is not to go out of the house. It doesn't matter how painful it is to stay in the wheel chair, he is very determined. He is very connected to reality and everything that happens. He does not want to know the actual name of his disease and denies remembering it. He is very good with computers and I don't think he wants to allow himself the chance to look it up on the Internet. It is fine, it is his decision. We think it will be really tough when he won't be able to come to the Day Center. All the children want to come to the in-patient unit with A. He is a leader, but is very calm. I watched him with younger children. He is unable to manually help them, but he explains everything.

DJ: Does he have brothers or sisters?

O1: He has a younger sister who is wonderful. She does not carry the disease. She is a healthy energetic child: the opposite of A, running everywhere, taking everything. If he gets a present, she has to look and pick out what she wants, but he is very supportive of his sister. It seems like they have a good relationship. His father is not home too much, he works on a construction site, sometimes leaves on Monday, and comes back only Saturday. He needs to go out of town. But he is supportive and makes an effort to help the family financially. His mother is lovely and supportive of A and her daughter. She looks

after both of them incredibly well. She is calm and creates a good balance that way.

DJ: It sounds like he has a very positive family environment, yet the Children's Day Care Center is really an essential part of his life.

O1: Their actual space is very small, they live in one room and there they made a small space for a bathroom, and an oven. It is very small for four people. It is something like two beds and one computer, and no other space. Being in a wheelchair takes the rest of the space. This to him is the outside world which he needs to be involved.

O1 goes on to describe the benefits of PPC to A's family:

It is incredible for the parents. Even if there are parents like A's mother who will never tell you they are having a hard time caring for their child. She never tells you this. But in the way she thinks when he is in the in-patient unit, you feel she is OK for a week, when she doesn't have to take him to the bathroom, take him out of the wheelchair, wash him, and feed him, and all this that takes a lot of time. She is a small person. And having another child who is healthy, caring for that child, to be safe, to be fed, to be loved, and caring for this child with all his complex needs, she will never say she is exhausted. But when he comes to the in-patient unit, during that week you see it on her face, you see "thank you".

For the 80% of children with life-limiting illnesses who are non-communicative and bed-ridden, death comes so slowly that it passes almost like a season. For these children

and their families, dying at home seems a fair assumption. But it is hard to imagine A dying at home in a space so small – unable to move even his hands or talk – and becoming increasingly short of breath, away from the comforting environment and human contact that he has come to love at HCS. As A is dying, he will not be able to ask to come to the inpatient unit, and his mother will never bring herself to ask (“. . . like A’s mother who never will tell you”) Yes, I suppose he may die at home. But, in that the case, the lack of closure for both his caregivers and his family will weigh heavily in their grief. That being said, there is room behind this resolute non-dying organizational facade for the exception as narrated by M1.

Yes. I remember we had a young patient, around 18 years of age or less, who died in the inpatient unit. As you say, we don’t have the children dying here. The service is organized so that we admit patients on Monday and they are discharged on Friday, so week-ends are at home, with the family. Now obviously if a case is in a terminal stage then we would keep them; but, as I said, there were just few occasions when parents wanted that to happen. And because those services are organized so that they are discharged on Friday, and we don’t – they don’t work on shifts on Saturday and Sunday – we have to admit that child to the adult inpatient unit with nurses – pediatric nurses – staying with them. So that was an extra arrangement.

[5.4.3] Viewpoint of the children and their families

From the third perspective – the perspective of the children, their parents, and the non-professional caregivers in the residential homes – the non-dying image is of little or no

account. When they first come to HCS, they are so far down and out – so vulnerable – that what PPC has to offer obscures any image – whether it is hopeful, dying, or non-dying – that is projected or advanced. Dying is not in their vocabulary, and fear of dying is really not in the child's mindset (Kubler-Ross, 1983, p. 126). In her supervision of the Children's Day Care Center, O1 has a concentrated exposure to the children who are able to communicate. Her comment about A's mother's thankful expression for the respite she receives is worth repeating:

But when he comes to the in-patient unit, during that week you see it on her face, you see "thank you".

To summarize, from the public's perspective, HCS is not a house of death. There are good people that do good things there, and it is worthwhile to support them. "Just do something for the good of it!" From the professional caregivers' point of view, they don't have to suffer with the children as they finally die but rather can make them a little better each day. What is more, a five-day work week leaves the weekend as respite for the day care and inpatient care staff. From the children's perspective, they are not coming to HCS to die; they are coming to be with their friends. From the family's and non-professional caregivers' standpoint the burden of dying clearly rests with them, but that burden is lessened by PPC, and they are never alone, even after the child dies.

This undying commitment to CHILLD care is reinforced by a deep and abiding compassion for abandoned and unwanted children.

[5.5] Compassion for abandoned and unwanted children

Compassion for orphans – children abandoned or unwanted by their families – is a compelling force behind the success of PPC in Romania. What is more, all children with life-limiting illnesses can be considered orphans – not always abandoned by their parents but many times left behind by our fast-paced society without adequate care and attention for their welfare. Compassion is an emotive word which deserves further interpretation and clarification.

[5.5.1] Compassion

Litvin provides a compelling definition of 'compassion':

Compassion can sit with the dying in silence, or with one giving birth, marveling equally in the miracle taking place. Compassion can join in suffering, accepting pain as a part of life. Compassion can jump into action, if action is called for and desired. Compassion can give to the poor or help heal the sick, without condescension or judgment or lack of respect. (Litvin, 2011)

Litvin's definition has its limitations. There is something about the definition that is too packaged, too armchair-easy and philosophical, and too noble. Where is the torment and frustration of the caregiver? Where does the normal life of the caregiver fit it? Most importantly, "accepting pain as part of life" is not in any PPC manual.

Using Litvin's definition of compassion, despite its limitations, R1 (HCS graphic designer) and G2 (HCS CEO) might have sympathy (i.e. the ability to share the feelings of someone else) or empathy (i.e. the ability to vicariously experience another's feelings)

but not compassion because they don't "sit with the dying in silence" or "join in the suffering". On the other hand, they are essential to the agency or 'take-action' aspect of compassion; they ". . . jump into action, if action is called for and desired". R1 has worked hard to develop a web site that reflects a positive image of palliative care. G2 is a key player in other findings described in this study – the balanced budget, the transparent structure and order, and the equitable balance of power – all of which are the agency of compassion. G2 points out that tempering and channeling compassion – harnessing its power – is as important as "jumping into action":

It is a great part of my activity here, managing relationships, mediating conflicts, and supporting people; it is a big domain.

Sympathy and empathy both have a strong element of sadness – of feeling sorry – but at the end of the day, they walk away. Brooks writes about the limits of empathy . . . that "Empathy is a sideshow" (Brooks, 2011, p. A21). He also quotes Prinz as supporting his view in a recent review of related research:

These studies suggest that empathy is not a major player when it comes to moral motivation. Its contribution is negligible in children, modest in adults, and non-existent when costs are significant. (Prinz, 2011, p. 10)

Prinz goes on to iterate the lack of action associated with empathy:

. . . empathy is not very motivating. So even if empathy elevates the level of concern, it doesn't do so in a way that guarantees action on behalf of those in need (Prinz, 2011, p. 14)

Compassion engages the sadness and suffering and does something about it.

Whenever Peanut, the tiny Roma orphan boy with cystic fibrosis, was brought into the Children's Day Care Center, nurses, aides, and physicians would swarm to him as if he was a people magnet. Peanut sits stolidly stoic in his walker until someone reaches out to him. His face lights up like a light bulb with the attention – like a soft toy that lights up when squeezed or hugged. Shall the outpouring of attention be called compassion, sympathy, empathy . . . or just attending to an amusing diversion? As I sat and watched from a couch in the divide between the Children's Day Care Center and the Inpatient Unit – much the same as the British children's television character Bagpuss watches from the pictures of him hanging on the wall – I saw them all satisfy Litvin's criteria for having compassion: "sitting quietly with the dying" (aide sitting at the bedside of the gaunt child who is seizing interminably despite medication), "joining in the suffering and accepting it as part of life" (the aide lying in bed with H as he cried from the pain of his uncontrolled hydrocephalus), "called to action when action is necessary" (C and T responding to G1 whose family was in danger of being evicted), "giving to the poor and wealthy alike" (T's response to G1's and M2's families), and "helping heal the sick" (D1, J, and C1 who tended to the child with phimosis and urinary retention) – and they do it with equanimity, "without condescension or judgment or lack of respect". There was no judgment or lack of respect in C's eyes as she looked at the pieces of the document in the plastic bag that had certified the Roma woman's independent bank account and that had been shredded by her irate husband. There was no chuckle or smirk from T as the mother climbed up the telephone pole far

enough that she could get over the fence around her house because the latch on the gate could not be opened from the outside.

Since the illnesses are not curable, "healing the sick" has a more spiritual connotation that D2 attested to.

DJ: But most of these children are going to die before they become adults, so why bother?

D2: Because everyone counts, everyone is a special being and is as valuable as I am. I think of everyone being created by God in an equal way and with eternal value. Maybe some from state's institution never experienced love that they should have; we might be the only ones to provide them with this love, to be God's arms for them. This is a strong reason to me. Having been here all these years it is sometimes a burden, and difficult.

In 'eternal value' there is a sense in which D2 is alluding to an undying image – an eternal, unending image – another important finding which threads through this study. There is also a hint of the psychological repercussions of compassion – the torment of D2 as a frustrated caregiver. 'Frustration', however, does not do justice to D2's feelings. This was particularly evident early in the history of PPC when the service consisted only of D2 and a nurse. The following exchange was recorded in a 2009 interview:

D2: I had a case, a young lady aged 17. She had severe arthritis and was immobilized in bed. She lived in a block of flats, a derelict building with no utilities. She lived in the corridor.

DJ: She was sort of homeless?

D2: Yes, in that block of flats many families lived like that. She suffered because of the cold. In winter it seemed it was colder inside than outside. We knew she needed lots of things, and we were not able to help her. If we took her some food and left it by her bed other people would come and steal it. It was more like trying to feed them all . . . we knew that with good care and in good conditions she would survive. But in those conditions . . . I was most painful (sic) not to be able to help families.

D2's anguish – her inability at that time to act on her compassion for this abandoned and unwanted child – led to the growth and sustenance of PPC by the addition of two important staff positions: a social worker and a psychologist – the one for the child and family, the other for the staff.

Now that the concept of compassion has been put in perspective, what does it mean to be 'abandoned and unwanted'? D2's arthritic patient is an example of being abandoned; for an example of being both abandoned and unwanted, I return to the story of the stolidly stoic orphan who was the focus of attention in the Children's Day Care Center. Peanut was abandoned and not wanted because his family is poor and his medical needs are overwhelming. Peanut is an 'orphan' and among the worst of the lot – a much-despised Roma with an incurable disease.

[5.5.2] Abandoned and unwanted: 'irrecoverables', Roma, CHILLD

What Graham Perolls saw when he returned to Romania after the 1989 Revolution gave unequivocal meaning to the term 'unwanted and abandoned':

. . . you know, to see these hundreds of children lying in iron cots, most of them totally motionless, staring up at you – it had a very big impact on me. (Perolls, 2001)

He saw hundreds of children dying of AIDS. But in the interview he made no direct reference to HIV/AIDS – he was overwhelmed by the suffering of the orphaned children, not by the disease. After all, disease (e.g. cancer, tuberculosis, malaria, HIV/AIDS) did not motivate him to found the hospice in Kent, UK. The suffering of his dying mother and father moved him to action, just as the suffering of the dying children in the orphanages moved him to develop PPC.

The bond between compassion and unwanted and abandoned children was made, and even as the orphanages were emptied and abandoned, the connection between Perolls' compassion and pediatric palliative care endured.

There are still orphans in Romania, but there are no "orphanages" – just residential placement homes. E, a hospital PPC-certified pediatrician, explains the basics of modern orphan care in a 2009 interview:

DJ: What about the children in the orphanages?

E: We don't have orphanages, it is a different structure. We have placement homes.⁶² Like foster parents.

DJ: But they are paid to take care of the children

E: Yes, of course

DJ: You do not have an orphanage here in Timisoara?

E: No. They live with families. We don't have placement homes here (in Timisoara). There is one somewhere in Lipova, and maybe nearby Resita, but the idea is to place them in families. There is a good and a bad side to this. Some stepparents take good care of them, others not so much.

E focused my attention on the quality of surrogate parents and omits to mention the most important issue: what happens to the children that can't be 'placed' in foster homes? What about the 'irrecuperables'⁶³ in the residential placement homes? In actuality the placement homes have become the New Age orphanages. M1 admits as much in describing the conditions in these residential placement homes:

M1: With Romania accessing EU we don't have the dreadful orphanages anymore. We build small, houses for about ten children. But building a house is not enough to look after a child with serious problems. You need staff to be prepared to look after the child. You need enough staff. These are problems

⁶² "Placement homes" are 10-15 bed homes where orphaned children wait to be placed in foster homes. The term is interchangeable with 'residential homes' – some children are never placed and become permanent residents.

⁶³ Irrecuperables are the orphans who were considered unfit to ever live in society (Morrison, 2004, p. 173)

which are not in the health system, they are sort of sorted out by the ministry of labor and social protection, but the condition of these children is very poor. We work with the local child protection service, and every week we admit two children with such severe disabilities.

DJ: From the residential homes?

M1: Yes, from the residential homes, and our staff visit these children in the homes, train the staff there, as for two "mothers" looking after ten children, bed bound and with very severe disabilities, it is unacceptable. They have to do everything: washing, cleaning, cooking, everything a mother does at home.

DJ: But these mothers have families also. Do these families live in the home?

M1: Yes, they have families, but they don't live there. They work there, they are employed there. Their salary is very low and is probably not motivating them to work there, but most of them are very nice people, they love these children as much as they can, but still it isn't enough. They need qualified staff. They need a doctor. The rule is that even if child protection services have a doctor employed, they have absolutely no right to prescribe for these children. Which I think should be a basic thing and easy to repair. Take a family doctor, employ him there, as there are plenty of children who need medical care, and give him the right to prescribe. No, these doctors can only work on the diet of these patients, what they eat, the number of calories, and they refer the children to a family doctor close to their residential home. This is another example of things going

strange. They say a family doctor can only have 1000 patients. Well, make a rule for family doctors working in such units to have the right, as they are doctors at the end of the day. It is very strange.

The homes do not meet the high standards set out by Mr. Hershey, but they are certainly a step above the teeming, iron-cotted orphanages of Ceausescu's Romania. The point needs to be emphasized that there are no 'normal' children in these homes. The children whom Malina is describing are the 'irrecuperables' of pre-Revolution Romania. How different is the stolidly stoic Peanut from the uncrying, motionless faces staring up at Graham Perolls? 'Normal' (healthy) orphans need some measure of medical care, but children in the residual homes need full measure.

There is more to this story of frustration and yet another reason why compassion for unwanted and abandoned children contributes to the development and continuing success of PPC.

All children with life-limiting conditions are "irrecuperables"⁶⁴, and PPC is all about these children. It is no surprise that 18% of the PPC patient population, i.e. 25 children, come from the local residential homes. Two of the children are taken into the inpatient unit during every admission cycle. They are embraced by the staff, just like Peanut is welcomed. They are nurtured by O1, T, and C. The children are educated by O1 (however their 'teacher' was lost to the recent Romanian debt crisis); and they are prepared for a sure future, albeit death. In short, PPC satisfies the high standards set

⁶⁴ "Irrecuperables" was a term used in Romania for children that were deemed unfit to live in society; an irrecuperables orphanage in Hirlau, Romania, provided the sociocultural context for an ethnographic study the institutionalization of children in Romania (Johnson, 2011, p. 169).

for orphan care by Hershey: these 'unwanted' children are embraced, nurtured, educated, and prepared for the future. This is another indisputable measure of success. PPC is the humanness at the end of the orphans' tunnel and a way out of the 'orphan problem'.

Finally there is a less apparent reason that compassion for unwanted and abandoned children is an important factor in the success of Children's HCS. In the aftermath of the Revolution and the AIDS epidemic, a Romanian pediatrician made a plea: "We must relearn to be human." (Hunt, 1990, p. 28) There is a sense in which the people of Romania are recovering from their grief and guilt regarding their orphans – the unwanted and abandoned children. In an interview with D3, she recounted her introduction to HCS in 1997 at the completion of her training in oncology:

I was very disillusioned through my schooling that the emphasis was not so much about the patient as it was about the diseases. And then our first child was not right (Down's syndrome). As I recovered from my grief and guilt, I was invited to Hospice Casa Sperantei . . . and they were doing everything!

What brought D3 to this tipping point? She had been in her 20's during the height of the AIDS epidemic. Had the pediatrician's plea "to be human" echoed through the years of her medical education and training? Or had D3 felt the wave of grief and guilt that swept the country? Had she become sensitized to the inhumanity of men and women? With the birth of her first child – a child who would have been deemed unwanted in pre-revolutionary Romania – she joined in the suffering and her compassion crystallized. She was no longer a sheltered witness to the tragedy. Recovery, healing,

renewal are active processes, and palliative care gave her the necessary agency. Her compassion for unwanted children joined that of Perolls and Malina in creating the success of PPC. D2, D1, C2, B1, G2, and R have all embraced PPC and answered the call to be more human.

The compassion for unwanted and abandoned children is an active force behind the scenes that has helped drive PPC in its success.

[5.6] Solidarity: like-minded people joined together in meaningful activity

What became evident as I interviewed and observed a wide spectrum of employees (nurses, physicians, social workers, administrators, fund-raisers, and receptionists) at Children's Hospice Casa Sperantei (CHCS) was the sense of solidarity: like-minded people were joined together in meaningful activity. I alluded to this finding in the unique paradigm of pediatric palliative care. Madalina and her mother valued the sense of solidarity that was part of their PPC experience. Similarly, G1's mother was gathered in and empowered by solidarity.

This finding – like-minded people are engaged in meaningful activity – may at first glance seem self-evident, but it deserves close scrutiny to sharpen its significance.

'Like-minded' people generally think the same, share common values, and abide by the same principles. Like-mindedness can also be thought about or viewed in terms of organizational culture. Morgan describes culture as "an active living phenomenon through which people jointly create and recreate the worlds in which they live."

(Morgan, 1997, p. 141) Organizational culture is rooted in an organization's history and collective experience. Schein is a bit more specific:

The culture of a group can now be defined as a pattern of shared basic assumptions that the group learned as it solved its problems of external adaptation and internal integration, that has worked well enough to be considered valid, and that can be taught to new members as the correct way to perceive, think, and feel in relation to those problems. (Schein, 2001, pp. 373-374)

A discussion of the individual organizational subcultures of Hospice Casa Sperantei – medical (e.g. RN, MD), paramedical (e.g. social worker, psychologist, child therapist, kinesiologist, aide), administrative (G2, M1), and general support (e.g. cleaning and kitchen staff, advertising, development, and accounting) – is a study in and by itself but beyond the scope of this thesis. However, the point needs to be emphasized that the unifying concept of organizational culture is complicated by the interplay of these subcultures which impact what is really going on. I1 (psychologist) alludes to these subcultures as “several small institutions” in the following interview:

There were years when the staff structure changed twice or three times: redistributing tasks, training, etc. And I am not just talking about what is happening in this building. There are several small institutions within this . . . the heart of a big network, growing very fast, training people, sharing experience, so I think sometimes people can be tired.

I1 is also alluding to complexities of organizational culture that are beyond the scope of this thesis. It is enough to say that a family is not always a 'big happy family'. On the other hand there is a sense of cordial collegiality that is appealing. R, the receptionist at the front door, sees all and hears all that comes and goes:

C1⁶⁵: What do you think the relationship between doctors and nurses is like?

R: Very friendly, cordial, they call each other by the name. I think I am the only one who says "Doctor". In this country, doctors expect to be called "Doctor", but here people call each other by the (sic) name; they have a good relationship.

The unspoken "shared basic assumptions" of PPC are: 1) we believe that these children are worth caring for despite their life-limiting illnesses; 2) serving the family and the child supersedes treating the disease; and 3) children come here to be better rather than to die.

[5.6.1] These children have value and worth

The first assumption – that these children are worth caring for – is epitomized by the case of M1⁶⁶, who has a terminal condition that gradually mummifies the skin, joints, and internal organs. She would have been remanded to die in an orphanage if not for the intervention of a pediatric hospice nurse and the partnership that developed between her adoptive family and PPC. Fourteen years later, as her life is slowly coming to a close, the partnership endures, and her value and worth are undiminished.

⁶⁵ C1 was my interpreter and transcriptionist and had worked at HCS as Director of Volunteers for several years prior to her current job as a saleswoman for an Austrian gun safe manufacturer.

⁶⁶ M1 was introduced in **[5.3.2.1] Homecare**.

No mention of it is found in the mission statements or the president's message in any of their annual reports, but the first assumption is integral to understanding what is going on at HCS. These children have value and worth; they are not to be discarded, neglected, put to the side, abandoned, or forgotten. The following is an excerpt from notes made while sitting one evening in the inpatient care unit.

One nurse and one aide are on duty. Multi-colored paper flowers are hanging from the 'ceiling' of the rotunda skylight; relatively fresh flowers were in a vase on the banister. As I am writing I am becoming increasingly aware of noise coming from the day room: the discordant music is coming from an electric key board 'played' by the patient girl superimposed on a recording (over and over) of a stanza of classic music, the laughing of the volunteers, and the shrieks of H⁶⁷. Upon peeking in, a volunteer teen was sitting on the floor next to the electric keyboard, giving the teen patient her full attention, whilst bobbing and weaving at some rhythm that may have matched the random-fun noise. Peanut⁶⁸ was added to the mix and became a focus of attention with his eyes wide open and a bright chipmunk smile (instead of a 40 watt smile, he had a 60 'watter') – free of the load in his diaper and in joy-full company. The changes in amplitude of H's happy shrieking corresponded to variations in volume from the keyboard: more excited when the music was loud and less so when the noise lessened. This is probably the epitome of 'hanging out': a cacophony of happy sounds.

⁶⁷ H is the blind boy with severe hydrocephalus

⁶⁸ Peanut is the Roma boy with cystic fibrosis

Even in the gloomy light of the ignominious night shift, these children were not only welcomed but embraced. No one asked them to turn the volume down or to close the door; instead, others joined the party. This element of the organizational culture – the value and worth of these children – is further displayed in the energetic body language of the nurse Juliana “stalking” Peanut and his loaded diaper.

D2 provides the coup de grace for this assumption in her 2009 interview:

“Because everyone counts, everyone is a special being and is as valuable as I am.”

The assumption that CHILLD are worth caring for is accompanied by an aptitude for working with children, especially incurably-ill children. D1 alluded to this aptitude when I was asked why she chose to work with children:

I realized that it was much harder to work with adults than children, and I wanted to try something new: children accept illness and problems easier; adults are always grumbling and complaining all the time.

In an interview with David Clark in 2002, D3, who became the Medical Director of HCS in 1996 and continues in that position today, commented about her own lack of aptitude for working with children:

. . . and for me it was particularly difficult to see children, to have children in my care, I am working with children just when the doctors are in leave, holiday, when they have holiday, because I find that particularly difficult to see them suffering and, you know, to accept the idea they are going to die

D3 works almost exclusively on the adult side of HCS. B (administrative assistant) alludes to this special aptitude for working with children in remembering her own hospice experience.

My opinion is based on my personal experience, of when the nurse came to care for my son. What I realized was that in the Hospice you won't find common people. All these people have something in their heart that is not there in every person. They show empathy, love, kindness, generosity. It is completely different.

B has an extended experience with HCS because she has worked on the staff as an interpreter/receptionist/coordinator/fund-raiser since her son's death in 1994.

A ten-year veteran nurse of HCS adds:

You have to be a special person to work here because you are totally committed to the patient – how do you say 'altruistic'.

M1 opines that the ability to care for children at the end of life is not learned as a skill but rather discovered as a gift or talent.

And even when we interview nurses we look for people who have the heart for palliative care other than the knowledge because knowledge can be built up in time. But if you are passionate and empathic about these patients, you either have it or you don't.

Not all of the more than 9,000 professionals who have been trained and certified at the Study Center have a gift or talent for PPC. The mission of the Study Center is to increase the awareness and visibility of palliative care to all that have an interest and to select those who have a passion for PC for education to be PC specialists.

[5.6.2] Serving the family and the child supersedes treating the disease

The second assumption shared by Brasov PPC is the conviction that serving the family and the child supersedes treating the disease. A good example of this approach is found in the following excerpt from field notes taken during a home visit in a Roma village.

We carried on to our next visit . . . but slowly because the condition of the road deteriorated into more holes than road. We went from one side of the road to the other trying to miss the bigger holes. Several 'house trailers' or, more accurately, house wagons in poor repair were scattered along the side of the road – about 20 horses were grazing on the lush green grass alongside a river; two men were pulling some discarded metal out of the river (which they commonly sell for 'scrap metal'); and another was walking with a long fishing pole along the bank.

We were welcomed at the gate by the girl patient and her mother, who then busily ushered us into her uncluttered two-room home. She quickly found a stool for me to sit on and covered it with a little red cushion. She is a small, energetic, wiry young woman. The house was clean but clearly 'worn'. The wall around the wood cook stove in the corner was yellowed from heat and soot covered much of

the ceiling of the big room – more concentrated over the stove. A six-eight inch hole was visible in another corner of the ceiling. The wall behind the sofa bed was adorned with four or five religious iconic pictures. An old pair of faded, high-topped orange sneakers lay under a small table next to the sofa bed – the only parts that remained orange were the heels. The floor was covered by a red rug which partially concealed an 18-inch in diameter crater just in front of the sofa/bed. The window dressings and the curtain about the entrance were spotlessly clean, white, with eye-catching needle work. The shelves in the closed cabinet were also fronted with the same smart dressings. She kept her 'papers' in a plastic bag in the cabinet. C needed pictures of her children, which she was able to find without hesitation. The plastic bag also contained the torn up envelope and papers that documented her account at a bank. She cannot read or write and had opened the account so that her stipend (she receives a stipend to care for her child) could be deposited directly in the bank and that she could be issued an ATM card. Her husband had torn it up when he discovered it. C sifted through the torn bits of paper with an unusually flat expression on her face. The husband is an alcoholic and would go with her when she picked up her check from the town hall; he would spend the money on alcohol. For a while in the past she lived with her parents in another village, but when she came to pick up her stipend, he would be there waiting for her (and the stipend). By having a debit card, she could get her money at any ATM.

The child patient is in remission from Hodgkin's lymphoma and sat brightly and politely next to her mother. They had been informed about hospice by the oncologist here in Brasov. She can stay enrolled with hospice until she has been in remission for five years. The child patient and her mother happily recounted attending the hospice-sponsored summer camp on the Black Sea last summer – especially the girl: her eyes widened; she smiled broadly; and she jumped in her seat. For the first few days of camp the mother was withdrawn and could not speak to anyone. Then she gradually began to smile and open up. T remarked that the mother has been badly traumatized and is very fearful.

The plight of this woman and her seven children – who are now in the company of a protective services agency – has already been highlighted in **[5.3.2.1] Homecare**. Serving the immediate needs of the family and the child – homelessness – took precedence over treating disease.

On the other hand, treating the disease rather than seeing to the needs of the family and child is the first priority of the acute pediatric hospital. Before D2 joined Hospice Casa Sperantei, she was trained as a hospital pediatrician and bore direct witness to acute hospital care.

I saw the needs of children and their family not being met by hospital care. I saw a few children dying at the hospital and saw that the staff was very uncomfortable and unprepared to deal with pain. Children dying of cancer were isolated in a room and staff was trying to avoid going in there. The child was in distress as the people were not prepared to see them. So I saw the need for this

and wanted to do more for the children than just give them medication: to help relieve their suffering and comfort them.

The head nurse of Children's Hospice Casa Sperantei recognized the superior care available in PPC when she first arrived. She had previously worked in a pediatric hospital and in an adult emergency care unit:

DJ: . . . did you know what to expect when you came to work?

D1: no, I didn't know and I had just heard about it; I was impressed by the service provided at the hospice compared to the hospital.

As a mother of a patient that died in 1994 and as a member of the HCS staff since that time, B's opinion carries considerable authority:

If you walk into a hospital you won't hear a nurse talk like any of the Hospice nurses do . . . never. You will never find a doctor talk to the nurse in a friendly way, as if they were a whole. At the hospital you would see "I'm the doctor and you are the nurse; I'm the king; you are a servant." Relationships between staff here are completely different from that in hospitals.

I1, a full-time psychologist, gives a broader, more diplomatic perspective.

People who were coming here had the feeling that "now I can do what I am meant to be doing": to serve the patient, serve the family. I don't know if you know that our health system is very different, the relationship between the

healthcare team and the patient. And here it is a different work philosophy and spirituality.

That is not to say that the acute hospital staff doesn't 'care' in the sense that they lack compassion or kindness. When speaking about a child hospitalized with leukemia, E, a pediatric hospitalist (pediatrician who works exclusively in a hospital), commented:

At the beginning of the year I lost a child who was abandoned and left here. He had family, but it was a gypsy family who lived far away from Timisoara. They brought the child into hospital, and he stayed for a year and a half. All staff members looked after the child. At weekends they took him home, like he was their own child . . . and the staff provided his clothes for the funeral . . . and everything for the funeral. I have good, caring staff here.

[5.6.3] Children come here to be better . . . not to die

The third assumption that children don't come to PPC to die but rather to live a little better was evident on the Monday that I first visited the inpatient unit. A fresh group of children had just been admitted. They were not just quieted and tucked away. Each child was carefully examined on rounds, and a preliminary plan of care initiated. Each child was to be then discussed in turn at the weekly staff meeting.

A nasogastric tube will be changed to prevent erosion of the nasal passage in one child; an arm will be splinted to the child's hand out of her mouth and ease the inflammation and skin erosion on fingers that were continually bathed in saliva; a mother will be taught how to clean and apply lotions to her child's genetically acquired dry skin; an

orphaned child is being 'stimulated' from the doldrums of his cystic fibrosis. At the conclusion of rounds we are all swept into the adjoining Children's Day Care Center by the enthusiasm by Cristina, the nurse who is fit to serve a queen (see **[5.3.2.2]** **Inpatient Care** above), where M3 was happily celebrating his 17th birthday with his fellow hospice friends and the staff. I described the event in my field notes:

Marton is having a 'surprise' birthday party in the day care center. I can't help but think that every birthday party is a 'surprise'. Marton is quite the photogenic 'ham': every time someone points a camera at him he gives them his full attention and a magnetic smile. Thomas (14 year-old boy with a brain tumor) is a new addition to the day center. He has a grey-tan cast to his skin so reminiscent of radiation with sparse coarse hair. There are balloons and a cake, and Thomas is using the handle of a large paint brush to serve as a hand mike in his role as emcee. The Roma mother has taken a seat next to me in the circle and was served some cake. She is a thin, simply coiffed woman wearing a red sarong festooned with flowers.

Just to iterate, children don't come here to die; they come to live a little better. O1, the Director of Children's Day Care Center, emphasizes the importance to the children.

None of the children think of the Hospice as a place for dying and sick people. To them it is just a different world. Not the sick type. They see there are children like them and are basically focused on the children in their group. They have problems at home but when they come to the Hospice it is a place to socialize in. They don't see the adult ward. Maybe it helps as we don't frequently have

children who die. It happens maybe once every other year, and in that case we talk to them and tell them the child got sick and died. Usually we have smaller children who stay in bed most the time and pass away there, but they are not in their groups. I stick with the fact that this is their social group; this is where they feel good. They come to the in-patient unit, they are a group, and they feel fine. They have parties, go out, and stay up late at night, they are happy to come. It is not like downstairs in the adult unit.

Death seldom needs to be discussed. Children don't die here; they come and go and always seem to go away a little better than when they came in.

To return to the finding – like-minded people are engaged in meaningful activity – in a 2009 interview, I asked D1 what it was that she liked about her job, and she responded:

I like my colleagues and the services that are provided; I like the way they work here; I like everything.

Her response summarizes the importance of organizational culture in creating a powerful agency that contributes to the success of HCS.

This segues to the second part of this finding – meaningful activity. Like-minded people are engaged in meaningful activity. 'Doing good things and helping others' intuitively comes under the umbrella of 'meaningful activity' but who is to define what is meaningful? What has meaning in our lives can be a deeply philosophic question that is far beyond the scope of this thesis; the question includes conceptions of being, the

existence of God, the pursuit of happiness, and a purpose to it all. Meaningfulness can also have a more pragmatic, less contemplative interpretation . . . such as having food and shelter and being free of pain. For some, caring for sick children holds enough meaning in itself to give purpose. For others, their involvement in PPC and dedication to its success has a higher meaning.

[5.6.4] God's work

From my own limited experience, I presumed that a divine or spiritual calling would be common to all providers of end-of-life care. L, a home care nurse in Oradea, corroborated my assumption:

I was working in the pediatric hospital and went on maternity leave for Lydia years. And when my little girl was almost two years old, I heard the ad on the radio. My motivation was personal, as that year one of my brothers died. I didn't know anything about the money. I came to the interview and understood that this was my calling.

In an early interview with Graham Perolls, David Clark asked him what motivated him to start the hospice movement in Romania:

I think the first thing to say is that – I don't want to over-spiritualise this – but I felt a very strong call in the first place from God to do this work, and my faith does sustain me through it. (Perolls, 2001).

There was no call or text message on his cell phone, but a concerted belief that God intended him to do this work. This same belief also motivated G2, a business executive

whom Perolls recruited to manage the business side of HCS. In his interview he remarked that he had some contact with hospice through his dying uncle. He did not necessarily share a talent for caring for children or even a compassion for unwanted children, but rather he saw it as 'God's work' and therefore meaningful:

All my working life I spent doing commercial activities, I thought to myself maybe it was a proposal from God for me to try doing something different – something more on the humanitarian side.

I questioned him further about what I interpreted to be a calling:

DJ: Do you mean a 'calling'? You said something about God.

G2: Yes, God, because nothing happens without God.

Early in my field work, I not-so-wittingly sought to corroborate my anecdotal experience by asking direct yes/no questions. As data accumulated, a 'divine calling' was more the exception than the rule. What is more, my question was biased and could have influenced the response. The bias is apparent in this interview with C4, a nurse in day care:

DJ: Does religion play a role in what you do?

C4: Yes. Many times I thought to myself that working here has made me realize the need to have a strong faith. Otherwise I wouldn't be here talking to patients every day or have the patience to deal with the situation.

DJ: Do you have a sense that you were called to do this?

C4: Yes. If I didn't, I would be working somewhere else

C4 expressed strong faith but not necessarily a divine calling. M4, a pediatric neurologist in Bucharest, was more emphatic and brought the truth value of my "limited experience" and bias down to earth when I asked her if she was called to do palliative care:

Well . . . for sure this has nothing to do with palliative care for me . . . is not the reason I am here. I am just interested in these disabled cases. I might say that I am lucky to see how this disease goes through years because we had some similar cases in the hospital, but they don't survey them during long periods of time.

In my interview with D1, she was more to the point without the need for going into the semantics of 'calling':

DJ: how does your own spirituality or religiosity play into your practice?

D1: I think that doing good things and helping others belongs to this spiritual.

Her simple statement epitomizes the concept of like-mindedness and also affirms the meaning and purpose of PPC. A divine calling is not a necessary condition for success.

[5.6.5] Not always perfect

This finding (Solidarity: like-minded people joined together in meaningful activity) is a consistent theme which will be developed in greater detail in the Discussion, but to avoid presenting an overly embellished or inflated interpretation of what is going on, it

is important to address some potential inconsistencies. As I left G2's office at the conclusion of our interview, the ever-perceptive B remarked, "So what do you think of this concept of 'family' here?" There was a touch of sarcasm in her voice that balanced the naive optimism implied by the concept of family. Indeed, expectations are diverse; the depth of understanding of PPC amongst the staff varies; and interpersonal conflicts roil beneath the surface. For example, G1's (Roma mother) initial expectations of PPC were beyond reason as T (home care nurse) explained in a joint interview with C (social worker):

She is the type of person who often feels she deserves more than what she is given, but C explains how much we can do, and where our limits are.

G1's mother had asked PPC to repair their cottage roof. This is an extraordinary request of PPC in any culture but is characteristic of the culture of the Roma – they scrap for every little bit. It is even more remarkable that PPC has remained successful in the Roma community – and not engendered ill feelings – as underscored by my exchange with G1's mother (GM):

DJ: Would you ask her if she could talk a little bit about her experience with the Hospice?

GM: It meant a lot. I cannot find words to express it. Hospice has helped us as much as they could.

A single mother and her two children who had spinal muscular atrophy had no such expectations. D2 describes their living conditions and marveled at the lack of expectation or entitlement:

They didn't go to school; they didn't go out to have contacts with other children because in that case the father was dead, and the mother struggled to look after them alone. And when she had to go to work because she didn't manage from the money which she had and left the children in the morning, she dressed them up; she took them to the toilet; and she left them by the table. They didn't have wheel chairs, let alone special wheel chairs; they were in the chair by the table, leaning on the table, and watching TV until the mother came home. She put some food on the table, and this was their life. And I was very affected seeing them with so little as children, not being able to, to go out, to be with other children and even they couldn't go to toilet all those eight hours when the mother worked. They trained themselves to wait until the mother comes home and the girl was quite happy, and you know, she took her in her hands and brought her to the toilet. They didn't have any equipment to help them with caring those children, so it was painful to see those children having so little and it was also a lesson for me and for my colleagues to see that they were content with their lives and they didn't ask for more and they were so happy when we started to go to see them

And there are also different levels of understanding. In the following exchange, C2 comments on a disconnect between the medical and administrative subcultures.

DJ: What is your sense about the organization? Does it work?

C2: I think those who are doing the medical part understand each other. But I think there is a gap between the medical and the admin team. They say they understand, but sometimes without meaning to you overhear things that are not right. I think they don't understand what we are doing.

DJ: Is it that they don't understand, or that they are not being honest?

C2: I think they don't understand because they've not been in our place working with people like we do. I believe that they want to do their best. But I think they either don't get the message from us, or don't understand what we are doing. It is bad because they are not passing on the correct information, which is important.

DJ: Can you give me an example?

C2: Maybe sometimes they don't know the boundaries of how much they should say or if they are saying the right things. It is very important to know who is going where.

Although these differences might be considered divisive, C2's opinion does not detract from the sense of like-mindedness expressed by G2, the chief executive officer, in this excerpt from our interview:

I was very much impressed by what I had seen here. As an engineer, I couldn't see myself working here, but I said to myself maybe it was time to do something different.

Just as there is a diversity of expectations and different levels of understanding, there are also interpersonal conflicts. The receptionist for the inpatient unit was very upbeat about the 'hospice family' atmosphere, but when she was asked specifically about negative aspects, she responded:

Sometimes colleagues are quite rude and harsh, but these are only remote situations which can be solved. It does not feel good when you put all your heart and soul into your work here, and they come and cut straight into your feelings.

However, in that same interview she describes a process of conflict resolution that is fundamental to the creation and maintenance of like-mindedness:

R: . . . and the team is pleased with their own work, pleased with themselves. Even if they have problems, every organization has problems.

C1: And the staff can solve these between themselves?

R1: Absolutely.

In her 2011 interview, D2 alludes to the process of conflict resolution that goes into being like-minded:

DJ: Tell me about your concept of 'team'.

D2: We depend on one another to care for the children.

DJ: What do you do when someone isn't fitting into the team?

D2: We sit down and talk it out.

[5.7] Equitable Balance of Power

Another factor that contributes to the success of HCS/PPC and bobs to the surface in the pool of data is an equitable balance of power. It seems inevitable that any study of social processes will involve an assessment of power and more specifically social power. I allude to the concept of power in regards to Ceausescu's oppressive pronatal policies (see **[5.4] "Children don't die here"**) and **[5.5] Compassion for abandoned and unwanted children**, the runner's image in the Marathon poster (see **[5.4] "Children don't die here"**), and the solidarity that exists between the professional caregivers and the families of CHILLD (see **[5.5] Solidarity**). Ceausescu created an ever more intrusive power structure to increase the birth rate in Romania. The image on the poster had the power of moral persuasiveness. Solidarity succeeded in empowering the families. Each of these involved both social structure and human agency.

That being said, power or power structure was never a topic of any conversation in the field, and I never viewed D3, G2, M1, or D1 as 'powerful' or power 'heavies'. They don't 'strut their stuff' or rely on rhetoric to motivate and dominate. But they are resourceful, and they have combined knowledge, expertise, moral persuasion, group dynamics, and charisma to broker an equitable balance of power. These are the basic elements of power.

[5.7.1] Knowledge

Imparting and acquiring knowledge is power. Education was such an early priority that the Palliative Care Study Center was built prior to (1997) the HCS inpatient unit (2002) (Mosoiu, et al., 2000, p. 66). Since the Study Center is not a part of a university, accreditation as a National Postgraduate Training Centre was achieved through the National College of Doctors (Mosoiu, et al., 2000, p. 66).

According to the Study Center administrative assistant, the Study Center has educated and certified more than 10,195 Romanians – physicians, nurses, social workers, psychologists, pharmacists, nurse assistants, volunteers, and lawyers since its inception. They have also provided training for 300+ professionals from Eastern Europe and Central Asia.

Since 1997 medical students at the Transylvania University of Brasov receive 14 hours of palliative care education. A Master's Program in Palliative Care is now being offered by Transylvania University in conjunction with HCS. Education in Romania has traditionally focused on structure and theory with minimal emphasis on agency and practical application. D3's own experience bears this out:

So just to give you an example in my training as oncologist I had two day course on pain control done by a surgeon who has never, never in his life given morphine.

At the Study Center, lectures on pain control for children present a theoretical or structural framework to treat pain in childhood and then a limited choice of medications

with pre-determined dose ranges for practical application. The case study format (a student or the teacher presents a case from their experience for analysis by the teacher and discussion by the group) that is commonly utilized at the Study Center (Hinshaw, 2011) imparts a form of discursive power – collective empowerment – that enlivens the body of knowledge and gives it agency. The first seeds of a new consensus – standards of palliative care practice – were sown at the Study Center.

[5.7.2] Expertise

Expertise is the proven ability to apply knowledge: knowledge and experience. The experience component of expertise is showcased to the public at the HCS Inpatient Unit. Experience literally lives in the home of the patient and family as homecare. With their expertise HCS developed a standard for the care of incurably ill patients – a new consensus of care. In 1999 the Ministry of Health and the National College of Doctors recognized palliative medicine as an official medical specialty. The consensus of the medical profession, the House of Health Insurance, and the Health Ministry had been that the focus of care is the disease, not the patient. For serious illnesses the patient comes to the hospital where curing the disease is the priority. If the disease is not curable, the patient was simply returned home to the family. A new consensus provides continuing care for incurably ill patients.

[5.7.3] Moral persuasion

Moral persuasion, appealing to the sense of right and wrong, can be an important source of power. The marathon poster urges the public to come and run (and

contribute money) "just for the good of it"! The poster also fuels the narcissism of the power elite. The power of moral persuasion in the poster is manifest in the dramatic increase in the number of 'hits' on the HCS website as well as the amount of revenue generated. And there is a strong moral tone to M1's admonition ". . . these are just decent standards of care!" C and T invoked the power of moral persuasion in this exchange in the field which I documented in my field notes:

I couldn't see or find the 'child' at first because she was on the bed against the wall covered over by a comforter. She cannot sit or walk, talk, see, or chew – mom feeds her very slowly with a spoon. G1 is 15 years-old and was normal (healthy) until she received polio vaccination at age five. She lapsed into a 'coma' and was hospitalized for three months. Mother stayed in the hospital with her for the entire three months. The father did not visit and showed no interest. They divorced. Her current husband is "very good" with G1 and is the father of her other two children. He is technically unemployed but is able to find a job in the village nearly every day. When I provocatively asked T and C why the mother hadn't abandoned her child (G1), they both looked at me aghast and almost in unison said, "But she's her child!"

Their moral indignation and persuasive conviction – that is to say their moral persuasiveness – was palpable.

The power of moral persuasion has another dimension. The power elite may not have a conscience as much as well-preened narcissistic self-view. Nevertheless, it may seem in their interest to feign conscience and contribute to fund-raising campaigns.

[5.7.4] Group dynamics

The positive, affirming power of group dynamics is best illustrated by the public relations leading up to the 2009 Bucharest marathon and the success it had with public at large and the power elite in raising money and awareness of PC. The success of the poster relied on understanding what motivates the public and how it may be influenced. This is a dynamic that reaches out, engages the external world, and projects diversity, otherness, and global citizenry.

A second internal dynamic is the cohesive strength or energy that allows like-minded people to engage in meaningful activity. It depends on cooperation rather than competition. I was intimately exposed to this group dynamic upon my 'insertion' or arrival in Romania (see **[4.2] Gatekeeping**). Each component of the study (day care, home care, and inpatient care) was addressed with the appropriate contingent, and within 30 minutes, a time frame for completion was settled upon, a means of participant recruitment was elected, and translation was arranged. Everyone is important and has a role to play. This was an equitable balance of power from the bottom up and the top down, as if a ball had a bottom and top. D3 did not want to expose the staff to additional responsibilities unless they wished to take them on. And the staff wished to have the sanction, leadership, and throughput of D3. In the end, everyone pulled together. There is a hierarchy but it is the group dynamic – a sense of solidarity and equity – which must be respected and engaged. This same solidarity and equity are channeled into patient care.

Another powerful group dynamic at play is that of the power elite who control the government and create their own regime of knowledge where wealth, incompetence, secrecy, mystery, and corruption hold sway (Siani-Davies, 2005, p. 33) (Gallagher, 2005, p. 313). In my interview with G2 (CEO of HCS), we were discussing taxes and the effect of the recent recession on the Romanian economy when he rounded on the power elite, politics, and corruption:

Because of corruption! Let me explain why they don't collect (taxes). There are a lot of people who don't pay taxes. I am not talking about small contributors to the budget, but rather big companies run by people who have strong contacts and relationships with politicians, at very high levels. So they are protected and encouraged to avoid taxes on one hand. On the other hand politicians have unconstrained access to the public funds. Public money is not spent wisely, and there is no reporting system. Politicians don't care; they often don't present reports; and the reports that are done are not very transparent. The biggest part of government contracts are given to people they protect. So it is corruption. On the other hand it is about promoting non-specialists. People who have nothing to do with a certain domain, in a very high government position. Starting with ministries, chief of departments . . . the kinds of people appointed in strategic positions, but who have nothing to do with that particular domain, and who were appointed for political reasons. So lack of competence, and, of course, bad management, leading to losses, and inefficiency; things like this contribute to the situation.

[5.7.5] Group/personal charisma

Who is the charismatic hero – who has received 'God's favor' at HCS? Is it G2 with his physical fitness, military bearing, short-cut hair, angular face, and tieless collar? Or is it D3 who is not so fit, a bit rumpled, and round-faced? Or perhaps it is M1 who is well coiffed, favors long skirts, and always seems to have a celebratory cake in hand and a smile on her face? Or, from another perspective, is it G2 who congenially took charge of our interview and used disciplined hand gestures for a touch of authority? Or is it D3 whose sharp, penetrating intellect is edged with a half-smile and whose buoyant laugh can be heard above all the others in the lunch room? Or, again, is it M1, whose warm persona is not so much maternal as nurturing? Each of these individuals has a certain presence and authority, and they may all have received God's favor, but none of them could match the heroic charisma of Sir Winston Churchill, General George Patton, President John Kennedy, or Lawrence of Arabia. My point is that 'charisma' is a perception and that perception is context dependent and powered by relationships. I would suggest that D3 has 'charisma' in that she has a certain charm that inspires commitment, but she would not stand out in a crowd as a charismatic hero; she lacks that tinge of narcissism and a certain temporal transience that characterizes our exemplary heroes. But she is emblematic of palliative care – the person whom everyone would like to be. D3 can be viewed in the same light as Dame Cicely Saunders – a certain confidence and warm promise of burning embers. Moreover, she brokers multiple links or relations in the power structure without dominating it. M1 (public

relations) touched upon this perception of charisma in our discussion of manpower development:

Definitely, another D3 would be the best; she is both competent on the clinical side – I don't think any other person working in palliative care would be able to compete with her at the patient's bedside – but also she has the vision on where the system has to go.

R1, website designer and publicist, puts it more plainly:

"You can't work in the Hospice without interacting with D3."

In my own experience, she has no pretentious airs when she enters a room (for example, into the administrative office at the Study Center or into the Pediatric Inpatient Unit), but she commands everyone's attention.

[5.8] By way of summary

By way of summary, the success of HCS/PPC is exceptional in many respects and is associated with a unique paradigm of pediatric palliative care which affirms life, is driven by compassion for unwanted children, and projects enduring humanity, power mindedness, solidarity, and fiscal responsibility.

While Brasov PPC's success may be largely contextual and moment-dependent, I discuss in the next chapter its significance in two important respects: 1) a model of PPC that may have broad application and 2) an explanatory theory of success in the context of power equity.

Chapter 6. DISCUSSION

In this chapter of the thesis, I restate the research question and then briefly review the study's theoretical foundation, methods, and methodological problems. The five major findings are summarized: unique paradigm of care, non-dying image, compassion, solidarity, and equitable balance of power. The unique paradigm of care is contextualized into Bhaskar's 'actual' domain of transcendental reality – what the children and families actually experience – and the specific characteristics that make their care unique are highlighted. The other four major findings are contextualized into Bhaskar's 'real' domain – the social structures, relations, and causal mechanisms underlying the success. From this complex multi-leveled reality, a model or standard of pediatric palliative care (home model) and a causal theory of success (power equity theory) emerge. The home model of pediatric palliative care (PPC) is an adaptation of medical home model proposed by the American Academy of Pediatrics. The power equity theory is measured against Foucault's theory of how established power and authority have been successfully challenged and will provide further insight to the applicability of Brasov's success across different communities.

Suggestions for educators are also folded into this discussion. Finally, recommendations for future research are made.

[6.1] The research question

What factors enable the success of PPC in Brasov, Romania? This research question was designed to explore the social structures and causal mechanisms underlying the

success of Brasov PPC. The question embraces three corollary questions: 1) what works in Brasov; 2) why does it work; and 3) will it work elsewhere? The answer to the first question is found in the first of the five study findings – the unique paradigm of PPC in Brasov. The second question – why it works – is addressed by an explanatory model of PPC which integrates the other four findings: a non-dying image, compassion, solidarity, and an equitable balance of power. The third corollary question – will it work elsewhere – is addressed in the discussion of the power equity theory.

[6.2] Theoretical foundation, methods, and methodological problems

This work takes its disciplinary origin from the most human and intimate aspects of medicine and finds a resonant voice in the postmodern tradition of qualitative research. I have replaced the strict objectivity and purposive simplicity of 'modernistic' positivism with a multiply constructed and transitional world where meaning replaces knowledge as the end game for research. I have no pretensions of abstract theory or universality. I can only 'know' what is within the narrow scope of my experience. Objectivity is replaced by reflexive subjectivity and transparency. I have exposed my biases, prejudices, and experiences to justify and make transparent my interpretations. Appeals for validity and reliability of the findings are answered with transparency. The three-layered ontology of transcendental realism (Bhaskar, 2009) (Miles & Huberman, 1994) provides a useful framework to contextualize the findings in this discussion. I use the methodological process of triangulation to look at the question from multiple perspectives and gain as full and complete a picture as possible (Fielding & Fielding, 1986, p. 28) (Ritchie, 2003, p. 44). The principal sources of data were interviews of

administrators, physicians, nurses, support staff, and families as well as ethnographic observations made in the inpatient unit and the day care center, during home visits, and 'on the road'. After gaining research ethical approval from Lancaster University (see **Appendix A. Ethics application**), I interviewed 40 individuals (see **Appendix E. Interview list**). Five home visits were made; five days were spent observing in the inpatient unit; and three days were spent with the children in the Children's Day Care Center. An amendment to the ethics application was approved to include the interviews from the exploratory trip in 2009 (see **Appendix A1. Application to amend research ethics approval**). The interviews were semi-structured and followed an iterative tradition of inquiry (Grbich, 2007, p. 20). For ethnographic observations, I was granted 'fly on the wall' status from the children and their families as I was largely ignored or politely tolerated.

It is worth iterating that the factors enabling the success of pediatric palliative care in Brasov, Romania, come from data which were collected from interviews and ethnographic field notes recorded in Romania during 2009, 2010, and 2011. The data was enriched by my immersion in Romania as a Fulbright Scholar for eight months and by my professional lifetime of caring for children with life-threatening or life-limiting conditions – first as a pediatric neurosurgeon and then as a palliative care physician. This measure of reflexivity did not exempt me from researcher naivety and inexperience, the vagaries of translation and transcription services, the selectivity and exclusivity of language, and difficulty with communication and access.

[6.3] Summary of findings

What enables the success of PPC in Brasov is a unique paradigm of PPC, silhouetted against a backdrop of living rather than dying, inspired by compassion for abandoned and unwanted children, driven by an organizational structure of solidarity, and secured by an equitable balance of power.

First of all, PPC in Brasov is unique in that home care, inpatient care, and day care are located in and coordinated from a single building located in the heart of Brasov. The central location facilitates wheelchair field trips for the day-care children in the city and is symbolic of the essential value of palliative care services to the community. The unique practice of routine admission provides the families and children respite, as well as regular symptom reevaluation and tune-up. These routine admissions to the inpatient unit at Brasov PPC are provided 24 hours per day, five days per week; children do not come to Brasov PPC in need of acute or terminal 24/7 care. 'Weekends off' provide respite for the PPC staff.

The second factor is a public image of living positively that promotes philanthropic giving "just for the good of it". There is no tacit allusion to terminal or end-of-life care in this non-dying image.

The third factor is the golden thread. Compassion, especially for unwanted and abandoned children, is a deeply embedded social phenomenon that provides inspiration to caregivers at every level of the organization and across organizations.

The fourth deep-rooted social force which contributes to the success of PPC is solidarity – the sense that we are all in this together, doing something meaningful. Caring for these children is worthwhile, and caring for their families is more central than treating their diseases.

Finally, the aforementioned factors are underpinned by an equitable balance of power which has been created by knowledge, expertise, moral persuasion, group dynamics, charisma . . . and a balanced budget.

[6.4] Findings in context

Contextualizing the findings in the three-layered ontology of transcendental realism (Bhaskar, 2009) (Miles & Huberman, 1994) helps make them more credible and lays the foundation for their application in other contexts and for an explanatory theory of success ([**3.3.2] Ontology: realism**). Bhaskar distinguishes three domains of reality: the empirical (experience and impression), the actual (actual events and states of affairs, in addition to the empirical) and the real (structures, powers, mechanisms, in addition to actual events and experiences) (Lawson, 1997, p. 21). The empirical layer of what appears to be success is the 'cover page' formulated by Clark and Wright (2003). The 'actual' layer of the success is not meant to contest the empirical success but rather to complement it with how children and their families actually experience PPC – the hands-on paradigm of care in which the findings of this study are embedded. The 'real' domain of reality includes the empirical (how it appears to be), the actual (what is), and the underlying explanatory social structures and generative mechanisms (why it is). It is in this third domain of the real that "the generative mechanisms of nature exist as the

causal powers of things” (Bhaskar, 1978, p. 50), (Lawson, 1997, p. 21), (Elder-Vass, 2007, p. 7). This is a transcendental argument: there must be something that makes the world the way it is.⁶⁹ Elder-Vass adds some clarity:

Causal laws are generalizations over many cases as well as an abstraction from multiple levels. The whole logic of scientific experiment depends on the generalizability of causes – if experimentation identifies causal mechanisms, it is the belief in their ‘enduring’ quality that renders them real rather than actual . . . as ways of acting of whole classes of things (Elder-Vass, 2007, p. 7).

[6.4.1] Empirical success claimed by Clark and Wright

A previous study, which looked at palliative care services in the 15 countries of Central and Eastern Europe, declared that Brasov palliative care was a ‘success’ – a ‘beacon’ of palliative care. Their claim was based on four streams of evidence: 1) hospice and palliative care in Romania was first developed in Brasov, 2) the founders had developed a national/international reputation, 3) a center for education and training had been created, and 4) Brasov was responsible for the incorporation of palliative care into national health policy. The discussion that follows will show that the claim represents only a glimpse of the reality that is underpinned by the findings of this study.

⁶⁹ Another example of a transcendental argument is Strawson’s ‘objectivity argument’. (Rorty, 1970, p. 207). For an experience to provide room for thinking of that experience itself, it must provide room for a distinction between ‘This is how things are’ and ‘This is how things are experienced as being’. Subject-independent objects exist because they provide room for such a distinction.

[6.4.2] Actual success: unique paradigm of care

The actual success of Brasov PPC is a product of human events and experiences from which a distinctive paradigm of care emerged. Several factors contribute to its uniqueness: the program is all under one roof; the children feel at home; regular admissions are scheduled to fine-tune symptom management and for routine respite; and inpatient and daycare are provided only 24/5.

[6.4.2] Actual success: unique paradigm of care – under one roof

Brasov PPC is laid out under one roof (day care, inpatient maintenance care, and home care). The home office of homecare, day care, the inpatient rooms, nurses' station, and the doctor's office are all located in the same building which is illuminated by a central two-story sky light. This structural arrangement enhances communication and encourages connectedness amongst the staff, the children, and their families. The uniqueness of this arrangement is sharpened by comparison with other countries that have similar resources. South Africa is one of four innovative international programs featured in the review of Knapp et al. (Knapp, et al., 2009) (see **[2.5.2]. South Africa**). In South Africa, day care is outsourced, and homecare is administered from a separate location. South Africa's St. Nicholas Children's Hospice has Sunflower House, which is an inpatient unit, and a detached home care program; three outlying community day-care centers were developed in settlement areas for the poor (Marston, et al., 2012, p. 30). Soweto also has a free-standing inpatient unit, a separate home

care program, and detached day care center in an old school building (Marston, et al., 2012, p. 36). Of the six models of PPC⁷⁰ that have been developed in South Africa, none provide comprehensive services under one roof.

[6.4.2] Actual success: unique paradigm of care – just like home

PPC Brasov is a place where children, families, and staff feel comfortable, where they can feel they belong, where they are fully understood and appreciated, where they know their caregivers and are known by them, where everyone is on the same side, and where every day is a new day – just like at home. For comparison, Poland (see **[2.5.5] Poland**) was also given ‘beacon’ status. Poland has undergone similar political changes and faces comparable resource limitations. But in Poland, there is no PPC ‘place’ to be called ‘home’; inpatient units are the exception. Services are limited to the last 3 months of life – as defined by government reimbursement; parents must ‘sign over’ their children – forego active treatment – to receive PPC (Karwacki, 2012, p. 263). Not everyone is on the same side.

[6.4.2] Actual success: unique paradigm of care – regularly-scheduled, routine hospicization 24/5

Every child is routinely hospitalized or ‘hospicized’⁷¹ during the year for re-evaluation, to fine-tune symptom management, and to provide respite for both the child and family.

The child is admitted on Monday and discharged on Friday. This arrangement gives

⁷⁰ The models include single service (homecare, day care, or inpatient care), ‘comprehensive’ children’s hospice (home care, day care, and inpatient care), hospital-based services, hospital-partnered services, integrated care, and network models (Marston, et al., 2012, p. 36).

⁷¹ I have introduced the term ‘hospicize’ to further differentiate acute hospitalization to resolve a medical crisis from a prescribed stay in the hospice residence for respite, surveillance, and reevaluation.

weekend respite for the staff and reinforces the concept that children do not come to the hospice to die.

In countries that have been praised for their innovation – Australia, South Africa, Florida, the UK, and Poland – CHILLD and CHILTD are only admitted for impending death, acute respite, or acute symptom management (Knapp, et al., 2009) (Clark & Wright, 2003). Routine surveillance and maintenance is limited to cursory homecare visits. Admission to the hospice is haunted by the specter of death. Hospicization in Brasov is a predictable, scheduled benefit of PPC, and death is not present.

[6.4.3] Real success

The deepest layer of reality is found in pre-existing, deep-rooted strata of social structures, social relations, and causal mechanisms. In the recesses of this layer are embedded the four other findings of the study: non-dying image, compassion, solidarity, and an equitable balance of power. Since these social structures and causal mechanisms define Brasov PPC's most enduring characteristics, each will be considered separately in turn.

[6.4.3] Real success: Non-dying image

Fear of death has an indubitable influence on social behavior (Jong, 2012) (Bourke, 2005, pp. 25-50). A non-dying image serves to lessen this fear. In Brasov no one comes to the inpatient unit to die. Children come to routinely update, maintain, and get the most out of their lives⁷². Routine reevaluation and check-up 24/5 instead of a 24/7

⁷² Slow deterioration is expected.

contributes to the non-dying image and provides respite for the staff. No “transition of care”⁷³ decisions need to be made; there is no point of abandonment, separation, or hopelessness. In contrast, a transition of care from ‘active’ treatment to palliative care or from pediatric facility to an adult unit is seen in all the countries named in my review of the literature (see **[2.5.] CHILLD Care in Different Parts of the World**).

[6.4.3] Real success: Compassion

Compassion emerges as a key finding. A strong element of agency or action differentiates compassion from other human ‘feelings’ such as empathy and sympathy. That is to say, compassion is more significant than just a ‘caring feeling’ that contributes to the success of Brasov PPC. Compassion is a fundamental, pre-existing causal mechanism underlying their success. There is also compelling pre-historic anthropological evidence that compassionate caring for one another is the primary social interaction that makes us human (Spikins, et al., 2010, p. 11). The evolutionary anthropologist Hublin (2009) has even suggested that compassion is fundamental to our success as a species.

Rather than considering ancient human altruism as proof of the moral values of our predecessors, one should instead see it as merely part of the spectrum of adaptations that have made humans such a prolific and successful species.
(Hublin, 2009, p. 6430)

⁷³ Brasov has no age limit for CHILLD; transition from a pediatric facility to an adult facility is not necessary.

If this anthropological position is to be believed, then caring for one another and especially for those who cannot care for themselves ought to be as basic to human kind as the air around us and the breath within us. However, the history of conquest, colonization, and enslavement of non-Europeans in the name of civilization strongly suggests that this viewpoint is naïve. The Indian caste system, ethnic cleansing in the Balkans, the holocaust in Germany, segregation in the US, and apartheid in South Africa highlight the dominant role that social exclusion plays in society (Volf, 1996, p. 60). Nonetheless, the success of PPC in Brasov is steeped in compassion for all children with life-limiting illnesses, especially those who are unwanted or have been abandoned – a viewpoint of social inclusion and acceptance. Their compassion is bound to the belief that these children have value and worth, is galvanized by an aptitude for working with incurably-ill children, and is as basic to them as the air around them and the breath within them. Indeed, compassionate caring is the working or organizational basis of their culture.

This compassion goes beyond the 9-to-5 hour work day and is more than a goodwill, after-hour gesture that is seen in the UK (Craft & Killen, 2007, pp. 26-27) (Davies, 2010, p. 6)⁷⁴. This compassion values and embraces all CHILLD and CHILTD – not just the poster children who can walk and talk. This is not to say that 'other' PPC programs lack compassion and an aptitude for caring, but compassion and an aptitude for caring for CHILLD and CHILTD have not been acknowledged in the literature as primary motivating factors for PPC.

⁷⁴ See **[2.5.3] United Kingdom**

[6.4.3] Real success: Solidarity

Solidarity was the name of an anti-communist trade union and social movement in the shipyards of Gdansk, Poland, which was emblematic of the anti-communist revolutions of 1989 in Romania, East Germany, Czechoslovakia, and Poland (Stokes, 1993, p. 12). In the ethos of the Independent Self-Governing Trade Union "Solidarity", the hospice movement was a symbol of humanity (Clark & Wright, 2003, p. 86). The trade union was responsible for making a provision for palliative care in the National Health Service of Poland (Clark & Wright, 2003, pp. 86-87). For PPC in Brasov, solidarity is a primary social mechanism underpinning its success.

I have defined 'solidarity' as the interaction of like-minded people engaged in meaningful activity, sharing common assumptions or beliefs, and abiding by the same principles (see **[2.8.3] An unsteady balance** and **[2.8.4.] Solidarity: a moral compass for power**). The first basic shared assumption is the same belief that binds compassion: these children have value and worth. The simple elegance of D2 (Head Pediatrician) statement is to the point ". . . everyone counts; everyone is a special being and is as valuable as I am". The second assumption that follows from the first is having an aptitude for working with incurably ill children. The third basic assumption is that serving the family and child supersedes treating the disease. Their model of care is underpinned by the notion that the child and family – "the human family" – are being served, rather than just the disease, and is powered by the solidarity of caregivers and family.

[6.4.3] Real success: Equitable balance of power

The elements of power that PPC has posited in equitable balance are knowledge, expertise, moral persuasion, group dynamics, and charisma. Knowledge is power and has influence. The Palliative Care Study Center is emblematic of the role that knowledge through education plays in Brasov. The Study Center was constructed before the Hospice Casa Sperantei inpatient unit and since 1997 has educated over 10,000 Romanians and more than 300 professionals from other countries in Eastern Europe and Central Asia (ACSC Coordinator, 2011). Education in Romania has traditionally emphasized theory and minimized practical application, but in Brasov the discursive power of the case study format is used to convey expertise as well as knowledge to the participants. Certifying exams are also case-based. The knowledge and expertise which have been forged at the Study Center have been shaped into standards of palliative care which were instrumental in having palliative medicine recognized as an official medical specialty. The power of moral persuasion was seen in the 2009 Bucharest Marathon fund raiser ("Come run for us . . . just for the good of it") and measured by the dramatic increase in website 'hits' and financial contributions. The cohesive energy in the group dynamic of the HCS staff that I encountered as I negotiated my research methods was tenacious and purposive. Finally, political corruption is widespread and weighs heavy on the social playing field (Siani-Davies, 2005, p. 21) (Global Integrity, 2010) (European Commission, 2011). HCS levels the playing field by both refusing and not proffering bribes. The success of Brasov PPC in the face such widespread and pervasive corruption is truly remarkable.

A certain power-full charisma⁷⁵ enlightens HCS. Their charismatic heroes require no adulation or parades but they are charming, inspire confidence, and seem to have gained "God's favor". D3 can be viewed in the same charismatic light as Dame Cicely Saunders⁷⁶, who also very persuasively brokered many powerful links and social relations in raising the awareness, knowledge, expertise of palliative medicine.

The combined empirical, actual, and real successes of Brasov PPC are all incorporated into an exceptional model of PPC: Brasov PPC provides a 'real' medical home for CHILLD and CHILTD.

[6.5] The medical home model: a standard for PPC success

In Chapter 2 (**[2.3.] The Medical Home**), I introduced the concept of a medical home and interpreted the formulation of the model as a response to the dehumanizing effect of medical specialization. However, the 'talk' (mandates and objectives set forth by the American Academy of Pediatrics [AAP]) is not well matched with the 'walk' (implementation and outcome in primary pediatric practice) of the model, especially the "inconsistent definitions and extent of medical home attributes" cited by the extensive review of the medical home model by Homer et al. (2008). The medical home model of PPC which emerges from this study applies the concept as proposed by the AAP and gives evidence of its successful implementation.

PPC in Brasov provides a medical home for children with life-limiting and life-threatening diseases. The types of interventions and supports are based on the real

⁷⁵ The Encarta dictionary defines 'charisma' as "a divine gift, a gift or power believed to be divinely bestowed".

⁷⁶ The inspirational founder of modern palliative medicine

needs of CHILLD and their families: symptom management, child respite (day care), caregiver respite (day care and inpatient care), and measures to combat the family's sense of powerlessness or "helplessness" (Dangel, et al., 2006, p. 101). The sense of helplessness is overcome by the familiarity and connectedness of a medical family. However, familiarity and connectedness are not the sole province of the physician as claimed by the AAP (American Academy of Pediatrics, 1992, p. 774). The medical family includes nurses, social workers, aides, day care supervisors, psychologists, and physical therapists.

In effect, Brasov PPC provides primary care to a very vulnerable and problematic subset of children. The PPC model manages the co-morbidities of life-limiting illnesses (for examples, malnutrition, skin breakdown, bed sores and skin maceration, poor hygiene, and immobility) because both the children and their illnesses are familiar to them. PPC emphasizes continuity of care and embraces all comers regardless of social and/or economic circumstances.

The supports that are needed to implement and sustain this model over time are the deeply rooted social mechanisms that underpin the medical home model of Brasov PPC: a non-dying mindset, compassion, solidarity, and an equitable balance of power. An explanatory theory of their success can also be found in these deeply rooted social mechanisms: power equity, *ex aequo et bono*.

[6.6] Power equity, *ex aequo et bono*: an explanatory theory of success

Ex aequo et bono is a Latin term often used in international law when a dispute is to be decided according to principles of equity rather than by points of law. (Anon., 2013).

When resolution of a dispute has no precedence, courts countenance equity and consider solely *what is fair and equitable . . . right and good . . . in the case at hand*.

According to Foucault (Foucault, 1994, p. 329), the fabric of society is rent with power imbalances. He uses the examples of the power of men over women, parents over children, the psychiatric profession over the mentally ill, the medical profession over the public, and administration or government over the way people live. As I pointed out in

[2.8.4] Power, Brasov PPC has faced power imbalances created by the medical profession, the government bureaucracy, and the omnipotence of the Communist power elite (Siani-Davies, 2005, p. 33) (Gallagher, 2005, p. 313). Brasov PPC has successfully redressed these power imbalances *ex aequo et bono* –according to what is fair and equitable . . . right and good . . . in the case at hand.

That Brasov's success can at least in part be attributed to garnering power equity. This explanation is consistent with Foucault's theory (Foucault, 1994, pp. 329-331) of why challenges to established power or authority have historically been successful. Foucault posited 6 commonalities of successful challenges (see **[2.8.5] International**

citizenship): 1) avow 'transversality' or transnational citizenship; 2) target the effects of power rather than confront the sources of power and authority; 3) contest the privileges of knowledge (and contest what is privileged knowledge); 4) engage the immediate problem rather than the "chief enemy"; 5) oppose efforts to separate

individuals from the society that nurtures them; and 6) preserve the right of self-determination and resist efforts to control “who we are” (Foucault, 1994, p. 328). I will explore the concordance of Brasov’s success with Foucault’s theory by considering each of these commonalities in turn.

[6.6.1] Transversality

“Transversality” is Foucault’s neologism which supplants ‘universality’ in his vocabulary. Instead of broadly referring to ‘all countries’ or ‘the whole world’ he settles for a less grand “more than one country” (Foucault, 1994, p. 329). Challenges to authority are successful when they are shared by “more than one country” in the form of transnational citizenship. Romania met annually with other countries in Eastern and Central Europe to learn from one another and to advance palliative care. As detailed in the review of literature (**[2.5.5] Poland**), the Poznan Declaration and the Eastern and Central Europe Palliative Care Task Force (ECEPT) were byproducts of these meetings (Knapp, et al., 2012, p. 256). The signatories of the Poznan Declaration became transnational citizens and raised the level of their social responsibility and authority beyond that of their individual countries. The standards of care developed by ECEPT also were a product of their shared knowledge and enhanced by the authority of transnational citizenship.

Palliative care was part of the anti-communist social, economic and political movement which swept through Eastern and Central Europe towards the end of the 20th century (see also **[6.4.3.3] Solidarity**). In Poland, for example, physician advocates of palliative care were also politically active in the trade union movement Solidarity and

helped enact a provision for palliative care in the post-Communist National Health Service of Poland. Hospice/palliative care was a symbol of renewed humanity for Solidarity (Luczak, 1993, p. 67) – a call to be more human. Not surprisingly, “to be more human” was also the clarion call for palliative care in Western Europe and North America in response to unnecessary suffering at the end of life (Kuebler-Ross, 1969, p. 23). A similar appeal was sounded by an anonymous Romanian pediatrician at the end of the Romanian Revolution of 1989 and in the aftermath of the AIDS epidemic: “We must relearn to be human!” (Hunt, 1990, p. 28) (see **[5.5.2] Abandoned and unwanted: ‘irrecoverables’, Roma, CHILLD**).

To capitalize on the importance of knowledge (see also **[6.6.5] Contesting the privileges of knowledge**), HCS choose education as its cornerstone. The Palliative Care Study Center was built before (1997) the HCS inpatient unit (2002), and a grant from the European Union helped establish a palliative care curriculum. By being a signatory of the Poznan Declaration, a member of ECEPT (Vice President of Education), and the recipient of a grant from the European Union, Daniela had become a transnational citizen promoting *what is fair and equitable . . . right and good . . . in the case at hand*.

She used her transnational fund of knowledge and citizenship to broker power equity at home with the Ministry of Health, the National College of Doctors, and the House of Health Insurance (see also **[5.8.2] Expertise**).

[6.6.2] Avoid direct confrontation with the power elite: target the effects of their power instead

In the context of this study, the development of palliative care in Central and Eastern Europe was impeded by lack of resources, restricted opioid availability, absence of government recognition and reimbursement, and a need for public and professional education (Lynch, 2009, p. 305), which are all heavily controlled by established power and authority in the region. HCS chose not to confront the power elite directly but rather to engage the effects of their power by lobbying for government resources, fundraising within their community, competing for a share of the State-mandated philanthropic donations (2% of employees' salary), seeking grants, focusing on education of the public and other professionals, creating standards of care as a basis for reimbursement, and by aspiring to "*what is fair and equitable . . . the right and good*" for more than just Romania – another reflection of their transnational citizenship.

[6.6.3] Treat the immediate problem

The medical home model is not an acute model of care; it is designed to avert the crises of illness by preventative maintenance and periodic surveillance. Nonetheless, social and logistical crises are inevitable for families that have sick children. PPC/HCS attends to the pressing social issues that the children and families face by solving the immediate problem without aspiring to replace the torn social fabric (inadequate care of orphans, prejudice against the Roma, poverty, corruption, et cetera.). For example, the immediate problem for the mother and child in the Roma village (see **[5.3.2.1]**

Homecare) was the threat of homelessness – not the diagnosis of Hodgkin's

lymphoma, not poverty, not her abusive husband, and not the stigma of being Roma. An application for social or low-income housing was doable and addressed the immediate problem. PPC found an equitable remedy for a number of intransigent injustices. Equity is discretionary and provides for the individual person *what is fair and equitable . . . right and good . . . in the case at hand*.

[6.6.4] Oppose efforts to separate the individual from traditional social milieu

Ceaușescu's Communist Romania attempted to replace the family, the social milieu that nurtures the individual, with the State (or in Foucault's words "government of individualization") (see **[2.7.] The orphan problem**). By bringing workers to industrial hubs in large cities, the State unlinked individuals from their community connections and made them more dependent on and more controlled by the State. Hospitalization, which is fundamental to the acute model of care⁷⁷, also disconnects the child from the family. Brasov's hospicization⁷⁸, on the other hand, reinforces the family unit by providing respite for the parents and child and by focusing on the child's quality of life. The PPC medical home model keeps the family together, facilitates connections in the community, and reflects *what is fair and equitable . . . right and good . . . in the case at hand*.

⁷⁷ The acute model of care responds to medical crises by hospitalization; the patient is discharged when the crisis is resolved. In contrast the medical home model avoids crises by preventive maintenance and health awareness, and by anticipating the natural history of the disease or condition.

⁷⁸ As a reminder, hospicization is the term coined for routine, non-acute inpatient holidays for respite and health care maintenance.

[6.6.5] Contesting the privileges of knowledge

Knowledge reflected by qualifications and certification may impart privileges and entitlements that are unwarranted. A non-clinical professor's knowledge of medical science does not necessarily entitle him/her to teach medicine to medical students if it is not accompanied by a practical knowledge of medicine. On the other hand, the clinician-teacher who pontificates "in my experience" should more humbly and more appropriately say instead, "in my very limited experience". Brasov PPC contested the privileges of existing knowledge in Romania with knowledge gained through transnational citizenship and by creating its own body of knowledge at the Study Center. The case study format brings the student to apply their knowledge to real cases presented by the instructor. Knowledge is applied to solving the case at hand rather than meted out in absolute doses, diagrams, tables, and equations in Power Chart. Staid, 'privileged' knowledge is replaced by new, more authoritative knowledge, and the students learn *what is fair and equitable . . . right and good . . . in the case at hand*.

D3's appointment as Chair of the Palliative Care Sub-Commission in the Ministry of Health was a pivotal step in garnering success for HCS/PPC. She presented a balanced portfolio of knowledge, expertise, moral persuasiveness, and charisma, but her critics claimed that she lacked qualifications: only a person with the privileges of knowledge accorded by a PhD could chair a sub-commission in the Ministry of Health! D3 went on to earn her own PhD to upend this traditional privilege of knowledge. Not only did she upstage her critics but also righted a power imbalance within the medical profession by creating special qualifications and certification in palliative care – a complementary

regime of knowledge compiled and endorsed by other transnational citizens. She garnered power equity and cleared the way for success by doing *what is fair and equitable . . . right and good . . . in the case at hand*.

The bounds within which power is possible (regime of knowledge) is to some extent determined by the power elite. The scope of power is exemplified in the 1980's word play on the initials of the Romanian Communist Party (**P**artidul **C**omunist **R**oman) **PCR** was transmuted to connections, acquaintances and relations (**p**ile, **c**unostinte si **r**elatii) (Siani-Davies, 2005, p. 33). Powerful local politicians known as "little barons" utterly ruled some areas by controlling the courts, the police, and the economy (Gallagher, 2005, p. 313). G2 (hospice CEO) also gave an account (see **[5.8.4]**) of the corrupt regime of knowledge created by the Romania power elite which begets privilege and entitlement but is shrouded in secrecy and mystery. His accusation of corruption has been substantiated by Global Integrity whose mission is to promote international accountability and transparency (Global Integrity, 2011)⁷⁹. Comparable findings were submitted by the European Commission⁸⁰ to the European Parliament⁸¹ and European Council⁸². (European Commission Report, 2011) Furthermore, G2's assessment of corruption in the Romanian health care system is iterated by Lewis (Lewis, 2006, p. 14). To garner power equity – *what is fair and equitable . . . right and good* – HCS/PPC did

⁷⁹ Global Integrity is funded in part by NATO, the United States Department of State, the World Bank, the Australian and Canadian International Development Agencies, the Open Society Institute, and the National Endowment for Democracy.

⁸⁰ The European Commission drafts proposals for new European laws and manages the day-to-day business of implementing European Union (EU) policies and spending EU funds.

⁸¹ European Parliament is made up of elected representatives from the member-states of the EU.

⁸² European Council consists of leaders of the member-states of the EU.

not buy into the corrupted regime of knowledge. Brasov PPC refuses to accept or proffer bribes.

[6.6.6] Right of self-determination

For Foucault's final common theme of successful challenges to power imbalances – upholding the right of self-determination as opposed to 'other'-determination – Brasov PPC is on target. The organizing premise of HCS/PPC was to provide what CHILLD, CHILTD, and their families needed – based on an extended assessment in the field (1996-2002). The 'package' included symptom management at home, periodic re-evaluation and maintenance checks (inpatient care), continuity of care (homecare, inpatient care, day care, and aftercare⁸³), respite (inpatient and day care), and a sense of familiarity, belonging, and solidarity. By providing reimbursement for only certain services, the 'other' House of Health Insurance could have determined the character of PPC. For example, the government decided that only the inpatient service would be reimbursed. If HCS had accepted government reimbursement as their only source of revenue, the character of the service might have changed from hospicization for respite and routine maintenance to hospitalization for acute symptom management. Acute symptom management includes actively dying children. Home care would fall by the way, and the medical home model would be abandoned. As another example, the Ministry of Health in Poland developed stringent criteria for PPC providers to be reimbursed which in effect limited the number of eligible providers. Furthermore, those services would only be reimbursed for certain diagnoses and only in the last three

⁸³ Aftercare refers to care rendered after the death of the child

months of life (Karwacki, 2012, p. 264). Providing reimbursement only for actively dying children requires impossibly strict criteria (as has happened in Warsaw) and defeats the purpose of providing the best quality of life for children with life-threatening and life-limiting illnesses. Such a reimbursement model might be appropriate for adult cancer patients but not for CHILLD and CHILTD. 'Others' (for examples, hospital administrators and health policy makers) might choose to determine the character of PPC by limiting reimbursement to a consult service; consult services have no direct patient responsibility or patient/professional bond and provide no continuity of care. Another 'other' policy might reimburse only homecare to keep non-paying patients out of the hospital. In my experience, forcing patients with a poor outcome (or income) out of the hospital and reimbursing palliative care only in the form discharge coordination is another ploy. These 'other' choices are *not fair or equitable and not right or good for the child and family*.

This theory of power equity is not simply a moral imperative or based on a moral authority; it shares the agency of other successful challenges of power and authority. It is contentious and demanding (contests the privileges of knowledge, oppose efforts to separate the individual from traditional social milieu, demands the right of self-determination), but at the same time is quietly assertive in doing something about the immediate problems at hand, in targeting the effects of power instead of the source, and in developing transnational authority which transcends the local or national exercise of power.

[6.7] Implications for practice

PPC *ex aequo et bono* is in good agreement Foucault's theory of why challenges to established power or authority have historically been successful. Perhaps this study will serve as a primer for PPC programs just getting started and a reference work for reinvigorating established programs. Brasov PPC does provide a template but not the only template for success; moreover, implementing the Brasov PPC medical home model will not assure success. However, in theory, if prevailing power imbalances are recognized and reconciled, success follows *ex aequo et bono* – what is fair and equitable . . . right and good . . . in the case at hand. Although this study is not meant to provide a recipe for PPC success in other countries or in other contexts within Romania, five features of Brasov PPC have particular implications for practice: 1) children with life-limiting vs. life-threatening illnesses, 2) care under one roof, 3) a safe haven, 4) routine in-patient admission (hospicization) to assure the best quality of life, and 5) 24/5 instead of 24/7 hospicization.

These implications are spelled out in turn below and then linked with the present-day challenges to PPC cited by Liben et al. (Liben, et al., 2008) in Chapter 2 (see **[2.6] 21st Century Challenges for PPC**).

[6.7.1] Children with life-limiting and life-threatening illnesses

A notable feature of Brasov PPC is that the majority of its children have life-limiting diseases instead of life-threatening illnesses. As I explained in my review of the literature (see **[2.1] Pediatric palliative care defined**), life-threatening illnesses are differentiated from life-limiting illnesses in that the 'threat' of life-threatening illnesses may not be constant or may even disappear. For example, HIV/AIDS and leukemia may

be held in remission and not need PPC for extended periods. Leukemia may even be cured. On the other hand, muscular dystrophy and severe cerebral palsy are examples of life-limiting conditions that progress unerringly to death during childhood or early adulthood.

[6.7.1] PPC for children with life-*limiting* illness (CHILLD)

Life-limiting illnesses are not only slowly progressive but care is also complicated: symptoms arrive from multiple organ systems and are often insidious; many of these children are bedbound, are unable to feed themselves, and cannot talk. The neurologist may have a passing interest in muscular dystrophy, cerebral palsy, lipid storage diseases, and glioblastoma, and the oncologist may be consulted in the course of a glioblastoma. But the chronicity, complexity, and incurability of life-limiting illnesses weigh heavily against the continued participation of the individual consultant in the care of the child.

Similarly, these children are not amenable to a pediatrician's medical home panel (see Review of the Literature **[2.3.] The Medical Home**). Navigating the maze of chronic multi-system diseases requires too much time and attention from a busy community pediatrician. A single CHILLD "stretches the limits of the primary care office practice" (Tripathi, et al., 2012, p. 112). Moreover, transporting a spastic, moaning or epileptic child with severe cerebral palsy to the pediatrician's office is no easy task, just as removing the child's clothes for a routine physical examination, drawing blood, or taking x-rays only increasing parental anxiety and the sense of powerlessness (Grinyer, et al., 2010, p. 508). This point is best made by one the participants in their study:

It would have been great if they could have offered a transport service to and from, that would make life easier . . . On your own with him in the care . . . if he was having a fit in the car and needing oxygen, I would be driving and I would have to pull over (Grinyer, et al., 2010, p. 508).

Such a CHILLD can be an unsettling spectacle in the waiting room and may even be repugnant to some wellness-oriented, storybook pediatricians. In summary, their care is beyond the scope of general pediatricians. In this scenario, the generalist becomes an inexperienced gatekeeper for specialists. However, as I mentioned earlier in the review of the literature (**[2.4] PPC and the Medical Home**), Tripathi et al. (2012) naively assert that

. . . with preparation, networking with other providers, and staff education and coaching, primary care providers have the potential to experience the unique and rewarding opportunity that comes with helping to maximize quality-of-life for such patients and their families (Tripathi, et al., 2012, p. 112).

The hard reality of caring for CHILLD is that most primary care providers would not welcome “the unique and rewarding opportunity that comes with helping to maximize quality-of-life for such patients and their families”.

This study suggests that the home model of PPC is particularly well-suited for CHILLD; furthermore, there is some suggestion that CHILTD would best be served by their primary disease specialist who is cross-trained in PPC.

[6.7.1] Disease-specific specialist care for children with life-*threatening* illness (CHILTD)

In contrast to most CHILLD, CHLITD are often mobile, communicative, and can feed and toilet themselves. Their illnesses are characterized by periods of normalcy punctuated by crises requiring acute hospitalization rather than hospicization.

Palliative care skills⁸⁴ are nonetheless necessary in the care of children with life-threatening illnesses such as cancer, kidney failure, heart failure, cystic fibrosis, et cetera and can be learned by their respective disease specialists (for examples, oncology, nephrology, cardiology, and pulmonology). In my experience, many of these specialists are compassionate about their long-term patients; they understand the systemic ramifications of the illness, the need for respite, and the value of routine maintenance to sustain quality of life. With sufficient knowledge about palliative care, these specialists can carry their children for the duration of the disease, even into adulthood, with only the occasional palliative care consultation. For the child and family, there is no perceived point of abandonment, separation, or hopelessness. At the onset of the disease, there is no 'just in case', enigmatic death-and-dying consult with palliative care to intimidate and confuse an already frightened child and family – just to serve the belief that early introduction of palliative care in the time course of the illness is better for the child and family. If and when the child dies, the specialist maintains his commitment and responsibility for the well-being of the child and family. Under this scenario, 'salvage' chemotherapy that has little or no benefit to the child is not an

⁸⁴ Palliative care skills include detailed history-taking, complex symptom management, facilitating difficult decision-making, et cetera.

option. To assuage the suffering (fever, shortness of breath, and pain) associated with life-ending complications of treatment such as disseminated intravascular coagulation and overwhelming sepsis, a cooling fan, anti-pyretic drugs, and analgesics may be more appropriate and humane than end-of-life intubation⁸⁵.

The absorption of the palliative care 'beds' into the pediatric oncology ward at Bethesda Children's Hospital in Budapest, Hungary, may be an exemplary case in point – of specialists providing continuing palliative care for their patients (see [2.6.6]) and not shunning them to separate 'death' beds. Indeed, the loss of palliative care beds or a 'palliative care unit' may not have been a failure for palliative care but rather a success for children with life-threatening diseases because Hungarian pediatric oncology specialists are willing and able to provide palliative care.

That being said, some specialists are locked into a treat-to-cure philosophy and have financial and career-advancing incentives to keep the child alive, regardless of the quality of that life . . . as part of a 'study protocol' or a series of short-term technical successes⁸⁶. Compassion is supplanted by salesmanship disguised as a heroic (or, more likely, narcissistic) drive to keep the patient alive, despite the human and material health care costs.

The implication for the practice of PPC is that there is a place for pediatric palliative care to be administered by disease-specific specialists who have been trained in PPC

⁸⁵ Intubation is the insertion of an endotracheal tube for the purpose of artificial ventilation. The process is traumatic, and the presence of the tube painful and provokes the cough reflex, both of which require sedation and analgesia.

⁸⁶ In the US a surgeon is often judged by the number of cases he has done and statistics such as 30-day mortality rate. In my experience patients have been left in pain and on a ventilator until they have passed the 30th postoperative day before allowing them to die.

and have access to a pediatric home care nursing infrastructure . . . who can clearly articulate the benefits and limitations of treatment to the family and avoid sweeping and narcissistic claims for success in the thin air of hope. The more important and enduring commitment from the specialist is to the child's wellbeing. The success of PPC for children with cancer in Budapest is not shared with those children with life-limiting illnesses. The vast majority of children eligible for palliative care in Hungary have life-limiting illnesses such as muscular dystrophy, severe cerebral palsy, lipid storage diseases, and glioblastoma still have no advocate and no place to call home.

The second implication for practice is to provide a place to call home.

[6.7.2] A place to call home

Grinyer has pointed out that the end experience for the dying child can become a frantic search for appropriate services rather than a seamless transition (Grinyer, 2012, p. 156). Care under one physical roof (see **[6.4.2] Actual success: unique paradigm of care – under one roof** above) streamlines logistics and communication and provides continuity of care; it is also a gathering point for the extended family of professional caregivers. A single building is an appropriate symbol for the PPC home model – a public home. Moreover, a structure made of bricks and mortar appeals to potential donors as a visible symbol of their philanthropy and/or in memory of a loved one. The implication for clinical practice is that the PPC home model provides seamless care throughout the life of the child to the very end, steeped in a culture of compassionate care – the singular pattern of human knowledge, belief, and behavior

which PPC exemplifies. The third implication for practice is to provide a safe haven for the children.

[6.7.3] A safe haven

The hospice or palliative care center needs to be a safe haven and home-like rather a place to die or a forbidding antediluvian 'aerial toll house' where a child's 'sins' are reconciled⁸⁷. The hospice house ought not to be the place to go when it is all said and done . . . when the party is over and the songs and laughter have died . . . where the discarded party hats and whistles are gathered. A safe haven is welcoming and pleasing to the children and their families as well as the philanthropic community. The implication for practice is that a hospice house has many attributes – a philanthropic objective, the center of integrated services for the child and family, and a good, safe place – but these attributes are diminished if the purpose of the house is to provide an option to dying at home. The fourth implication for practice for practice is providing measures to maximize quality of life.

[6.7.4] Routine in-patient admission to maximize quality of life

Routine admission to maximize quality of life for complicated patients permits symptoms to be thoroughly reevaluated and their load on suffering to be reduced. I have already alluded to the difficulty associated with assessing a child during a brief office encounter. During a five-ten-day stay, basic problems with sleeping, eating, and being can be directly witnessed, addressed, and the outcome confirmed. Medical crises are prevented or averted. In-house stays also provide planned respite or care

⁸⁷ See Chapter 5. Findings: **[5.5.2] Standpoint of the professional caregivers.**

'vacations' for families. The implication for clinical practice is that routine hospicization improves the quality of life for both the child and the family. The last implication for practice is providing for the professional caregivers.

[6.7.5] A 24/5 in-house program complemented by 24/7 home care

Although access to care is available 24/7 through the home care service, the hospice house is open 24/5 (24 hours each week day). The implications for clinical practice is that closing the hospice house for the weekends (24/5) removes the illusion of acute, life-saving care, provides respite for the staff, and reduces hospice costs.

[6.8] Suggestions for educators

Compassion is one of the factors that enabled the success of Brasov PPC. A culture of compassionate care has been created in Brasov. To sustain a culture – a pattern of human knowledge, belief, and behavior – depends on having the capacity for learning and transmitting that culture to succeeding generations. Palliative care skills (detailed history-taking, symptom management, facilitating difficult decisions, et cetera) are units of knowledge which can be taught. But can compassion really be taught or is it an intrinsic quality to be nurtured? Thus compassion presents two very problematic issues to educators, especially in light of four-decade history of dehumanization and compartmentalization in medicine (see **[3.1] Disciplinary origin** and **[2.2] Specialization**): 1) whether compassion can be taught, and, more importantly, 2) how compassion fatigue or burnout can be prevented. Each of these issues will now be addressed in turn.

[6.8.1] Teaching compassion

The findings of this study appear to agree with UK Prime Minister David Cameron's emphatic statement, "You can't teach people compassion!" (Borland & Groves, 2012). If compassion cannot be taught, should having this gift be a major prerequisite for admission to medical or nursing school? The answer to this question is beyond the scope of this thesis but deserves further consideration. Indeed, compassion is notoriously difficult to discover and even measure in undergraduates (Pence, 1983, p. 190). And if we are to immerse students who have no such gift in the virtue of compassion, do we risk creating a generation of charlatans or medicine show operators who are able to tweak every fiber of our being for their own benefit and profit? In my experience, learned, rehearsed, imitated, or simulated compassion is off-putting and stressful from the patient's point of view.

The evidence, however, suggests that compassion can be taught. Pence posits that compassion can be taught but not by exposure to a well-respected role model or attendance in an introductory course in medical ethics. Rather the educational system must reward the virtue of compassion just as it values diagnostic skills and fund of knowledge (Pence, 1983, p. 191). Diagnostic skills and knowledge are part of the Brasov culture of compassion.

Brasov PPC provides an educational and working environment that is built around compassion – a culture of compassion. The medical director, head pediatrician, and head pediatric nurse, were attracted to palliative care as an alternative to the traditional dispassionate care of children with life-limiting and life-threatening illnesses. Indeed,

this study supports Pence's contention that compassion can be taught in an environment that values compassion as much as diagnostic acumen and technical expertise (see **[2.6.3.] Advance strategies that support caregivers and health-care providers**). The study also corroborates Cummings' (2012) vision of a culture of compassionate care (Cummings & Bennett, 2012, p. 6). That being said, educators who wish to create a culture of compassion cannot ignore compassion burnout.

[6.8.2] Compassion burnout

Some of the causes of compassion fatigue or burnout are introduced in the review of the literature (see **[2.6.3.] Advance strategies that support caregivers and health-care providers**). The findings of this study specifically address compassion fatigue resulting from compassion being 'taught out' of students and young staff, death overload, and the callousness caused by families who ask for more than can be provided. First of all and by way of iteration, this study strongly suggests that the success of Brasov PPC is built around a culture of compassion – a culture that instills compassion. Secondly, Brasov staff psychologists are very sensitive to death overload; nurses who are beginning to experience compassion fatigue are temporarily taken out of the field and directed into an education track. Callousness or insensitivity towards families who ask for more than the staff can provide is averted by purposely describing the limitations of PPC when families are first introduced to the program.

The suitable medium for educators to create and maintain a culture of compassion is through palliative care.

[6.9] Future research

In **[2.5.3.] United Kingdom** and **[2.9.3] Current challenges to PPC**, I drew attention to the inequitable provision of PPC and the need for a widespread change in the working or organizational culture of PPC services. Developing a culture of compassionate care and garnering power equity are key factors in the success of Brasov PPC. Insight to the further development of PPC in other Balkan countries may be gained by exploring their respective power relationships and imbalances. While such scoping studies are informative, participatory action studies (see **[3.3.4] Epistemology: Critical emancipatory positions**) are more challenging and may be more worthwhile in changing the working culture of PPC in other countries of Central and Southern Europe, especially in Poland and Hungary.

This study casts considerable doubt on the success and stability of PPC in Poland and Hungary⁸⁸. Although exploring the factors that limit PPC in Warsaw, Poland (see **[2.5.5] Poland**) will nicely complement this study, a change-management case study in the newly-founded children's hospice in Katowice may have a more positive impact on the continuing development of PPC in Poland.

PPC in Hungary (see **[2.5.6] Hungary**) begs to be explored. The current status of PPC and the balance of power in Hungary is simply unknown. The absorption of PPC into the pediatric oncology service at Bethesda Children's Hospital in Budapest and the emergence of Dori House for Children in Pecs occurred since Budapest was declared a

⁸⁸ Poland and Hungary were also designated 'beacons' of palliative care (see **[2.9.2.] Pediatric palliative care in different parts of the world**).

beacon of PPC. Are the Hungarian oncologists able to provide a real medical home for CHILTD? Do routine outpatient visits offer sufficient opportunity for surveillance and symptom management? What provision is made for respite? How is the child's death managed? Do the children die at home? As for the CHILLD in Hungary, Dori House for Children is also prime candidate for another change-management or participatory action case study.

Chapter 7. CONCLUSION

This final chapter brings this journey of discovery and investigation to an end. I would like to step away from the interpretive confines of the study methodology and methods to reflect on the importance of this study to me in my personal journey and its significance for the delivery of compassionate care for children. To bring you, the reader, on board, I will share a few anecdotal experiences, each of which represents a signpost along this journey.

My journey began when I entered medical school with idealistic aspirations of being a family doctor or medical missionary – “to do right and good”. I was drawn to the science of the nervous system in textbooks of neurosurgery, neurology, and psychiatry – the unity of form, function, and behavior in diseases which affected the nervous system. The neurological manifestations of vascular disease, syphilis, tuberculosis, prematurity, hydrocephalus, syringomyelia, and spina bifida were absolutely fascinating. Since I was more of a ‘doer’, I rejected the aloof analysis of neurology and the mystery of psychiatry to embrace neurosurgery.

In the year of general surgery required prior to neurosurgery training, I thrived in a supportive environment and was even named Most Outstanding Surgical Intern. The images that commemorate the beginning of my neurosurgical training were the Jeffersonian serpentine brick walls, the gracious magnolia trees of the Rotunda, and The Lawn (surrounded by the bungalows reserved for the best students) of the University of Virginia. In retrospect now, it was in the shadows of this idyllic environment that I was first introduced to my own powerlessness in the ‘real’ world. I

have alluded to the 'brutalization' – the physical rigor, sleep deprivation, chronic fatigue, and psychological abuse – that characterized my early training . . . "an erosion of values, dignity, spirit, and will" (Maslach & Leiter, 1997, p. 17). In retrospect now, at the conclusion of this thesis, my sense of being and purpose was held together by a single golden thread – compassion – that anchored my subsequent encounters with established power and authority. My journey did not lead to a new position of power or dominance but rather to a viewpoint of what is fair and equitable . . . right and good . . . in the case at hand. This restorative perspective is a direct result of this study and my experience in Romania. The steps which were taken along the way parallel those of Brasov PPC and others who have successfully challenged established authority (see Foucault in **[2.8.4] Power** and **[6.6] Power equity, *ex aequo et bono*: an explanatory theory of success**). These steps include targeting the effects of power rather than the source of power, contesting the privileges of knowledge, treating the immediate problems rather than the big picture, preserving the right of self-determination rather than allowing it to be determined by 'others', opposing efforts to separate the individual from the society that nurtures it; and reaching out beyond the conceptual confines of PPC in my own country (transversality) (Foucault, 1994, pp. 329-331) – all too familiar themes in this thesis.

[7.1] Targeting the effects of power

When I first started the Palliative Care Program at Penn State University, many of the requests for consultation came from nurses. Unfortunately, nurses have no control over the management of patients; only the attending physician can initiate a consult. A

young man with Down's syndrome was hospitalized with pneumonia and then placed on a ventilator for respiratory failure. After successful treatment of his pneumonia, he could not be weaned from the respirator – despite multiple attempts and a prolonged stay in the intensive care unit. The only option presented to the family was tracheostomy and chronic respiratory treatment. His elderly parents thought that he enjoyed a good quality life prior to the pneumonia and were concerned about his care at home or in a chronic care facility with a tracheostomy and respiratory therapy. His nurses in the intensive care unit asked that I “take a look at him”. His attending physician agreed to the consult. After reviewing his x-rays, talking to his parents at some length, and examining him, I opined that each time an attempt was made to remove the breathing tube, he became very anxious and short of breath – then panicked. I suggested that he be extubated while treating his anxiety and shortness of breath with small doses of intravenous morphine. The attending physician disagreed and opined that with my suggestions would lead to certain respiratory failure. However, the attending agreed to transfer the responsibility for his care to palliative medicine. Needless-to-say he was successfully extubated with small doses of morphine and the family at his side; he was rapidly mobilized and discharged home. There is no lesson here other than the effects of power (respiratory failure and anxiety) were targeted rather than confronting the power and control of the attending physician. The prejudice against using morphine in the medical profession is pervasive – many believe its use leads to respiratory failure and is tantamount to euthanasia. Listening to the family led to what is fair and equitable . . . right and good . . . in the case at hand.

In another case, a prominent member of the community was dying of heart failure. He was in the intensive care unit but did not wish to be intubated and placed on a respirator as a final measure to assuage his heart failure. Nevertheless, he was in severe pain. In responding to his nurse's appeal, I noted his pain started shortly after intravenous bumetanide was administered to assuage his heart failure. One of the side effects of the drug is severe muscular cramping. I spoke to his physician, who sardonically voiced surprise that I did not recommend morphine to ease his pain and thus end his life. He was happy, however, to stop the bumetanide. The patient died peacefully 48 hours later without pain . . . without morphine. Listening to his nurse led to what was fair and equitable . . . right and good . . . in the case at hand.

Another nursing request that morphed into a consult was an unconscious patient in the intensive care unit who had severe diabetes and who was known to be non-compliant. When admitted, he was complaining of severe pain in addition to being ketoacidotic, confused, and agitated. His ketoacidosis was corrected, pain medication was administered, but he became unresponsive. The physician staff had become exasperated with his non-compliance and recurring admissions to the hospital. His lifetime Medicare benefit had been exhausted so that his care was now at the expense of the hospital. His admissions had become a contest about how fast he could be made well enough to be discharged. In any case he would be readmitted on a biweekly basis to someone else's watch and be another attending's responsibility. Out of frustration, my request to be consulted was granted. His assessment was further complicated by kidney transplantation, leg amputation, hypertension, and chronic pain. My nursing

partner and I also uncovered a web of deceit, cocaine and marihuana abuse, and social instability to the point of virtual homelessness – except for his hospital community. Nurses and medical students would listen to and reinforce his woes, trials, and tribulations. And he would cook cinnamon rolls and bring them to sell to the staff. This becomes a very long story but one that is life-limiting. We addressed his chronic pain and addiction; his illicit drug supplier was identified; he was transitioned to an independent nursing home before moving back to his home on his parents' property; and his diabetes was tightly managed by multiple home visits and telephone calls. He was admitted to the hospital only twice in the following year. Needless-to-say palliative care is not just an immediate end-of-life service; it cares for complicated patients with life-limiting illnesses. By acting as his primary physician, we did what was fair and equitable . . . right and good . . . in the case at hand.

[7.2] Contest the privileges of knowledge

As physicians, we like to listen to ourselves talk, or we listen for what we want to hear. A trap shooting friend recently told me that he had awoken 3 days ago with vomiting and a severe headache – severe enough for him to go to the Emergency Room at the University Hospital. This 37 year-old man was born with spina bifida and hydrocephalus; his spine had been repaired at birth, and the hydrocephalus treated with a diversionary shunt. He had last been seen for his shunt 12 years ago. The attending physician in the Emergency Room 'pumped' his shunt, and based upon his "ten-year experience with shunts", he opined that the young man had probably "grown out of his shunt" and didn't really need it anymore. The headache was most assuredly

caused by migraine. He was medicated and sent home to be followed by his primary physician. Since the headache was still present the next morning, he saw his primary physician who opined that the headache could not be migraine because it persisted. He diagnosed a 'head cold' and prescribed a synthetic narcotic and decongestants. When I listened to Mark, the headaches were most severe in the morning and were associated with vomiting. His "thinking wasn't so sharp"; he was unsteady on his feet; and he could not look upward. The subcutaneous tract of his shunt tube curled around the back of his ear, down his neck and chest, and then into his abdomen; it was hard with calcification and taut with tension. These are the classic, textbook signs and symptoms of life-threatening shunt failure. I had him seen by a neurosurgeon at the University of Virginia who confirmed the diagnosis with computerized tomography (CT). Mark's shunt was replaced that night; the tube had become disconnected and choroid plexus had been aspirated up into the tip of the catheter (to partially occlude the opening and thus the flow of fluid) by the preoperative 'pumping' of the shunt. Pumping the shunt was shown to be non-diagnostic and to risk occluding the catheter more than 20 years ago. Notwithstanding a textbook history and physical, the neurosurgical 'team' wanted to monitor his intracranial pressure overnight prior to replacing the shunt. This tactic would have provided a false reading because of the occlusion and would have increased the risk of postoperative infection. When Mark opted not to have his pressure measured, the team cautioned him in the strongest terms that he would "never know how high the pressure was". Nonetheless, he recovered uneventfully and was discharged within two days . . . but not without two additional 'routine' (but

unnecessary) CT scans. Such are the privileges of knowledge that deserve to be contested. In each instance his caretakers – the emergency room physician, the primary care doctor, and the neurosurgical team – listened for what they wanted to hear instead of listening to the patient. And they lost sight of what is fair and equitable . . . right and good . . . in the case at hand.

I was trained like so many generations of neurosurgeons who came before and after me to only use codeine in the treatment of postoperative pain. Codeine was believed to be the only narcotic that did not suppress respirations: as respirations decrease, the intracranial pressure goes up, and the risk of death becomes urgent. Unfortunately, codeine is very constipating, cannot be given intravenously, and provides poor analgesia. Patients with back, neck, and extensive cranial surgeries are left to suffer their postoperative pain. My compassion contested what proved to be no more than a myth. Small doses of morphine given at frequent anticipatory intervals provide good control of pain without compromising breathing. Listen carefully to the patient to be fair and equitable . . . right and good . . . in the case at hand.

Another example of privileged knowledge is that shaving the scalp is necessary to reduce the risk of infection following cranial surgery. I followed this dictum until a teenage girl became despondent when told that her hair would be shaved before surgery to remove a malignant brain tumor. She cared more about losing her hair than the threat posed by either the surgery or the malignancy. Compassion contested the privilege of knowledge. The hair and scalp were cleansed in the usual way; her hair was parted along the line of the incision; and the incision was made and closed without

infection. Because it made so much difference to the children and made the surgery only a little more difficult, I thereafter stopped shaving prior to surgery . . . over 600 surgeries without infection. Listen carefully to the patient to be fair and equitable . . . right and good . . . in the case at hand.

[7.3] Treating the immediate problem

The family of a 12 year-old boy asked me to see their son because of complications associated with his malignant brain tumor. The moderately malignant tumor had been removed several years prior, but a small nubbin of tumor had grown back accompanied by a large cyst to cause increased intracranial pressure and severe headaches.

Dexamethasone was used as a palliative to reduce his headaches. After several months the headaches recurred and the dose of dexamethasone was increased. He soon developed dexamethasone toxicity: truncal obesity, agitation, acute pancreatitis and abdominal pain. The immediate problem was the dexamethasone toxicity. The dexamethasone could be stopped if the intracranial pressure could be relieved. Guided by my compassion for the boy's unnecessary suffering, I recommended removal of the cyst and the part of the tumor which did not invade the underlying brainstem. He recovered uneventfully from the surgery, was weaned from the dexamethasone, and lived two more years before he succumbed to the tumor. The family sent pictures of his first deer hunt just prior to his death. Compassion for unnecessary suffering led to what was fair and equitable . . . right and good . . . in the case at hand.

An 82 year-old man suffered a major hemisphere stroke that rendered him unable to speak and completely paralyzed on his right side. I was asked to see him because he

repeatedly pulled the nasogastric tube out that had been placed for nutrition. He refused to eat and shook his head “No!” each time the nasogastric tube was inserted. A surgical gastrostomy had been recommended, but his children were ambivalent about the surgery. The immediate problem seemed to be consent for the gastrostomy, but in truth it was the ambivalence of his middle-aged children. I listened to the children as they recounted his life and achievements. At 18 years of age he became a professional athlete in both Canadian football and hockey – football in the spring, summer and fall, and hockey in the winter. He went on to be a player-coach, general manager, and owner of a hockey team in the US. Until the day of his stroke he played golf when the weather permitted. He was a kind man who was beloved and respected in the community. And he also recognized that he had come to the end of a good life. When his children decided to forego the gastrostomy and allow him to eat as he wished, he expressed gratitude with tears and an affirmative shake of his head. Compassionate listening led to what was fair and equitable . . . right and good . . . in the case at hand.

I created the palliative care service at Penn State University in the same time frame as palliative care came to fruition in Brasov – the turn of the 21st century. The immediate problem was the total lack of compassionate caring on the adult side of the hospital. With the moral (but not financial) support of the Chairman of Anesthesia, I approached the Dean of the College of Medicine for financial backing. He, in turn, convened a meeting of the departmental chairmen who all lamented the paucity of resources and space. Nevertheless, I was granted space – a room previously used by visiting community physicians to hang their coats – and recruited a very talented and

experienced hospice nurse who had been sequestered away in a research lab writing grants. Nursing continued paying her salary. The Chairman of Medicine agreed to bring together a 'task force' which served 'to pass the word' by engaging members of the staff who were considered key players or change agents. About the same time I was asked to join a committee sponsored by the American College of Surgeons to create a national consensus on surgical palliative care (Dunn & Johnson, 2004).

Meanwhile, on the ground⁸⁹, my colleagues were many times not aware of or chose to ignore compassionate caring, or were rutted into their own routines. To increase our credibility, our consults in the hospital chart were detailed, typed, and often accompanied by sketches. Most patients who are candidates for palliative care have long, complex histories which are not always taken into account when their treatment plan is crafted because it is so time-consuming. My example of homeless diabetic man is a case in point. Frequently treatment is based on hearsay or incorrect information, as was the case for the 12 year-old boy with a malignant brain tumor. My recommendations were all drawn from evidence which was referenced by peer-reviewed literature. Nevertheless, I was not one of them (I was 'other') and even had a complaint lodged against me with the 'Conflict of Interest Committee' that I did not respect "professional boundaries". The complaint was dismissed, but it represented a prodigious undercurrent of professional resentment which threatened to drag down the new palliative care program. I continued to focus on the immediate problem at hand –

⁸⁹ I have used this military metaphor before in describing the actual delivery of care as contrasted to healthcare policy – on the ground versus in the air, in the field versus in the 'war room'.

the lack of compassionate caring – and it was particularly wanting in the medical and surgical intensive care units. After all, I had been a patient in both units.

The head nurse in the surgical intensive care unit asked me to see a patient who was dying from surgical complications and suffering severe pain. I asked the patient's attending physician, who happened to be the Chief of Cardiovascular Surgery, if I could see his patient. He replied, "Sure, please do, if you think you can help". On the next day this same attending accosted the head nurse and threatened her with bodily harm if she ever again requested a consult without his permission.⁹⁰ Parenthetically, that same head nurse went on to head up a community hospice. Once the ice was broken, however, palliative care gained acceptance. Again through nursing, I was granted office space in the medical intensive care unit where the need for compassionate caring was immediate. Being present and visible was an important aspect of our progress. We took on the most difficult and seemingly impossible patients which were bottling up⁹¹ the unit and coordinated an enduring discharge. The homeless diabetic man and the patient with Down's syndrome referenced earlier are cases in point.

There was no lack of compassion in the pediatric intensive care unit or on the pediatric oncology ward. The oncology ward was particularly keen about palliative medicine but lacked the necessary nursing infrastructure. Pediatric oncology was generously funded by a wealthy philanthropic foundation which reduced the influence of reimbursement on

⁹⁰ This example deserves a broader context. This surgeon has a reputation for being very competent, blunt, and to the point. Under this bullying exterior is a very compassionate man who is deeply committed to his patients and did not relegate their care to the physicians in training whom he supervised. Regrettably, he was taught that end of life care was synonymous with "giving up".

⁹¹ The ability of the intensive care unit to admit acute patients is controlled by discharging treated patients. A bottle 'neck' to the flow of patients is created by those who cannot be discharged.

the vision of PPC. Nonetheless, I chose to go where the need was greatest, anticipating that pediatric oncology was already moving in the right direction. In retrospect, PPC could easily be built into pediatric oncology rather than serve as a stand-alone consulting service if the pediatric oncology physicians and nurses could be cross-trained in palliative care.

[7.4] Preserve the right of self-determination and control of who we are

A considerable attempt was made in my training to blunt my compassion and mold me into the role of a dispassionate, well-ordered neurosurgeon, but I preserved and sustained my compassionate doing. After my heart transplant, I returned to pediatric neurosurgery. My experience as a person with life-threatening disease confirmed my suspicion about a growing hollowness in medicine – a lack of what was fair and equitable . . . right and good . . . in the case at hand. This hollowness was meant to be filled by palliative care, not by pediatric neurosurgery. A blustery cardiology colleague once remarked to me in casual conversation, “Palliative care is what I think I would like to do when I retire!” In my opinion he was already involved in the compassionate doing of palliative care. He simply doesn’t acknowledge his compassion because the science of cardiology holds more societal value, just as the neurosciences had for me. A transformative change in his specialty – cross-training in palliative care – is not going to happen in his generation, but the substance of change is already present.

In retrospect, this theme of self-determination or the process of controlling one’s identity also has had a negative effect on the development of the Penn State Center for

Palliative Care. I hired two part-time medical hospitalists⁹² (part of the time they attended as hospitalists and part time for palliative care) to help handle the increasing volume of patient referrals. Both were known for their clinical acumen and talent for teaching, but both eventually admitted that they “wore different coats” when they were attending for acute hospital care versus attending for palliative care. Attending as hospitalists meant saving or preserving life at any cost with token consideration for quality of life. They failed to understand the full potential of palliative care – preserving quality at the end of life. I suspect they saw me as an egregious authority who was trying to change the way they practiced medicine. After all, I wasn’t even a doctor – only a surgeon . . . and a children’s surgeon to boot! This formidable barrier was still present when my journey changed course and took me to Romania and casts a dark shadow on the prospect of cross-training specialists. On the other hand, physicians who fill the roles of hospitalists, emergency room physicians, and radiologists, for examples, have no or little enduring contact with patients and attract a cast of characters who are content to remain journeyman physicians.

[7.5] Opposing efforts to separate the individual from the society which nurtures it

Part of the reasoning behind taking on the most difficult and seemingly impossible patients which were bottling up the medical intensive care unit was to interrupt the recurring cycles of ‘band-aide medicine’⁹³ for chronic, life-limiting illnesses – discharging

⁹² Hospitalists practice only in the hospital, that is to say they have no outpatient or office practice.

⁹³ Band-aides are small adhesive bandages whose only purpose is to cover a wound. For children they are often embossed with colorful fantasy characters (Barbie, GI Joe, Elmo, et cetera) with a broad mandate

the patient as soon as possible, only to readmit them a few weeks later. Insurance companies in the US will allow a limited number of day's hospitalization for a particular diagnosis. Readmission renews the reimbursement cycle. To interrupt the cycle, we created mutually agreed upon goals of treatment for our patients and then returned them to the social milieu that would nurture them. Alternative resources in the community were always available. The 'back pressure' or danger of this tactic was that "who we are" would become defined by our skills in discharge planning and coordination. The highest priority, however, was to return the individual to the society that nurtures it – not to get the patient out of the hospital to improve patient flow.

In any case, children with life-limiting illnesses often lack adequate resources in the community to nurture and sustain them – which is one of the appeals of the Brasov home model of palliative care with planned admissions for illness maintenance and respite.

[7.6] Transversality

Foucault used this term to play down the unworkable assertions of a 'universal' struggle. 'World peace', for example, may be a universal struggle but lacks substance, structure, and agency. Transversality also emphasizes the value of looking beyond one's country of origin or local sphere of influence for leverage to help resolve power imbalances. I joined representatives from other States in the US to create a 'transversal' consensus on surgical palliative care under the auspices of the American College of

to cure all 'hurts'. Band-aide medicine is a term I use for a quick, temporary remedy to a complicated illness.

Surgeons. By taking my work to Romania I was able to reach beyond the conceptual confines of reimbursement, resources, and entitlement that have come to define medical care in the United States (US) (Brill, 2013). The findings of this study give substance to the unequivocal success of Brasov PPC and meaning to the term compassionate caring. Some aspects of their success may be workable in other countries but not all countries. For example, the downside of applying the unique paradigm of care in the US is that our resources are often perceived as unlimited. PPC for children and families in Romania is restricted by very limited resources to which access is regulated by a complicated application process. Empowering families to apply for those resource entitlements to improve quality of life contributes to the sense of solidarity and the home model of Brasov PPC. Families in the US, on the other hand, have the American expectation that resources are unlimited; they are entitled to the best although the 'best' may be based on another family's anecdotal experience or the latest advertised 'special' offer of a for-profit healthcare system. Satisfying their unworkable expectations instead of achieving quality of life becomes the objective. But prolonging the existence of a terminally ill child with cystic fibrosis in an intensive care unit is not a realistic expectation and weighs heavily on the healthcare system that ranks last in healthcare performance and first in healthcare expenditures (Davis, et al., 2012, p. v).

However, as I pointed out in ([2.2] **Specialization**) healthcare systems and health policy makers are increasingly compelled to address the attendant social issues of fragmentation, discontinuity, inequity, and cost caused by specialization. Overall

improvements in healthcare equity and quality are likely to require healthcare reforms which are not directed at specific diseases but rather at people, especially those who suffer multiple conditions and co-morbidities (Starfield, 2006, p. 23). In this context, the unequivocal success of Brasov PPC is all the more provocative.

Nonetheless, Brasov PPC's success is packaged by the findings of this study and bound by the golden thread of compassionate caring but is far from being a universal solution for PPC. I argue that Brasov's success is more 'transversal', to be shared by "more than one country" (see **[6.6.4.1] Transversality**), in Eastern, Central, and Southern Europe.

[7.7] Full circle

My journey to achieve power equity has been a process of reconciliation that has led me full circle from the compassionate aspirations of a youthful medical student to the compassionate doing of a senior medical investigator. My journey may seem so unusual that it cannot be traced by other travelers. Nevertheless, this journey is meant to be shared. My reflections are not a lament of what could or should be done differently – a road not traveled. The most important aspects of this shared journey are the underlying mechanisms and processes that move us forward.

The Bucharest marathoners (2010) ran just for the good of it. The home model of Brasov PPC is not only plain 'good' but has the potential to transform the care of children with life-limiting diseases elsewhere. For the good of children with life-

threatening illnesses, the specialists who care for them ought to becoming cross-trained in PPC and not renege on the difficult job of compassionate caring.

Brasov PPC has shown Romania can learn to be human again (in answer to the challenge of an anonymous post-1989 Romanian pediatrician). By embracing these two transformative changes in how children with life-limiting and life-threatening diseases are managed, PPC becomes more, rather than less, human (in response to Kubler-Ross' challenge in 1961), is sustained by compassion and solidarity, and is guided forward by *ex aequo et bono* – what is fair and equitable . . . right and good . . . in the case at hand.

Appendix A. Lancaster Ethics Application and Amendment



Institute for Health Research

LANCASTER UNIVERSITY

Application for Ethical Approval for Research Project

1. **Title of Project:**

The Development of Pediatric Palliative Care in Romania

2. **Project Co-Supervisors:**

Dr. Anne Grinyer

David Clark, PhD

3. **Appointment held by supervisor and institution** where based:

Dr. Anne Grinyer, Senior Lecturer in Health Research, Lancaster University

David Clark, PhD, Director of the Glasgow University Dumfries Campus

4. **Researcher** (Applicant):

Dennis L. Johnson, MD

<p>5. Appointment held by applicant:</p> <p>Part-time PhD student, Lancaster University</p> <p>Professor of Surgery, Pediatrics, and Medicine, Penn State College of Medicine</p>
<p>5. No of studies applicant is currently undertaking (give brief details):</p> <p>Only this project</p>
<p>6. Place where work will be carried out:</p> <p>The interviews will be conducted in the palliative care and hospice units in Brasov, Bucharest, Targu Mures, Pitesti, Timisoara, and Oradea, Romania.</p> <p>The ethnographic studies will be carried out in the homes of children and their families that are located in Brasov and the surrounding areas served by Hospice Casa Sperantei.</p>
<p>7. Names and appointments of any associated Research Workers (including degree students where applicable)</p> <p>Ms. Oana Predoiu, language interpreter and transcriptionist, Hospice Casa Sperantei, Brasov, RO</p>

<p>8. Summary of research protocol in lay terms (maximum length 150 words).</p>
--

Background

A model of care for children with life-limiting diseases (CHILLD) has been developed in Romania that may be more authoritative and worthy of public acceptance than the current paradigm of pediatric palliative care (PPC) in Great Britain and the United States.

Aims

The purposes of this study are to 1) develop an oral history of PPC in Romania, 2) define the model of PPC in Brasov, Romania, and 3) corroborate the model with children and their families in Brasov.

Methods

- a. External experts who are familiar with palliative medicine and its development in Romania (e.g. Graham Perrolls, founder of Hospice Casa Sperantei in Brasov, and Kirsteen Cowling, a nurse from England who was the first pediatric palliative care nurse in Oradea, Romania, at Hospice Emmanuel) will be interviewed to define the developmental issues for PPC in Romania.
- b. Clinicians and academics in the 6 major centers of PPC will detail the development of PPC in each center and address the issues identified by external experts
- c. The prototypic model of PPC in Brasov will be elucidated in the process

of interviewing the clinicians in Brasov.

- d. The outcome and validity of this model will be substantiated by ethnographic study of participating children and families in Brasov

9. Anticipated dates of starting and finishing study:

1st December 2009 – 1st March 2011

10. Please indicate the categories of participants to be studied (number, age, gender):

Interview participants will include 20-30 health care workers (men and women) – physicians, nurses, social workers, and administrators – ranging in age from 18 to 65 years. An equal number of family units (children ages 4-18 years) will be recruited for the ethnographic part of the study.

11. How and from where will participants be recruited?

Interview participants will be recruited during visits to the 6 institutions that provide pediatric palliative care in Romania: Brasov, Bucharest, Timisoara, Oradea, Targu Mures, and Pitesti. The visits will be organized by Dr. Daniela Mosoiu, Medical Director, Hospice Casa Sperantei, and founder and president of the Romanian National Association for Palliative Care. Ms. Oana Predoiu will serve as a guide and interpreter. Ms. Predoiu will also organize an internet discussion board to facilitate asynchronous communication with and

amongst interview participants. The discussion board will be used to provide the standard information sheet that includes the background and purpose of the research project. Potential participants will have at least 2 weeks to explore and resolve any ethical reservations that they may have. A recruitment 'snow ball' effect ("people you should talk to") is anticipated even in this introductory phase.

Participants for the ethnographic phase of the study will be recruited from the families and children served by the visiting hospice nurses in their homes and from the 7-bed inpatient hospice. In the first instance the nurses will screen out those children and families who do not wish to participate. Potential participants will be told about my research, given an information sheet, and invited to contact me if they wish. To insure voluntary participation, we will not attempt to persuade them to take part.

12. What significant discomfort (including psychological), inconvenience or danger could be caused by participation in the project?

I acknowledge the time constraints placed on busy clinicians and will make every effort to minimize the inconvenience of the interview. Strict confidentiality will be assured to assuage any fear of governmental inquiries and/or political reprisal. That being said, candidates for the study who refuse to be recorded or who do not wish to participate will not be persuaded

otherwise. The tenor of the discussion topics will be open, and any specific inquiries will be made in the spirit of exploration and discovery rather than from the viewpoint investigation, condescension, or privileged superiority. Interviews will be conducted without any psychoanalytic attempt to evoke subconscious conflicts that might provoke strong emotions and psychological discomfort.

The Brasov model of PPC will be critically examined from the child and family's point of view in the ethnographic phase of the project. Is the clinical model valid? Does the model meet the needs of the end user? An interdisciplinary panel of pediatric experts framed a needs consensus for the Institute of Medicine in 2003: ". . . competent, compassionate, and consistent care to meet their physical, emotional, and spiritual needs." This question itself may evoke discomfort and fear (e.g. fear that existing services may be withdrawn). During the immersion process, the model will be evaluated for how well it provides for these needs. For example, spiritual needs revolve around their perception of death and what is happening to them. What do I (as the researcher) hear, see, or feel about their awareness or concept of death? Physical needs include relief of pain and other symptoms. What is done to relieve pain, shortness of breath, and nausea? Emotional needs evolve from loneliness (i.e. no one understands what is happening to me . . . everyone is turning away) and impending loss. If the child appears withdrawn (face to the wall), is the child 'crossing over' or

transitioning to death, or is the child depressed because no one knows that s/he is dying?

I anticipate that the majority of children in this population will be nonspeaking because of the stage of their disease or the nature of their illness (neurologic); that is **not** to say that they do not communicate. Body language is often more telling than spoken language. In this context the key to assessing whether spiritual, physical, and emotional needs are being met is to interpret body language as objectively as possible.

The researcher's goal is to blend in and not interfere with the nurse/family/child interaction. However, passive observation and note-taking can easily be interpreted as rude behaviour or bad manners. Although our presence will not go unnoticed, our interaction with the families and children shall not impede or upstage the flow of care. The sort of interaction that I anticipate and how potential discomfort might be handled is based on my experience as a clinician making house calls in the US. Several potential points of entry into the social milieu of the home can serve as portals of active or participatory observation. For example, the child might be in the bed watching TV or playing a video game; the mother would greet us at the door with a list of questions or a box of medications; and the grandmother would be in the kitchen preparing macaroni and cheese. Each mini-hub of activity represents a point of entry. I would commonly 'see to' the child (it is very

unproductive to **go to** a child with the sole purpose of asking questions because the 'answers' are most often neutral, bland, and/or uninformative) and the nurse would sit together with the mother to discuss a particular problem that had arisen or to review what had happened since our last visit. Needless-to-say the grandmother in the kitchen or the father working in the garage or barn would also be included or at least acknowledged. Language may certainly be a barrier but could also be used to advantage. My usual interaction with children is a form of play/clowning socialization that allows the child control (and therefore confidence and safety) and at the same time allows for more spontaneous flow of age-appropriate conversation. I envision teaming with the interpreter – one of us manning the digital recorder and making notes while the other would be interacting with the child. This addresses the specific question of how the child is affected or how the child perceives his/her care. As an example, I would not barge into the child's space or room but rather roll a silly ball in through the door or play hide-and-seek with a 'muppet' . . . maybe use a camera as an introduction ("Would you like to see a picture of yourself?"). I must be invited to enter the child's world or I will be blocked and ignored. ***This socialization process is designed to minimize any discomfort, fear, and/or mistrust.***

It is important to acknowledge that I bring my own personal feelings as well as my experience as a pediatric neurosurgeon and hospice medical director to this project and that they may affect the results. I also acknowledge that

children usually know that they are dying although caregivers try to conceal it from them, and that the children themselves often conceal their knowledge from their caregivers. (Bluebond-Langner M. **The Private Worlds of Dying Children**. Princeton University Press, Princeton, New Jersey, 1978) To a large extent this study is about communication and awareness.

Finally, the researcher will inevitably be asked his opinion about treatment and care. A stereotyped or dismissive response may be interpreted as offensive, hurtful, and non-caring. A contextual response would be appropriate; for example, in response to the question "Is there anything else that can be done?" I would say "I think your nurse is doing a great job . . . is there something that is worrying you?"

13. Details of any payments (including out-of-pocket expenses) made to participants:

No payments will be made to any of the participants as it is not anticipated that they will incur any costs as a result of taking part in the study.

14. How will the design of the study ensure scientific validity?

This study follows on the field work methods developed by Clark and Wright. (Clark D, Wright M. **Transitions in End of Life Care: Hospice and**

Related Developments in Eastern Europe and Central Asia, 2003,

Open University Press, Philadelphia) in documenting the development of palliative care in over 60 countries worldwide. An oral history of pediatric palliative care in Romania, the first aim of the study, will encompass a broad spectrum of caretakers and caregivers in Romania and abroad.

To achieve the second and third aims of the project (to define and validate the Brasov model), the field notes, notes on interviews, interview transcripts, and whatever other data collected will be part of a working document or data set. Patterns, connections, similarities, or contrasting points of view will be marked on the document. Particular attention will be given to the 'native' point of view – to elicit local categories (e.g. what services do the children and families value – that may differ from American or English core values?) Data will be qualitatively analysed using cross sectional indexing to identify themes across the data set. The analysis will use a sorting and sifting process that will code data according to recurring themes and will draw out the contextual similarities and differences. As themes emerge and explanations evolve, they will be tested against the variety of cases, and alternative explanations sought from different perspectives.

Validation or 'reality testing' will be done with some of the participants as conclusions begin to develop (i.e. they will be asked to comment on the conclusions). Finally, has the research question (How are children with life-

limiting illnesses care for in Romania?) been answered? Is another question more appropriate?

15. Will the results be of benefit to the participants involved in the study?

The study will help elevate the priority of pediatric palliative care in the Romanian healthcare system and provide evidence with which to lobby the Ministry of Health for healthcare resources. The project will give the interview participants a renewed sense of self-worth and a feeling that they are part of a meaningful and vital organization. Sympathetic and compassionate listening, which is inherent to ethnography, may have a cathartic – even therapeutic – effect.

16. What procedure is proposed for obtaining consent? (Copy of information and consent forms must be enclosed)

The interview participants will be contacted by Dr. Mosoiu well in advance of the actual field work. The participants will receive electronically an **Information Sheet** that explains the purpose of the research and how the 'data' or recordings will be used. An internet discussion board will be posted as least 2 weeks prior to the interview. For participants that are unwilling to

affix their signature to an official document, verbal consent and copyright release will be audio-recorded.

In the ethnographic phase of the study, consent will be obtained from parents or those in *loco parentis*. However, the children in St. Andrew's Hospice, for example, are all abandoned by their parents and are wards of the state; consent will be obtained from the Director (Florian Pena) or Deputy Director (Manuel Amirela) of Child Protective Services in Pitesti. Every attempt will also be made to obtain 'real' consent from children even though they have impaired understanding or communication. If the child clearly withholds consent or shows distress (e.g. grimace or aversive behaviour), the implicit wishes of the child will prevail.

All research participants will be made aware of their right to refuse to participate or withdraw from the investigation whenever and for whatever reason they wish. The feasibility of obtaining consent from severely impaired or vegetative research subjects deserves further elaboration. In my previous visit to Romania, most children in the inpatient hospice centers could communicate only in a very limited way because of the nature of their neurologic impairment or because of the advanced stage of their disease.

17. What system will be utilised for the storage of data and does this comply with the Data Protection Act 1998? (Please give Registration Number).

This project complies with the eight principles of the Data Protection Act of 1998:

1. Data (data defined as audio- and video-recorded interviews) will be processed fairly and lawfully (see 18 below).
2. Complies with at least one Schedule 2 condition: the data subject will give his/her written or verbal consent to participation
3. Complies with at least one Schedule 3 criteria: "medical purposes" includes the purposes of preventative medicine, medical diagnosis, medical research, the ***provision of care and treatment and the management of healthcare services***.
4. Data will be obtained for the lawful and specified purpose of medical research (The research question is ***How are Children with Life-Threatening Illnesses cared for in Romania?***). The interviews will be semi-structured and focused on how, when, where, and why pediatric palliative care has developed in Romania.
5. Data will be adequate, accurate, up to date, and kept relevant to the purpose.

6. Data will be stored in the Hospice History Archive at the University of Glasgow Dumfries Campus as a permanent historic reference which will be available to the academic community for legitimate research and for verification of publications emanating from the data. For the purposes of academic integrity (e.g. for verification of published statements or 'testimony'), the digital recordings of interviews taken from physicians, nurses, and other clinicians/administrators will be referenced and archived by name and associated institutions (for example Marinela Murg, Hospice Emanuel, Oradea, Romania). Children and their families will be referenced by a case number and name of the institution (Case #6 Brasov).
7. Data will be safe-guarded against unlawful processing and against accidental loss, destruction, or damage in the Hospice History Archives at the University of Glasgow in the custody of Professor David Clark. Data will be processed in accordance with the rights of data subjects under this Act.
8. Personal data shall not be transferred to a country or territory outside the European Economic Area unless the same level of protection for the rights and freedoms of data subjects in relation to the processing of personal data is ensured

18. Will audio or video recording take place? What arrangements have been made for storage? Will tapes be destroyed at the end of the Research?

Two separate recorders will be used to guard against file corruption and mechanical malfunction. Furthermore, three duplicates will be made to insure against loss or damage in travel. With the consent of the participants, one recording will be electronically transmitted 'home' via internet e-mail (see CONSENT, #3). Two copies of audio recordings will be kept by the author for 5 years following completion of the study and then destroyed.

19. What particular ethical problems do you think there are in the proposed study?

A concerted effort will be made to anticipate and avoid ethical problems. In both proposing and carrying out research, I think it is essential to be open or transparent about the purpose, potential impact, and source of support that might introduce bias. The purpose of this study is 3-fold:

1. To detail the model of PPC in Brasov, Romania
2. To describe the resources or healthcare services available to and needed for CHILLD at the end of life.

3. To determine if and when available services are actually accessed, and how are symptoms such as pain, immobility, and shortness of breath managed. Nutrition and hygiene will also be assessed

The potential **impact** of substantiating the paradigm of PPC in Romania is that it may set a standard of care for other Balkan countries and enhance my colleagues' ability to compete for limited healthcare resources. My Romanian co-authors will control or provide a check on any potential adverse effects of publication. Finally, the model may contribute to a more cost-effective and responsive restructuring of PPC in the US and England.

The only potential **source of support** other than my personal funds will be a traditional Fulbright Scholarship.

With guidance from the Code of Ethics of the American Anthropological Association (approved June 1998), my primary ethical obligations are:

- To avoid harm or wrong – understanding that the development of knowledge can lead to change that may be positive as well as negative: see section 16 above. What if **The Development of Pediatric Palliative Care in Romania** finds its way into the hands of an enterprising journalist as **The Death of a Romanian Child** to create a negative public imagine that constricts the flow of much-

needed philanthropic aid to the hospice movement? What if the Ministry of Health uses our research to show how pediatric palliative care is adequately funded or could do with less? This ethical concern needs to be taken into account when publishing the results of the study – from phrasing a title, presentation of the results, content of the discussion, and minimizing any speculation in the conclusion. Any publication will be co-authored by Dr. Daniela Mosoiu whose first concern is the well-being of the children. Exploiting dying children for ***pure*** research is shameful. The results of this research will be ***applied*** to the well-being of and on behalf of the participants.

- To respect the well-being of the participants: see section 12, 15, and 16 above
- To work for the long-term conservation of historical records. The data will be permanently stored in the Hospice History Archive at the University of Glasgow
- To consult actively with the affected individuals or group(s), with the goal of establishing a working relationship that can be beneficial to all parties involved. Substantive relationships have already been developed in all 6 centers that serve children with life-threatening illnesses in Romania – especially in Brasov where the network of care for children with life-limiting illnesses is centered.

Problematic as it may be to anticipate ethical dilemmas, it is important to be consistent and clear about the goals of the project and my role as a facilitator – not as an expert. On the other hand, I am an experienced physician and will answer questions within the scope of my expertise and experience. However, in order to avoid ethical dilemmas, my responses will be couched in terms of what is available and feasible in the Romanian healthcare system, not what is done only in the United States of America or England. For example, during a recent exploratory tour of a pediatric hospital that offered palliative care in Timisoara, I was asked to confirm the diagnosis of 'regional pain syndrome' in an adolescent girl (who had previously been diagnosed with hysteria) and offer an opinion about the use of the drug ketamine in its treatment. In my experience the use ketamine for adolescent pain syndromes is problematic in the best of hands. The 'regional pain syndrome' is synonymous with 'causalgia' which responds well to surgical sympathectomy or to transcutaneous electrical neurostimulation (TENS). Sympathectomy requires a level of experience and sophistication that is not available in Romania. TENS, however, is well within their purview, and hydrotherapy would be an innocuous complementary treatment. Both modes of therapy are available at an excellent rehabilitation hospital in Oradea – not far away. I seldom opine authoritatively in discussions with colleagues, but rather generate a collaborative thought process – a process of critical thinking – from which an 'answer' emerges.

Moreover, any 'new' technology or treatment from outside the country ought to be supported by the technical and personnel infrastructure to address complications and minimize suffering.

In another instance, I was asked what could be done with a neurologically impaired pre-teen to salvage or improve speech. Advanced speech therapy is available in the USA and UK, but its efficacy depends on a long-term commitment and would, in any case, not achieve the mother's goal. Mother is a nurse and social worker; her husband has emotionally abandoned her and their child. Her aging parents are no longer able to help care for him. Her real question was ***Who will take care of him when I am gone?*** She is a devout Romanian Orthodox Christian, and I suggested that she might look to her faith for an answer. The answer was reflexive, not authoritative.

At first glance ethnographic research seems innocuous enough: no intervention is plied, and the researcher is but a 'fly on the wall'. But does the presence of a researcher in the home of a dying child create a spectacle – an unfavourable distortion of reality that will remain in the family's memory of the child? In my brief exposure to PPC in Romania, the overriding theme is trust, giving and caring for one another. Our presence in the home will be interpreted as another example to working together for the sake of the child. We mean to celebrate the child's life as well as commemorate the death. The potential cathartic and therapeutic effect of this synergy outweigh any

emotional burden.

Appendix A1: Application to Amend Research Ethics Approval

In the original application for ethics approval, I did not anticipate some of the logistical obstacles encountered 'on the ground' in Romania. In addition, several opportunities to enhance the study became apparent after my arrival at Hospice Casa Sperantei. This application seeks approval for 3 amendments: 1) to change how the study is introduced to the participants, 2) to recruit participants from the Children's Daycare Center, and 3) to include interviews done during an exploratory field trip in 2009 in the data to be analyzed.

Introducing the study to participants

In the original protocol, Dr. Daniela Mosoiu, and medical director of Hospice Casa Sperantei was to play key a role in recruitment and obtaining consent:

Section 11 (page 3 of the application): *How and from where will participants be recruited?* Participants for the ethnographic phase of the study will be recruited from the families and children served by the visiting hospice nurses in their homes and from the 7-bed inpatient hospice. In the first instance the nurses will screen out those children and families who do not wish to participate. Potential participants will be told about my research, given an information sheet, and invited to contact me if they wish.

Section 16. (page 7): *What procedure is proposed for obtaining consent?* The interview participants will be contacted by Dr. Mosoiu well in advance of the actual field work.

However, access to participants has proven more complex. For the children and families, Dr. Mosoiu is a distant figure of authority and difficult to relate to with any

familiarity. In discussions with the staff, the supervisor of the daycare center and the nurses are better suited to introduce the study, explain my presence, and obtain consent.

Expand the scope of recruitment

In the ethnographic phase of this study, the scope of participant recruitment was limited to the pediatric nurses, families, and children of Hospice Casa Sperantei (HCS) in Brasov, Romania. HCS includes a 7-bed inpatient unit and a homecare service that serves about 140 patients. HCS also has a daycare center adjacent to the inpatient unit.

I am requesting to extend the scope of recruitment to include children with life-limiting illnesses who attend the Children's Daycare Center. I anticipate that I will observe and/or interview 4-6 children in the Center.

Include 2009 interviews

Six major centers provide pediatric palliative care (PPC). Prior to obtaining ethical approval for the current research project, I visited these centers and interviewed 12 professional providers to explore the feasibility of conducting such a study.

I am requesting that I be able to include these interviews in the data set. Written consents were obtained at the time of the interviews; however I propose to update those consents now that I have ethical approval for the study. Requests for the renewed consents will be sought with confirmatory emails.

Appendix B. Information sheet for children and families

INFORMATION SHEET

You are being invited to take part in research on how children with life-limiting illnesses are cared for in Romania. Before you decide whether or not to participate it is important that you understand why the study is being done and what it will involve. Please take time to read the following information. If you have any questions that are not answered in this information sheet please contact me (contact details are given at the end of this sheet). Please take a week to think about whether you would like to participate.

In order to participate, you will be asked to sign a **consent** form. If you wish to participate but cannot sign the form, your verbal consent can be recorded. If for any reason you are reluctant to attach your signature to a form, your recorded verbal consent is acceptable. You will also be asked to sign a **copyright release** to give the University of Glasgow rights to make scholarly use of the archived recordings and field notes.

Why is this research being done?

This research hopes to gain a better understanding of how end of life care is currently provided to children with life-limiting illnesses in Romania which includes the paediatric palliative care program in Brasov. The research is being undertaken in order to

appreciate more fully the effect that end of life care has on the young people and their families.

Why have I been invited to take part?

You have been invited to take part because you and your family are in the care of Hospice Casa Sperantei. Your participation may be in the form of an interview or in simply allowing us to observe while the nurses from Casa Sperantei administer care.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide not to take part, we will make no further contact with you.

What will happen if I agree to take part?

If you agree to take part, we will accompany the nurses to your home during their usual rounds and be present during the entire visit. If you choose to be interviewed, it will last approximately 45 minutes.

Do I need to fill in any forms?

Before you take part in the study you will be asked to sign a consent form. You will also need to sign copyright release form that will give us the right to publish information from the interview.

Do I have to take part if I have signed the consent form?

You will be free to withdraw from the study without giving a reason, even after you have signed the consent form, for up to two weeks after your interview. After that, the

information you have given me will be included in the study and it will not be possible to separate it out from the rest of the information I receive from other participants. During the interview you may request to stop the recording at any time to discuss or clarify how you wish to respond to a question or topic before proceeding. In the event that you choose to withdraw during the interview any recording made of the interview will be either given to you or destroyed, and no transcript will be kept of the interview. If you wish to withdraw at a later date, the transcript will be returned to you or destroyed and not used in the study. If you wish to place restrictions on the use of some portions of the interview, those portions will be edited out of the final copy of the transcript.

What will happen to the information I give you?

The interview and field notes from the project will be typed up as a transcript. I will listen to your interview and read the transcript and then combine it with the information I have from other interviews. When I have finished interviewing, I will write up the results and publish them in an article or in a book. The publication will provide knowledge about end of life care for children with life-limiting diseases, what their needs are, and how to plan services for the future. The information may also be presented at conferences and meetings. Finally information will be secured archived for the use of other scholars at the University of Glasgow, which will retain exclusive rights to their use.

Will my taking part in this study be confidential?

I will not tell anyone that you are taking part in the study. The interview and any other information you give will be anonymous to everyone except to us. You will be referenced by a case number. All identities will be anonymised in all publications.

All written information – including your consent form, the copyright release form, and the transcript of your interview – will be kept securely in perpetuity in a designated locked cabinet at Hospice History Archives at Glasgow University. All information stored on computers will be accessed only by me using my personal password. The recording of your interview all other electronic data will be will be stored for 5 years and then deleted.

To iterate, your identity will remain strictly confidential. That is to say, names of the participants will not be used in any publication or report that may come from the project.

After the interview

If you are upset after the interview and wish to receive support, please contact:

Oana Predoiu ([oanapredoiu@yahoo.com](mailto: oanapredoiu@yahoo.com)), Hospice Casa Sperantei, Str. Sitei 17A,
500074 Brasov, Romania. Tel. 0721 946200

If after the interview you feel the need to make a complaint this can be done by contacting Dr. Daniela Mosoiu (daniela@hospice.ro), Medical Director, Hospice Casa Sperantei, Str. Sitei 17A, 500074 Brasov, Romania.

Who is doing this research and how can they be contacted?

I am working on my own on this project with the assistance of Oana Predoiu. I can be contacted at:

Dr. Dennis Johnson

Hospice Casa Sperantei

Str. Sitei 17A

500074 Brasov, Romania

My email addresses is:

dljohnson1006@yahoo.com

Appendix C. Consent form

Project title: Pediatric Palliative Care in Romania

Please initial each box

1. I confirm that I have read the Information Sheet for this research study and I understand what it says.

☐
2. I agree to take part in an interview that will be audio-recorded, transcribed, and used for the purposes of this research.

☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time up to two weeks following the interview without giving any reason, without my legal rights being effected.

☐
4. I have had explained to me the purposes of the project and what will be required of me.

☐
5. I have had the opportunity to consider the information and ask questions about the research. I understand that the researchers are available should I wish to ask them further questions about it (contact details are on the Information Sheet). I understand that the recordings and data will be electronically transmitted to dljohnson1006@yahoo.com to preserve their integrity and safety

☐
6. I agree that extract of my interview may be quoted in publications

☐

Name:

Signed:

Date:

Address:

Appendix D. Brasov case mix

Diagnosis	Number of patients	Percentage	
Cancer	23	17	
Cerebral palsy	43	32	
Muscular dystrophy	11	8	
Hydrocephalus	11	8	
Spina bifida	8	6	
Cystic fibrosis	8	6	
Renal failure	5	4	
Congenital heart	5	4	
Spinal muscular atrophy	5	4	
Other	15	11	
Total	134	100	

“Other” included very rare diagnoses such as epidermolysis bulosa, traumatic tetraplegia, postencephalitic tetraparesis, West syndrome, osteogenesis imperfecta, tuberous sclerosis, leukodystrophy, and severe undiagnosed mental retardation (with presumed genetic abnormality). Six cerebral tumors are listed under cancer.

Appendix E. Interview list

Participant	Date interviewed		
Philanthropic founder	2001		
Chief executive officer	2009, 2011		
Medical director	2002, 2009, 2011		
Head pediatrician	2009, 2011		
Head nurse inpatient unit	2009		
Head nurse home care	2010		
Psychologist	2011		
Psychologist	2011		
Social worker	2009		
Social worker	2011		
Day care supervisor	2011		
Day care child	2011		
Web site designer	2011		
Receptionist/coordinator	2011		
Receptionist/coordinator	2011		
Study Center coordinator	2011		
Volunteer coordinator	2011		
Mother and child at home	2011		
Mother and child at home	2011		
Total	23		

Appendix F. Interview with O1 (Coordinator of Children's Day Care Center)

DJ: Tell me a little bit about your background.

O1: Studies, or experience, or everything?

DJ: Everything, I would like to know more about how you came here. Your background?

O1: I studied kindergarten and primary school teaching for 3 years in college. During University I found out about Hospice. I didn't know too much, there was an ad for volunteers and I wanted to help. I came to the course wanting to find out more about the institution before getting more involved. I went to the one week course and decided I wanted to come work with the kids. I had some experience in babysitting healthy children, and then I started at the Day Center. I took about 2 month, the interview and everything. I worked as a volunteer for about 2 and a half years, coming at least 3-4 times/week in the morning, to Day Center. I loved it and was very interested in working here. The person who worked here at that time was excited to have me. So she decided she would give up half of her job so I could be hired as a part timer also. She would be paid less, I would be paid and we would work together. I started University during this job. I worked for another 3 years, during which my colleague went on maternity leave, then came back for 1 year, and I decide I would go abroad. I went to Geneva for 6 months or more. When I came back I got jobs in kindergartens, a foundation, and then came back to the Hospice. I started working again as a play therapist. That will be one year in May 2011.

DJ: So you are full time now?

O1: Yes

DJ: Were you studying in Geneva?

O1: I was working with an 11 year-old child as an au-pair. He was healthy but came from a dysfunctional family. The parents were divorced; the mother was never there, so he needed someone to be attached to. He was fine while I was there, but I think something broke up again there when I left. He was very mad, his mother kept writing and telling me to come back. I came back to Romania because my mother was ill, she had breast cancer. I tried to explain, but he wouldn't understand.

DJ: You were his surrogate mother.

O1: Exactly. And we had a very good relationship. He was nice. He did everything I asked, but I didn't push him into doing them. I asked him and gave him time to do those things. He found it very easy. I was his attachment figure.

DJ: I think it is so wonderful that Hospice has such a talented young woman. It is amazing. Which high school did you go to?

O1: High school was 4 years of holiday and was an agricultural one, so it has nothing to do with this. The teachers never asked me anything. But it helped me choose what I wanted to do. I finished high school as I was very determined to pass the exams at the end and go to University.

DJ: Did it come natural to you to become a teacher and work with children?

O1: I always wanted to work with children because they are exciting and wonderful and always exploring. I feel that we are losing something that they have. They are like a sponge, eager to get as much as they can. I was always intrigued by this. My sister who is 3 years older also went to this university, but just by chance. She didn't want to do that, so went on to study foreign languages. But I had the chance to find out what that university was like, and decided this was what I would focus on.

DJ: It must be hard to work with the children that you work with here.

O1: It is not hard. Everyone thinks this, but once you are past the pity you feel and realize it doesn't help them in any way, they are just children, and young adults. They are people like we are, and have dreams like we do. It is OK just to be there for them. Sometimes it is wonderful to see that just by being there you put a smile on their faces. Perfect in the end.

DJ: Tell me about some of your kids.

O1: I will start with Andrei who is the leader of the group. He is 17 and has muscular dystrophy. He is now at the stage where he only uses his hands, but gets tired very easily. But he has such a strong will that he won't get up. He told me that the worst thing to him is not to go out of the house. It doesn't matter how painful it is to stay in the wheel chair, he is very determined. He is very connected to reality and everything that happens. He does not want to know the actual name of his disease and denies remembering it. He is very good with computers and I don't think he wants to allow himself the chance to look it up on the Internet. It is fine, it is his decision. We think it

will be really tough when he won't be able to come to the Day Center. All the children want to come to the in-patient unit with Andrei. He is a leader, but is very calm. I watched him with younger children. He is unable to manually help them, but he explains everything.

DJ: Does he have brothers or sisters?

O1: She has a younger sister who is wonderful. She does not carry the disease. She is a healthy energetic child . . . the opposite of Andrei, running everywhere, taking everything. If he gets a present, she has to look and pick out what she wants, but he is very supportive of his sister. It seems like they have a good relationship. His father is not home too much; he works on a construction site, sometimes leaves on Monday, and comes back only Saturday. He needs to go out of town. But he is supportive and makes an effort to help the family financially. His mother is lovely and supportive of Andrei and her daughter. She looks after both of them incredibly well. She is calm and creates a good balance that way.

DJ: It sounds like he has a very positive family environment, yet the day care center is really an essential part of her life.

O1: Their actual space is very small, they live in one room and there they made a small space for a bathroom, and an oven. It is very small for four people. It is something like two beds and one computer, and no other space. Being in a wheelchair that takes the rest of the space. This to him is the outside world which he needs to be involved.

DJ: Did he get an education?

O1: Yes, I think 2-3 classes. Age 7 he was already struggling not being able to walk. He fought this disease and didn't accept that he could not walk. If he fell out of the wheelchair he would not call for help, but if someone saw him he would say he was just looking for something on the floor. It was a difficult time for him and he felt ashamed going to school. His mother felt it was OK to go to school for a while and come to the Hospice for the rest of the time. He wasn't able to write and was tired in the wheelchair.

DJ: How did he come here? Did he know about the Hospice? Sick people and Hospice usually means dying.

O1: None of the children think of the Hospice as a place for dying and sick people. To them it is just a different world. Not the sick type. They see there are children like them and are basically focused on the children in their group. They have problems at home but when they come to the Hospice it is a place to socialize in. They don't see the adult ward. Maybe it helps as we don't frequently have children who die. It happens maybe once every other year, and in that case we talk to them and tell them the child got sick and died. Usually we have smaller children who stay in bed most the time and pass away there, but they are not in their groups. I stick with the fact that this is their social group; this is where they feel good. They come to the in-patient unit, they are a group, and they feel fine. They have parties, go out, and stay up late at night, they are happy to come. It is not like downstairs in the adult unit.

DJ: Who is your oldest patient? I saw someone listed in pediatric unit as 38?

O1: She passed away around Christmas. There is a girl who is 27, so 1 year younger than me. She doesn't usually come to Day Center. She was admitted as she had depression problems. Her mother was depressed and the child was using her to do all sorts of things. Both of them needed medical treatment, so we helped the mother to be admitted in a psychiatric unit and we brought the child here. She took part in Day Center activities, but was very defensive. She had a smile on her face all the time, but behind that she was exploring her chances of using people. She was involved in everything we did, but to please me and other people. There was a nurse, who behaved a bit like her mother, brought everything to her and the girl tried to push the limit. The nurses noticed and set some boundaries. The mother is better now, all act as if they are better, and she doesn't want to come to Day Center anymore. I think at home it is easier to keep the image that you shed on other people. We keep telling the nurse who visits them that we will find a way of bringing her here. But it is difficult to carry her; she is very skinny and tall. They live on the third floor. I told her we would find volunteers and make it possible for her to come, but she does not want to. Hopefully they won't end up in the same situation again.

DJ: Do you remember what her diagnosis was?

O1: No, but I can look it up.

DJ: How many children come to the Day Center?

O1: We have 54 who come. There are children who go to normal school and come during holidays when we cover as much as we can of this number. We can cover 20 around the year, and the rest can come during holidays.

DJ: What is your youngest?

O1: Denisa is two.

DJ: And she sits OK with the group?

O1: No, she is not with the group. Usually when they are so young they come with their mother. I invite the mother to stay here and interact with the children. If they are older than three or four, I can work with them. But it depends on the time. I can usually work with them until 10 and from 1:30 PM to 2 PM. Then they go back to the in-patient unit. When they are so young it is difficult to connect to an environment, following treatments in hospitals, it is a big emotional impact to them. It is difficult for them to come. They don't come in the Day Center group; they are just around and play in the spaces I provide them. They are still in the age of egocentrism, playing with their own toys, maybe next to someone, but still with their own toys.

DJ: You developed an interest, you went away, came back. This unit is exceptional, it is probably the only one in Central, Southern and Eastern Europe, and free standing not attached to a hospital. It has survived. The one in Poland and in Budapest didn't survive. I wonder why.

O1: I think it is hard until you create the relationships with the families and children, until they understand what you offer. When families see what they need and connect to

what you offer, I think it is a long way until they can establish that connection. And once that connection is made I think you start on a road and keep going on it. Especially with the children that are not connected with other social environments. We have children from school, who come and still appreciate Hospice although they are in a normal school, they feel it is a safe environment, and feel that even if they have their treatment they are still emotionally comfortable. It is very good for them and good for the family. This feeling of safety of their family and themselves is very important, and keeps the bond between families and Hospice.

DJ: So like a haven for them.

O1: I don't think they hide here. I think they are in a place where they think it is OK to be there. To be themselves and be exactly the way they are. On the outside they are sick, not feeling good, they are maybe in a hospital, in a bed, not actually a person. Here they feel as a complex person, who has feelings and can identify other who has the same problems. They realize they can be the way they are now and live their life still.

DJ: It sounds like this is something that they create themselves.

O1: Yes, I think so.

DJ: What do you offer them? They sense that this is a safe place because it is acceptable to see other people like them. But what are you offering?

O1: We offer explanation for everything. If they need to follow a treatment, we explain why they have to. If they come to the day care center I explain to them why we do

these things, and give them the sense of control. Let them know they are the ones to decide and make the choice. In other places I think choices are made for them, and no matter what they decide, we know better. In other places it is a bit like this: "you need to take this medication because you need to. I am the brilliant one, you are the sick one, and you need to take that". Here we explain to them what the treatments are for, what blood tests are for. In hospitals they don't do this because they don't have time. And I don't blame them. In hospitals you usually have 2 nurses for 20 patients or something like that. You start with one and by the time you've finished with the last one it is time to go home. We explain everything to them and give them time to decide when it is OK to do things.

DJ: You are not a mother to them. How do you think they see you?

O1: A carer. This is how I feel and this is what I project I am. I am here to care for them when they need me, and if they need my guidance, I am here. This is what I feel that they are seeing, and it has been confirmed by a 21 year old boy who looks like a ten year-old, but his needs and desires, sexually, are that of an 18-20 year old. He is interested in girls. My colleagues thought he would like one of them, but I told them that he only sees us as carers. He cares about me, I can see that. He is happy when he sees me, he speaks to his family of me, but he doesn't nurture any other feelings. It is such a big difference; even it is hard to see. He went through a deception with a volunteer that came out of the blue and made him hope. It was a crazy story. He came here and started crying, he was so upset. I was there for him as I felt I needed to support him in his suffering. He was really upset. I was there, and obviously he doesn't

connect me with those types of feelings. I am not his mother with that type of attitude, but I am the person who is here when he needs me.

DJ: But you are not one of them either.

O1: No, I am a carer.

DJ: You care for them.

O1: Yes. I am someone who is around.

DJ: You don't really so much care for them as you care about them.

O1: Yes.

DJ: Part of the objective that leads into things is that the daycare center provides respite for the family. What is your sense about that? Do you get a feeling that that is an important part of progression? Do the parents express their gratitude for that, or is it just something that you read?

O1: It is incredible for the parents. Even if there are parents like Andrei-'s mother who never tell you they are having a hard time caring for their child. She never tells you this. But in the way she thinks when he is in the in-patient unit, you feel she is OK for a week, when she doesn't have to take him to the bathroom, take him out of the wheelchair, wash him, and feed him, and all this that takes a lot of time. She is a small person. And having another child who is healthy, caring for that child, to be safe to be fed, to be loved, and caring for this child with all his complex needs, she will never say she is exhausted. But when he comes to the in-patient unit, during that week you see it

on her face, you see "thank you". We have parents that you don't need to see it on. They say, "Can I have Vlad admitted, please? It is not that I don't love my child; it is not that I feel overwhelmed, but it is so good for me, at least for a week, when I can just get my health straight and not having to worry about his needs. I have needs, too, and just to take care of myself for a little while." We have all kinds of parents who either tell you, or you see on their faces. These are active children who come to Day Center. Then you see children who are in the in-patient unit, and have the aspect of a baby, they don't talk, they have the basic needs, don't usually need another environment, as noise bothers them, light bothers them. Those parents feel overwhelmed. They feel that their child doesn't give anything back. They put so much effort into washing and caring for them, and they don't get any response. It is extremely hard for the mums. They might make a noise when they want to be fed, but that is all. And they are 20 years old or so. It is extremely difficult. You can see it when you are here and you care for them, it is like "thank you God for that week". The impact is big for those parents.

DJ: Of the 50 or so patients that you have in Day Center, most all of them can talk, and are reasonably interactive?

O1: Yes.

DJ: Their intelligence is probably a little bit below normal, do you think?

O1: Yes. So we have children who are 18 and are at the intellectual age of about 6-7. Those who are stuck somewhere are usually stuck at the age of a 6-7 year old. We

have children who are normal for their age, but they have speaking difficulties. You just have to wait patiently until they tell you what they want. We have 2 children who only interact through body language, they don't speak. They smile when they see you, they grab your hand, they throw things on the floor to see if you are attentive?

DJ: You have tremendous sense of what is going on and great human sense, intuition, I think. I admire that. How do you think that they would feel about me being here and watching them? How would you feel about that?

O1: I think it would be OK, but I don't know how you could get involved into doing things with us. They are not used to having someone just watch them, they are used to people coming from the outside and doing things with them. Not doing much, but sitting at the table with them, and not somewhere in the back, just watching. I always say to volunteers, don't stay behind them and talk to them. It is very difficult for them, they are not able to turn around and see the conversation. All the time when they are in a wheel chair it is difficult to have someone behind their back, not like a threat, but the impact is still very big. I encourage people to stay in their eyesight so they can see you. When someone is here they know that they are here, even if they are unable to see the person. I always tell them when new people come why they are there, how long they are staying, what they will do. I always encourage people to stay with us even if they interact just a little bit, helping and giving a child a pen. But they are in our group. I think they would understand that it just involves observing without harming the child. They would understand that you would observe and get to know the children, and put everything together into a paper. I think it gives them a sense of it being OK.

DJ: Do any of the nurses speak English?

O1: I think T who is a nurse in home care.

DJ: I think some of them can understand a few things.

O1: Yes, D1 understands, but it is difficult for her to speak.

DJ: I interviewed her couple of years ago and we needed an interpreter. I wonder how the nurses would feel about doing the same in the in-patient unit, just observing and helping out.

O1: I don't know for that you need to speak with D1, because that is the space that she is responsible for.

DJ: Would you do me a favor and mention what I talked to you about? Otherwise it will be easier for you to talk to her than interpret what I am saying.

O1: Would you like me to go and speak to her now and give you an answer?

DJ: I would

O1: OK.

Appendix G. Ethnographic observation during homecare visit

May 11, 2011

T, C, (pediatric social worker), and I headed out of the hospice parking alley in our white Dacia emblazed with HOSPICE. C apologized profusely for not speaking English, but she is quicker to pick up what I'm trying to say than T. She is a jolly woman with curly auburn hair who reminds me of a female Friar Tuck. Her smile takes in her whole broad face. Though she is relatively young, she has a big motherly, loving appearance. As C1 said, "She is one of those people that is bigger than life!" She laughs heartily at her 'poor' English language skills, but her face became very still and serious when she told me that being a social worker for these Roma families was a never-ending job – there was always another problem.

We picked up a Roma woman and her daughter at a bus stop (she had come to town to have her daughter's vision checked) because C was helping her fill out some papers (forms) to make the family eligible for 'social' housing and to renew her daughter's certificate of disability. She, her husband, their normal four year-old girl, the 15 year-old girl patient, and their seven year-old boy live and sleep in the one-room house that is owned by the 'family'. The family is planning to sell the house, and then they will have no place to live. The woman and child had come to Brasov from their village by bus, and we gave them a ride back home.

On the way, we stopped at the curb where C had arranged to meet a mom to give and explain some 'papers' – an application for a wheelchair. While C was discussing the forms, T explained that C's driver's license had been suspended for a month because

she had passed another car over a solid line (with the police watching). We carried on out of Brasov until my count of horse-drawn wagons outnumbered the count of cars on the road.

We pulled off the dirt road near the gate to their home, and the mom climbed up a laddered cement telephone pole to crawl over the fence . . . because the gate latch was broken and could not be opened from the outside. The dirt yard was cluttered with discarded debris (a child's shoe, broken toys, bottles, et cetera). A dog and an enthusiastic puppy met us at the gate. Up in the corner of this 40'X30' yard was a small shed which contained three pigs ("one to eat for Christmas, one to sell, and one to keep for next year").

The inside of the house (a 100 ft² space) was also cluttered but clean: wood-burning cook stove, a table with a few dirty dishes, two cabinets, a double bed, and a smaller bed/sofa. Mom kept her 'files' on top of one of the cabinets in a shoe box which she reached by climbing up on the arm of the sofa.

I couldn't see or find the 'child' at first because she was on the bed against the wall covered over by a comforter. She cannot sit or walk, talk, see, or chew – mom feeds her very slowly with a spoon. G1 is 15 years-old and was normal until she received polio vaccination at age five. She lapsed into a 'coma' and was hospitalized for three months. Mother stayed in the hospital with her for the entire three months. The father did not visit and showed no interest. They divorced. Her current husband is "very good" with G1 and is the father of her other two children. He is technically unemployed but is able to find a job in the village nearly every day. When I provocatively asked T and C why

the mother hadn't abandoned her child, they both looked at me aghast and almost in unison said, "But she's her child!" When I explained to T that I was told that most Roma families abandoned impaired children, she told me she would explain later.

When I asked mom what hospice meant to her, she responded by saying "Everything . . . I cannot express well enough how much it means to me." Then she began to cry and smile at the same time . . . with the four year-old climbing up into her lap and trying to comfort her by snuggling and stroking her chin. She went on to talk about the hospice Christmas party where all the children received gifts, even the siblings. It was a year that the presents were the only gifts that they received. "They care about all the children!"

We carried on to our next visit . . . but slowly because the condition of the road deteriorated into more holes than road. We went from one side of the road to the other trying to miss the bigger holes. Several 'house trailers' or more accurately house wagons in poor repair were scattered along the side of the road – about 20 horses were grazing on the lush green grass alongside a river; two men were pulling some discarded metal out of the river (which they commonly sell for 'scrap metal'); and another was walking with a long fishing pole along the bank.

We were welcomed at the gate by the girl patient and her mother, who then busily ushered us into her uncluttered two-room home. She quickly found a stool for me to sit on and promptly covered it with a little red cushion. She is a small, energetic, wiry young woman. The house was clean but clearly 'worn'. The wall around the wood cook stove in the corner was yellowed from heat and soot covered much of the ceiling of the

big room – more concentrated over the stove. A six-to-eight inch hole was visible in another corner of the ceiling. The wall behind the sofa bed was adorned with four or five religious iconic pictures. An old pair of faded, high-topped orange sneakers lay under a small table next to the sofa bed – the only parts that remained orange were the heels. The floor was covered by a red rug which partially concealed an 18-inch diameter crater just in front of the sofa/bed. The window dressings and the curtain about the entrance were spotlessly clean, white, with eye-catching needle work. The shelves in the closed cabinet were also fronted with the same smart dressings. She kept her 'papers' in a plastic bag in the cabinet. C needed pictures of her children (to complete her application for housing), which she was able to find without hesitation. The plastic bag also contained the torn up envelope and papers that documented her account at a bank. She cannot read or write and had opened the account so that her stipend (she receives a stipend to care for her child) could be deposited directly in the bank and that she could be issued an ATM card. Her husband had torn it up when he discovered it. C sifted through the torn bits of paper with an unusually flat expression on her face. The husband is an alcoholic and would go with her when she picked up her check from the town hall; he would spend the money on alcohol. For a while in the past she lived with her parents in another village, but when she came to pick up her stipend, he would be there waiting for her (and the stipend). By having a debit card, she could get her money at any ATM.

The child patient is in remission from Hodgkin's lymphoma and sat brightly and politely next to her mother. They had been informed about hospice by the oncologist here in

Brasov. She can stay enrolled with hospice until she has been in remission for five years. The child patient and her mother happily recounted attending the hospice-sponsored summer camp on the Black Sea last summer – especially the girl: her eyes widened; she smiled broadly; and she jumped in her seat. For the first few days of camp the mother was withdrawn and could not speak to anyone. Then she gradually began to smile and open up. T remarked that the mother has been badly traumatized and is very fearful.

The purpose of the visit is 'social': six of the mother's seven daughters have been placed in an orphanage ("orphanage – but not those big ones we used to have with hundreds of children") because the father abuses the mother and the children. The abuse was discovered or exposed by the children's hospital where one of daughters was taken with frost-bitten feet after staying out in the winter snow with her mother after she had been beaten, slashed across the face with a knife, and thrown out of the house. The prosecution of the father has been ongoing for three years; meanwhile there is no restraining order to keep him out of the home. The home belongs to the husband's grandmother, and the wife has no place to go. Assuming the father will be convicted, she will likewise be homeless. Application for social placement is being made so that the mother can get all her children back and have a place to live. The mother's allowance for caring for her disabled child must be renewed every year. The entire application process must be repeated.

As we got back into the car, I commented on the level of poverty . . . to which C responded, "Poverty? Our next stop will show you real poverty."

As we carried on down the 'road' I pointed out what appeared to be a shanty town in the distance and asked, "Is that where we are going?" They responded, "Yes, indeed, that is a Roma village". I was struck by the number of people that were out on the road, and I saw a man-drawn, four-wheeled wagon for the first time – the big man was not harnessed but stood in the usual place of a horse and pushed against a cross bar. This size of cart would normally be pulled by one or two horses.

Each home and small yard was separated from the next by some assorted metal partitions – giving me the appearance of a kennel. The alleys between blocks of 'pens' were unusually narrow but allowed passage of our little Dacia.

At our first stop the boy patient was in the children's hospital with a 'liver problem'. With a diagnosis of cerebral palsy and epilepsy, his seizure frequency had increased, and he had been vomiting. The mother alerted C, and a nurse visited the home to find the child patient to be dehydrated and in need of intravenous fluids. She called an ambulance for him to be taken to the hospital. Anyone can call an ambulance – they are free.

The clutter in the yard gave way to a very neat two-room home which was attractively and colorfully appointed. A four year-old daughter was eating some sort of pudding with a spoon while we talked; when she dropped the spoon on the floor, the mother quickly scooped it up and put it in the sink. A picture of the boy patient was hung on the wall next to a wedding picture of his parents. The mother and father were very welcoming and well-dressed. Even though she was smiling, mom expressed some anxiety or nervousness over my presence and explained that she hadn't had enough

time to clean the house. Mom was very tearful in explaining that the doctor didn't tell her what was wrong with her son – she was visibly comforted by T explaining that it would take some time to figure out what was wrong. I purposefully did not ask to record the conversation because of her anxiety. She apologized that she would need to leave soon for work – she works an early morning and an evening eight-hour shift.

The purpose of the visit is to initiate application for a wheelchair – an application process that takes six months before the chair company can even fit the child. His certificate of disability is also due to be renewed. Again, teary-eyed, she expressed her appreciation for hospice – especially of the field trip to the Black Sea last year. The parents demonstrate a lot of fondness and affection for these two workers. An older son was at school instead of at home. During our excursion, C made a phone call to and received another from the social worker managing this child's case in the children's hospital. "We work together but the networking is not always good – sometimes fragile".

The last visit was a little less inviting: dad showed us in from the gate, explaining that the dog that was on a cable in the yard would not bite. (T has been bitten by a dog and was actually pulled to the ground, only to be saved by C, who beat off the dog with her purse.) The father disappeared when we entered the home. An adolescent boy was watching a game of soccer on TV but kept his attention trained on us. The mom, who appears to be in her 40's, was holding a small boy with cerebral palsy. Another wheelchair application is being made. Dad was standing out in the alley with some other people clustered around the car. C spoke briefly with him before getting back into

the Dacia (sometimes the clerks at the Insurance House refuse to take applications from social workers and insist that a parent come – she was telling him that she would try to submit the application but that he might have to go himself)

T expressed concern that they were putting themselves in physical danger whenever they enter this village – a village that had a reputation of violence and thievery. No one from hospice has ever yet been accosted or harmed. However, a package of diapers had been taken from a nurse's car – which had been left unlocked while she was seeing the patient.

The processes that stood out today were advocacy and crisis intervention. This was a routine day for these two workers, but three of the five families were in crisis.

Appendix H. Ethnographic observation in Children's Day Care Center

April 28, 2011

C3 (age 19), A (age 17), V1 (age 16), V2 (age 15), M4 (volunteer), an aide, O1, and myself were present on another fine day. Vali has advanced muscular dystrophy: he can move his fingers slightly but they are non-functional. The kitchen aide fed him at lunch. He had a slight cough after lunch; his head tends to loll to the left side – worse at the end of our day. By O1's account he does not receive much attention at home. A younger brother is very active in sports and school, and an older sister is severely mentally and physically impaired – requiring complete care. Mother manages the home and is overwhelmed; father works and is seldom there. Weight loss has been dramatic in the last 3 months.

C3 arrived first and was given a puzzle to piece together. He smiled at me, and I managed to find a piece or two. Vali was the last to arrive – with a flat expression on his face when he looked at me. O1 tells me that he is 'shy' about new faces and does not invest a relationship in volunteers who don't seem to be 'keepers' (i.e. stay very long).

Everyone was smiling and/or laughing – O1 is ostensibly fond of all of them. All of the boys participated in the discussion of where we are to walk today. During the discussion A used the top of the puzzle box to scratch his head and orbits . . . or just something with which to diddle.

Our excursion took us to an upscale four-story department store: we walked every aisle on every floor, moving from one floor to another via a three-wheelchair elevator. There were several book kiosks in the store; we would stop at each kiosk and sometimes look through some of the bigger pictured books. Three female clerks gave us polite smiles. The boys seem completely oblivious to passersby.

A was particularly curious and interested and asked questions about the merchandise non-stop. At one point he jokingly said, "Let's catch the escalator!" All the boys know their limits in terms of safety in the wheelchairs, and they will often caution the 'driver' (especially if they are new) to back down curbs or to slow down. A knows the limits but shows no fear; he is very bright and can speak some English – wants to know and see as much as he can. When he was six years old, a 'new' four year-old boy with muscular dystrophy was introduced to his group. A commented, "He won't need a chair for a while." As his disease has progressed, he has expressed no sense of doom, hopelessness, or anger. Andrei likes to keep his fingernails long because it gives him a little more 'reach' and purchase with his fingers. He is very adept at moving a spoon or fork into a functioning position. 'Seeing' was the process rather than 'wanting'. And they were also 'doing' instead of watching (moving, through doors, up and down elevators)

V1 was particularly excited and animated – especially when recounting the things he saw and the elevator rides.

C3 (with me as the driver) was more interested in maintaining contact with other members of the group – a people-person.

Companionship vs. loneliness

Friendship vs. aloneness

Exposure vs. isolation

Change vs. stasis

Excitement vs. dullness

O1 is a tiny, vivacious, attractive young woman, and the boys seem to adore her. She is a bit of a light bulb in a darkened room; when the light is turned on there is excitement about the light. But then the light is taken for granted, and that's when companionship and friendship predominate.

There is also a process of discovery (boys keep track of where they have been and where they have yet to go) which is why the outings are so important; the element of sharing is shown in O1/A exploration of books and showcases . . . as well as with V1 recounting the day's activities.

Appendix I: Ethnographic observations in inpatient unit

May 23, 2011

The PPC 'team' was meeting in the Children's Day Care Center when I arrived. What could look like little parcels were left in each bed of the main patient room; another child was left in a four foot-high play pen in the smaller patient room. A gypsy mother and her child were also in the smaller room; mother's clothes are in bright colors and her little girl colorfully dressed with large red and white cotton balls in her braid hair and with multiple brightly colored layers. The only other parents present are the father and mother of H who were just dropping him off (Dad carried him in). Dad was wearing calf-high green rubber boots but not dressed like a farmer. C2 listened intently to Dad; they chatted for about 5 minutes; and he left. Mom also then chatted with C2 with a look of concern on her face; the look of concern gradually turned to a smile before she left (presumably separately).

Charts for the patients are all laid out on the nurses' station. No chairs were in the nurses' station, so I pulled a free-standing chair from D2's office (just in back of the station with the door open) and wrote some notes at the desk. Andrei and a volunteer were waiting at the couch where I usually sit. It is hard to find a sound chair in hospice; most of them are 'donations', i.e. discarded to hospice. This chair is one such unsound chair suspended on a prayer. The first person out of the conference room was Chief Nurse, followed by other nurses (D1, C4, and J), D2, C (pediatric social worker), pediatric home care nurse, and the aides. O1 stayed in the room to welcome her first day care boy Andrei and the female volunteer.

The tempo gradually picked up as D2 donned a smock and began examining children.

The three nurses were close by, either watching, multi-tasking, or helping with the child being examined: e.g. undressing the child and holding the child up while D2 auscultated the back. D2's routine included the abdomen, the skin showing, the abdomen, back, arms, legs, throat and neck. It did not include the eyes, ears, or genitalia.

In the first bed was a three year-old girl with microcephaly and cerebral palsy but no seizures. She and her older brother (who was also admitted) are both orphans. First thing this morning she was crumpled up on her side in the corner of crib. As we were tending to H's fussing, I turned around to see this little monkey-like child half standing, gripping the rails with both hands, peering through the rails with large ears and small eyes, and one leg beyond the rails – but still soundless. She did not shy to or startle to touch and was semi-cooperative to examine – more wiggly and squirmy than resistant. The immediate management issue is severe interphalangeal maceration from sucking the second, third, and fourth digits of the left hand. Her clothes are clean and without unpleasant odor.

The second bed lodges a 13 year-old boy also with microcephaly and cerebral palsy, but he also has controlled epilepsy. He turns expectantly to sound, motion, or people and smiles whole-mouthedly. His palate is arched high; his gums are hypertrophic; and his teeth appear as little stumps in a clear-cut forest. He has the appearance of a baby bird waiting to be fed – with his head extended and his mouth opened unusually wide. His face, arms, and legs are sun-burned from the weekend. "Some parents just don't have good sense." (J, nurse in blue) Last week he developed urinary retention and infection

associated with phimosis, so part of the inpatient management is stretching the foreskin over the glans. Of course his sunburn will be treated gently with lotion. He is fed by mouth with a syringe. Half of each small syringe-full is pumped back out of the corner of his mouth – to be swept back in by the attentive nurse.

The 11 year-old boy in the third bed is the least expressive of the group: blind, brown eyes wide open and not wandering, but expressionless; turns to sound but not to light or motion. His seizures are controlled and his spastic paraparesis attributed to encephalitis. The flexor posturing of his arms is used to his advantage: he has the habit of pushing his fingers into the back of his throat until he gags and vomit. His flexor posture is held by pulling his pajama bottoms up over his elbows and then tying his empty pajama arms around as a sort of belt – effectively though gently restraining his arms and hands. Although nutrition is an issue for every one of the room's occupants (except H), none of them appears skeletal.

In room two, the first bed is taken up by the four year-old brother of the girl in the first bed of the main room. He is very active and cannot be contained in a crib, so he occupies a four-foot-high play pen from which he cannot see 'out'. He pulls to stand but cannot walk; he raises himself up into a crawling position because his legs below the knee remain flexed (on his 'hands and knees"); he can attend to caregivers but is also busy with everything else. He shares his sister's diagnoses but not the interphalangeal maceration. His constant activity is frequently punctuated by self-stimulatory activity (for example, rhythmic movements of his pelvis and back, turning his head back and forth). He is a mouth-breather, much the same as his sister and the boy in bed two.

According to the medical staff, these children don't get much attention at the orphanage. Stimulation is part of the service that will be provided here.

The second bed is occupied by a ten year-old Roma child and her mother. The child has an unidentified genetic disorder (by D2's admission) characterized by severe developmental delay, dextrocardia, and ichthyosis. The Roma village that they live in includes about 1000 people; several cases of congenital heart disease, cystic fibrosis, and Down's syndrome also come from that village. The child is dressed colorfully in multiple layers. Red and white cotton balls adorn her braided hair. Her mother presents herself in a flowered red dressing gown with her hair back in a pony tail (tied by colorful curly strings); she wears no make-up. She is attentive and respectful. All of their belongings are well-organized at the bedside. The child's skin will be treated with more lotions, and she will receive some kinetotherapy.

J was explaining a difficulty with one child and apologized for her 'poor English'. I commented that I was more interested in what was in her heart. To which she responded, "I feel it is there every day!"

Everyone seems intent on keeping the doors closed.

These three nurses are somehow my favorites. D1, the head nurse, almost always wears red in some part of her apparel and has a small bandanna around her neck; she has one darkened tooth in her smile. Her movements are graceful, and her conversation is quiet and measured. C2 is the public face of the unit: a kind, 'open' face with listening eyes; she could be nurse to a queen. And then there is J: light blue

smock and pants, straight shoulder-length hair, two pairs of low-fashion spectacles, and gray-green eyes that seem almost mischievous. I watch her stand off to the side watching the children in the day care center laughing and smiling; I see her at the bedside with D2, more intense and inquiring than the others; I watch her don rubber gloves, crouching to stalk a child with loaded diaper in a stroller like a lioness about to pounce on her prey (for the child's benefit of course).

There is plenty of light here without the bulbs.

I returned to the inpatient unit at about five PM. One nurse and one aide were on duty. A housekeeper was busy washing the floors and a teenage female volunteer was casually looking at the montage of picture on the wall. A pediatric home care nurse was waiting for a ride and just 'hanging out'. She has never been outwardly friendly nor even acknowledged me. However, this evening she asked, "Dennis, do you have any questions?" as she sat at the nurses' desk. Such a late breakthrough!

All of the children were quiet in the main room – all seemed to be 'resting' including H, who was curled up on his left side (with his blind eyes still open). The activity level increased with the aide asking the homecare nurse about the child's macerated hand and the applied splint. The splint seems to be less than a perfect solution. H and the orphaned girl were roused out into the day care center, where they stayed with the inexperienced volunteer for about 20 minutes. H seemed irritable so the red-haired aide (reminiscent of a spark plug) brought him back to his bed. He continued his irritability until the nurse and aide double-teamed him with attention – he received some medication and juice by nipped bottle, and the aide lay on the bed with him talking to

him soothingly and rubbing his legs. The orphaned girl was brought back into room and parked in her stroller, and the volunteer took a seat in the corner behind bed two with her hands in her lap offering a spirited nervous smile. She has trouble engaging these children – maybe her first time.

My walk from my residence at the Study Center to the Hospice is about an eight km round trip and takes me through the town center which is the main on-foot human thoroughfare: nice shops and restaurants with canopied tables in the streets, tattoo parlors, ice cream vendors, and street singers. There are many young fashionable couples walking hand and hand, small groups of young men and women 'strutting their stuff', older well-dressed and well-kitted older tourists, prostitutes, regular people passing in the process of their day, two Roma men checking the change box of a telephone booth, groups of school children, a very young Roma woman carried a child and followed by two others looking for 'something', a female Ronald McDonald clown twisting long, narrow balloons into imaginative shapes, a 30ish Roma woman begging subtly of a waiter through the decorative bushes surrounding an outdoor restaurant, an impossibly tall, dark, large, bricked church with sloping tiled roof, an old man begging with outstretched hand from tourists sheltered under canopies, pigeons of every mix of shades of white, brown, and black/gray swarming over bits and pieces of ubiquitous pretzels, and finally a fashionably dressed (new, expensive-looking, decorated, tightly-fitted jeans) woman and her apparent teenage son rummaging through a pile of discarded clothing and trash on the corner of a back street . . . stuffing their finds into a

large plastic bag (also I walked by the same spot later and found the plastic bag half full still in the same place).

Here are layers of vulnerability. Tolerance is one thing – quite separate from acceptance.

REFERENCES

ACT/RCPCH (2003), *A guide to the development of children's paediatric palliative care*, London: ACT/RCPCH.

ACT (2008), *Children's Palliative Care: Descriptions and Definitions*, London: ACT.

Ahmed, S. (2004), *The Cultural Politics of Emotion*. New York: Routledge.

American Academy of Pediatrics, 1992. The Medical Home: Ad Hoc Task Force on Definition of the Medical Home. *Pediatrics*, p. 90:774.

Anon. (1988), *Behind the Big Red House: The Story of Helen House*. Oxford: Helen and Douglas House.

Anon. (1998), *The Corner-stone Poznan Declaration*. [Online]

Available at: <http://www.oncology.am.poznan.pl/ecept/declaration.php>

[Accessed 29 December 2012].

Anon. (2003, 2004, 2005, 2007, 2008, 2009, 2010), *Annual Report Hospice Casa Sperantei*. Brasov: Hospice Casa Sperantei.

Anon. (2005), *Project Appraisal Document on a Proposed Loan in the Amount of Euro 110.0 Million to Romania for a Judicial Reform Project*, Geneva: The World Bank.

Anon. (2008), *Pediatric Palliative Care Task Force Final Report*. [Online]

Available at:

<http://www.dpw.state.pa.us/Resources/Documents/Pdf/Publications/PPHCReport/00->

ExecutiveSummary.pdf

[Accessed 10 August 2010].

Anon. (2010), *ACT Newsletter*. [Online]

Available at: www.act.org.uk

[Accessed 10 July 2012].

Anon. (2010), *Global Integrity: Independent Information on Governance & Corruption*.

[Online]

Available at: www.globalintegrity.org/report

[Accessed 14 August 2011].

Anon. (2010), *WHO Definition of Palliative Care*. [Online]

Available at: [Http://www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/)

[Accessed 2010 August 2010].

Anon. (2011), *American Academy of Pediatric Family-Centered Medical Home Overview*.

[Online]

Available at: www.medicalhomeinfo.org/abkout/medical_home/

[Accessed 24 July 2012].

Anon. (2011), *Report from the Commission to the European Parliament and the Council:*

On Progress in Romania under the Co-operation and Verification Mechanism, Brussels:

European Commission.

Anon. (2012). *Internet World Stats: Usage and Population Statistics*. [Online]

Available at: <http://www.internetworldstats.com/stats.htm>

[Accessed 18 October 2013].

Anon. (2012), *Life Force -- Pediatric Palliative Care Team*. [Online]

Available at: <http://www.islingtonpct.nhs.uk/>

[Accessed 2012].

Anon. (2012), *Life Force Referral Form*. [Online]

Available at: <http://www.camden.nhs.uk/gps/palliative-care>

[Accessed 4 July 2012].

Anon. (2013), *Ex Aequo Et Bono, Law & Legal Definition*. [Online]

Available at: <http://definitions.uslegal.com/e/ex-aequo-et-bono/>

[Accessed 2013].

Anon. (2013), *The Medical Home*. [Online]

Available at: <http://www.medicalhomeimprovement.org/>

[Accessed 2013].

Anon., n.d. [Online]

Available at: [www.togetherforshortlives.org.uk/about/who we are](http://www.togetherforshortlives.org.uk/about/who_we_are)

[Accessed 18 October 2013].

Baba, M. & Hain, R. (2012), *Pediatric Palliative Care in the United Kingdom*. In:

Pediatric Palliative Care: Global Perspectives. London: Springer, pp. 269-298.

Bacon, F. & Loewy, B. (1628), *The Works of Lord Bacon: Philosophical Works*. London: Henry G. Bohn, York Street.

Berg, B. (2004), *Qualitative Research Methods for the Social Sciences*. New York: Pearson Education, Inc.

Bernstein, R. (1991), *The New Constellation: The Ethical-political horizons of Modernity/postmodernity*. Cambridge: MIT Press.

Bhaskar, R. (1978), *A Realist Theory of Science*. London : Harvester.

Bhaskar, R. (1999), *Roy Bhaskar Interviewed* [Interview] ([The following interview was originally published in Issue 8 of The Philosophers' Magazine (TPM) as well as <http://www.philosophers.co.uk/current/bhaskar.htm> 1999).

Bhaskar, R. (2009), *Roy Bhaskar: Transcendental Realism and the Transitive and the Intransitive* [Interview] (2 February 2009).

Birkmeyer, J. et al. (2003), Surgeon volume and operative mortality in the United States. *N Engl J Med*, Volume 349, pp. 2117-2127.

Bluebond-Langner, M. (1978), *The Private Worlds of Dying Children*. Princeton, New Jersey: Princeton University Press.

Borland, S. & Groves, J. (2012), 'You can't teach people compassion': PM hits back as *Strictly's* Arlene Phillips says nurse ignored dementia patients. [Online]

Available at: PUBLISHED: 16:01 EST, 25 March 2012 | UPDATED: 18:24 EST, 26 March 2012 <http://www.dailymail.co.uk/health/article-2120256/Cameron-doubles-funding->

[dementia-research.html](#)

[Accessed 22 January 2013].

Bourke, J. (2005), *Fear: A Cultural History*. London: Virago Press.

Bowling, A. (2005), Quantitative social science: the survey. In: *Handbook of Health Research Methods: Investigation, Measurement and Analysis*. Maidenhead: Open University Press, pp. 190-214.

Brill, S. (2013), Bitter pill: How outrageous pricing and egregious profits are destroying our health care. *Time (Special Report)*, 4 March, pp. 14-55.

Brooks, D. (2011), The Limits of Empathy. *New York Times*, 30 September, p. A21.

Byock, I. (1994), When suffering persists. *J Palliat Care*, Volume 10, pp. 8-13.

Callahan, D. (1993), *The troubled dream of life: living with mortality*. New York: Simon & Schuster.

Carter, A. (2001), *The Political Theory of Global Citizenship*. London: Routledge.

Cassell, E. (1991), *Nature of Suffering and the Goals of Medicine*. New York: Oxford University Press.

Centeno, C., Clark, D., Lynch, T. (2007), *EAPC Atlas of Palliative Care in Europe*. Milano: IAHPC Press.

Centeno, C. et al. (2013), *EAPC Atlas of Palliative Care in Europe 2013*. Full Edition ed. Milan: EAPC Press.

Charmaz, K. (2006), *Constructing Grounded Theory*. London: SAGE.

Chester, B. (1998), The privilege of working with children faced with death: An interview with Barbara Sourkes. *McGill Reporter*, 23 April, p. 1998.

Clark, D. (2005), *Cicely Saunders: Founder of the Hospice Movement*. Oxford: Oxford University Press.

Clark, D. & Wright, M. (2003), *Transitions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia*. Buckingham: Open University Press.

Cochrane, H., Liyanage, S. & Nantambi, R. (2007), *Health and Care Partnerships Analysis*, London: Department of Health UK.

Cole, T. & Carlin, N. (2009), The suffering of physicians. *Lancet*, 374(9699), pp. 1414-1415.

Colwill, J., Cultice, J. & Kruse, R. (2008), Will generalist physician supply meet demands of an increasing and aging population?. *Health Affairs*, Volume 27, pp. 232-241.

Cooley, W. (2004), Redefining primary pediatric care for children with special health care needs: the primary care medical home. *Curr Opin Pediatr*, Volume 16, pp. 689-92.

Council on Pediatric Practice (1967), Pediatric Records and a "medical home". In: *Standards of Child Care*. Evanston, Illinois: American Academy of Pediatrics, pp. 77-79.

Craft, A. & Killen, S. (2007), *Palliative Care Services for Children and Young People in England*, London: Department of Health.

Crowe, D. (1995), *A History of the Gypsies of Eastern Europe and Russia*. New York: St. Martin's Press.

Crowe, D. (1997), The Roma Holocaust. In: *The Holocaust's Ghost*. Edmonton: The University of Alberta Press, pp. 179-202.

Cummings, J. & Bennett, V. (2012), *Compassion in Practice: Nursing, Midwifery and Care Staff, Our Vision and Strategy*, London: Department of Health, National Health System, Commissioning Board.

Dangel, T., Fowler-Kerry, S., Karwacki, M. & Bereda, J. (2006), An evaluation of a home palliative care program for children. *Ambulatory Child Health*, Volume 6, pp. 101-114.

Davies, R., 2010. *Community Children's Nursing Provision*, openlibrary.org: Open Library.

Davis, K., Schoen, C. & Stremikis, K. (2012), *Mirror, Mirror on the Wall: How the Performance of the US Health Care System Compares Internationally, 2010 Update*, New York: The Commonwealth Fund.

Donnelley, J. et al. (2005), The needs of children with life-limiting conditions: A healthcare-provider-based model. *Am J Hospice & Palliative Medicine*, Volume 22, pp. 259-267.

Doyle, D., Hanks, G. & MacDonald, N. (1998), Introduction. In: *Oxford textbook of palliative Medicine*. Oxford: Oxford University Press, pp. 1-8.

Dunn, G. & Johnson, A. (2004), *Surgical Palliative Care*. Oxford: Oxford University Press.

EAPC Pediatric Taskforce (2007), IMPaCCT: Standards for paediatric palliative care in Europe. *European Journal of Palliative Care*, pp. 14:2-7.

EAPC Task Force for Palliative Care in Children (2009), *Palliative Care for Infants, Children, and Young People: The Facts*, Padua, Italy: Fondazione Maruzza Lefebvre D'Ovidio Foundation.

Elder-Vass, D. (2007), Re-examining Bhaskar's Three Ontological Domains: The Lessons from Emergence. In: *Contributions to Social Ontology*. New York: Routledge, pp. 160-16.

Ewing, G. et al. (2004), Recruiting patients into a primary care based study of palliative care: why is it so difficult?. *Palliat Med*, Volume 18, pp. 452-9.

Ferreira, L. (2010), *Children's Project on Palliative/Hospice Services: Hospice Association of the Witwatersrand Pediatric Palliative Care Program*. [Online]

Available at: http://www.nhpco.org/files/public/chipps/chipps_issue21_nov-2010.pdf

[Accessed 10 July 2012].

Feudtner, C. et al. (2007), Shifting place of death among children with complex chronic conditions in the United States, 1989-2003. *JAMA*, Volume 297 , pp. 2725-2732.

Fielding, N. & Fielding, J. (1986), *Linking Data*. London: SAGE.

Field, M. & Behrman, R. (2003), *When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*. Washington, D.C.: The National Academies Press.

Fonseca, I. (1995), *Bury Me Standing: The Gypsies and Their Journey*. New York: Vintage Books.

Foucault, M. (1994), The Subject and Power. In: *Michel Foucault: Power, The Essential Works of Foucault 1954-1984*. New York: The New Press, pp. 328-348.

Fox, E. (1986), Medicine is a humanity. *West J Medicine*, Volume 145, pp. 553-554.

Fraser, A. (1995.), *The Gypsies (The Peoples of Europe)*. London: Wiley-Blackwell.

Gallagher, T. (2005), *Modern Romania: The End of Communism, the Failure of Democratic Reform, and the Theft of a Nation*. New York: New York University Press.

Gladwell, M. (2002), *The Tipping Point: How Little Things Can Make a Big Difference*. New York: Back Bay Books.

Goldman, A., Beardsmore, S. & Hunt, J. (1990), Palliative care for children with cancer - home, hospital, or hospice?. *Arch Disease Childhood*, Volume 65, pp. 641-643.

Goldstein, J. (2001), *Console and Classify*. Chicago: University of Chicago.

Grbich, C. (2007), *Qualitative Analysis: An Introduction*. London: SAGE.

Grinyer, A. (2009), *Life after Cancer in Adolescence and Young Adulthood*. New York: Routledge.

Grinyer, A. (2012), *Palliative and end of life care for children and young people: Home, hospice and hospital*. Oxford: John Wiley & Sons, Ltd..

Grinyer, A., Payne, S. & Barbarachild, Z. (2010), Issues of power, control and choice in children's hospice respite care services: a qualitative study. *International Journal of Palliative Nursing*, Volume 16, pp. 505-10.

Hancock, I. (1997), *Ceausescu's Master Race and his Gypsy 'Robot Work Force'*.

[Online]

Available at: <http://www.geocities.com/Patrin/robotwork.htm>

[Accessed 29 September 2009].

Hancock, I. (2002), *We Are the Romani People*. Hertfordshire, UK: University of Hertfordshire Press.

Harding, R., Sher, L. & Albertyn, R. (2010), *The status of paediatric palliative care in sub-Saharan Africa: an appraisal*, London: Kings College.

Hawley, B. (2010), Pediatric palliative care and hospice: Pennsylvania's model of collaboration. *Pediatr Nurs*, Volume 36, pp. 61-5.

Heath, J. et al. (2010), Symptoms and suffering at the end of life in children with cancer: an Australian perspective. *Med J Aust*, Volume 192, pp. 71-75.

Heckler, T. et al. (2008), Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. *Klin Padiatr*, Volume 220, pp. 166-74.

Holloway, I. & Wheeler, S. (2009), *Qualitative Research in Nursing and Healthcare*. London: Wiley-Blackwell.

Holt, E. (2010), Romania's health system lurches into new crisis. *The Lancet*, Volume 376, pp. 1211-1212.

Homer, C. et al. (2008), A review of the evidence for the medical home for children with special health care needs. *Pediatrics*, Volume 122, pp. 922-937.

Hospicjum Cordis (2012), *History Hospicjum Cordis*. [Online]
Available at: <http://www.hospicjumcordis.pl/pl/cordis/historia/>
[Accessed 8 July 2012].

Hospicjum Cordis (2012), *Our doctor Jola*. [Online]
Available at: <http://www.hospicjumcordis.pl/pl/cordis/nasza-doktor-jola/>
[Accessed 8 July 2012].

Huang, I. et al. (2010), Measuring quality of life in pediatric palliative care: Challenges and potential solutions. *Palliative Medicine*, Volume 24, pp. 175-182.

Hublin, J. (2009), The prehistory of compassion. *PNAS*, Volume 106, pp. 6429-6430.

Hu, J. et al. (2003), Role of surgeon volume in radical prostatectomy outcomes. *JCO*, Volume 21, pp. 401-405.

Hunt, A. & Burne, R. (1995), Medical and nursing problems of children with neurodegenerative disease. *Palliat Med*, Volume 9, pp. 19-26.

Hunt, K. (1990), Romania's Lost Children: A Photo Essay by James Nachtwey. *New York Times*, 24 June, p. 28.

Hynson, J. & Drake, R. (2012), Pediatric Palliative Care in Australia and New Zealand. In: *Pediatric Palliative Care: Global Perspectives*. London: Springer, pp. 379-402.

Jentsch, B. (1998), The 'Interpreter Effect': Rendering Interpreters Visible in Cross-Cultural Research and Methodology. *Journal of European Social Policy*, Volume 8, pp. 275-289.

Jong, J. (2012), *Death and Deities: A social cognitive perspective*. [Online]
Available at: <http://beta.in-mind.org/issue-15/death-and-deities-social-cognitive-perspective>
[Accessed 16 January 2013].

Kaplan, R. (2005), *Balkan Ghosts: A journey through History*. New York: Picador.

Karwacki, M. (2012), Pediatric Palliative Care in Poland. In: *Pediatric Palliative Care: Global Perspectives*. London: Springer, pp. 251-268.

King, N. & Horrocks, C. (2010), *Interviews in Qualitative Research*. London: SAGE.

Kissane, D., Clarke, D. & Street, A. (2001), Demoralization syndrome -- a relevant psychiatric diagnosis for palliative care. *J Palliat Care*, Volume 17, pp. 12-21.

Kligman, G. (1998), *The Politics of Duplicity: Controlling Reproduction in Ceausescu's Romania*. Berkeley: University of California Press.

Knapp, C. (2010), E-Health in Pediatric Palliative Care. *Am J Hosp & Palliat Care*, Volume 27, pp. 66-73.

Knapp, C. et al. (2012), Pediatric Palliative Care and the Medical Home. *J Pall Med*, Volume 15, pp. 643-645.

Knapp, C. et al. (2008), Partners in Care: Together for Kids: Florida's Model of Pediatric Care. *J of Palliative Medicine*, Volume 11, pp. 1212-1220.

Knapp, C., Madden, V. & Fowler-Kerry, S. (2012), *Pediatric Palliative Care: Global Perspectives*. London: Springer.

Knapp, C. et al. (2009), Innovative Pediatric Palliative Care Programs in Four Countries. *J Palliative Care*, Volume 25, pp. 132-136.

Kubler-Ross, E. (1983), *On Children and Death*. New York: Touchstone.

Kuebler-Ross, E. (1969), *On Death and Dying*. New York: MacMillan Publishing.

Laugesen, M. & Glied, S. (2011), Higher fees paid to US physicians drive higher spending for physician services compared to other countries. *Health Affairs*, Volume 30, pp. 1647-1656.

Lawson, T. (1997), *Economics and Reality*. Oxford: Routledge.

Lee, P. (2005), The process of gatekeeping in health care research. *Nurs Times*, Volume 101, pp. 36-38.

Lewis, M. (2006), *Governance and corruption in public health care systems*, s.l.: Center for Global Development.

Liben, S., Papadatous, D. & Wolfe, J. (2008), Paediatric palliative care: Challenges and emerging ideas. *Lancet*, Volume 371, pp. 852-879.

Litvin, J. (2011), *Compassion*. [Online]

Available at:

http://www.chabad.org/library/article_cdo/aid/160887/jewish/Compassion.htm

[Accessed 25 August 2011].

Lubitz, J. & Riley, G. (1993), Trends in Medicare payments in the last year of life. *N Engl J Med*, Volume 328, pp. 1092-1096.

Luczak, J. (1993), Palliative/hospice care in Poland. *Palliat Med*, Volume 7, pp. 67-75.

Lynch, T. et al. (2009), Barriers to the Development of Palliative Care in the Countries of Central and Eastern Europe and the Commonwealth of Independent States. *J Pain Symptom Management*, Volume 37, pp. 305-315.

Mack, J. et al. (2009), Peace of mind and sense of purpose as core existential issues among parents of children with cancer. *Arch Pediatr Adolesc Med*, Volume 163, pp. 519-524.

Malouin, R. & Merten, S. (2010), *Measuring medical homes: Tools to evaluate the pediatric patient- and family-centered medical home*, Washington DC: National Center for Medical Home Implementation, American Academy of Pediatrics; US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

Marston, J., Nkosi, B. & Bothma, A. (2012), Paediatric Palliative Care in South Africa. In: *Pediatric Palliative Care: Global Perspectives*. London: Springer, pp. 27-39.

Maslach, C. & Leiter, M. (1997), *The Truth About Burnout: How Organizations Cause Personal Stress and What to Do About It*. San Francisco: Jossey-Bass.

Mays, N. & Pope, C. (1995), Rigour and qualitative research. *BMJ*, Volume 311, pp. 109-12.

Meltzer, L. & Huckabay, L. (2004), Critical care nurses' perceptions of futile care and its effect on burnout. *Am J Crit Care*, Volume 13, pp. 202-208.

Michaels, C. & Carello, C. (1981), *Direct Perception*. Englewood Cliffs, New Jersey: Prentice-Hall, Inc.

Milberg, A., Strang, P. & Jakobsson, M. (2004), Next of kin's experience of powerlessness and helplessness in palliative home care. *Supportive Care in Cancer*, pp. 12:120-128.

Miles, M. & Huberman, A. (1994), *Qualitative Data Analysis: An Expanded Sourcebook*. London: SAGE.

Morgan, G. (1997), *Images of Organization*. Thousand Oaks, CA: Sage Publications.

Morrison, L. (2004), Ceausescu's legacy: Family struggles and institutionalization of children in Romania. *J Fam History*, pp. 29:168-182.

Morrison, R. et al. (2008), Cost savings associated with US hospital palliative care consultation programs. *Arch Int Med*, pp. 1783-1790.

Morris-Travers, D. (2012), *Every Child Counts*. [Online]

Available at: <http://www.everychildcounts.org>

[Accessed 30 June 2012].

Mosoiu, D., Andrews, C. & Perolls, G. (2000), Global perspectives: Palliative care in Romania. *Palliative Med*, Volume 14, pp. 67-97.

Mulhall, A. (2003), In the field: notes on observation in qualitative research. *J Adv Nursing*, Volume 41, pp. 306-313.

Osztolyn, A. (2011), *Politics can be Different* [Interview] (1 June 2011).

Palfrey, J. et al. (2004), The pediatric alliance for coordinated care: Evaluation of a medical home model. *Pediatrics*, Volume 113, pp. 1507-1516.

Payne, S. (2007), Qualitative methods of data collection and analysis. In: *Research Methods in Palliative Care*. Oxford: Oxford University Press, pp. 139-179.

Pence, G. (1983), Can compassion be taught?. *J Med Ethics*, Volume 9, pp. 189-191.

Perolls, G. (2001), *Founder Hospice Casa Sperantei* [Interview] (15 September 2001).

Perolls, G. (2001), *Philanthropist* [Interview] 2001.

Porter, R. (1997), *The Greatest Benefit to Mankind: A Medical History of Humanity*. London: W.W. Norton & Company.

Postovsky, S. & Arush, M. (2008), Care of a child dying of cancer: The role of the palliative care team in pediatric oncology. *Pediatric Hematology and Oncology*, Volume 21, pp. 67-76.

Prinz, J. (2011), *Is Empathy Necessary for Morality?*. [Online]

Available at: subcortex.com/IsEmpathyNecessaryForMoralityPrinz.pdf

[Accessed 1 October 2011].

Reid, R. & Trescott, C. (2012), *Service delivery innovation profile*. [Online]

Available at: <http://www.innovations.ahrq.gov/content.aspx?id=2703>

[Accessed 18 September 2012].

Ritchie, J. (2003), The applications of qualitative research methods. In: *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: SAGE, pp. 24-46.

Ritchie, J. & Lewis, J. (2003), *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: SAGE.

Robert Graham Center (2008), *Building a primary care workforce for the 21st century*, Washington, DC: The George Washington University School of Public Health and Health Services.

Schein, E. (2001), Organizational Culture and Leadership. In: *Classics of Organization Theory*. Fort Worth: Harcourt College Publishers, pp. 373-374.

Schieber, S. et al. (2009), *The unsustainable cost of health care*, Washington, DC: Social Security Advisory Board.

Shea, S. & Lionis, C. (2010), Restoring humanity in health care through the art of compassion: An issue for the teaching and research agenda in rural health care. *Rural Remote Health*, Volume 10, p. 1679.

Sia, C., Tonniges, T., Osterhus, E. & Taba, S. (2004), History of the Medical Home Concept. *Pediatrics*, Volume 110, pp. 1473-1478.

Siani-Davies, P. (2005), *The Romanian Revolution of December 1989*. Ithaca, New York: Cornell University Press.

Smyke, A. et al. (2007), The caregiving context in institution-reared and family-reared infants and toddlers in Romania. *J Child Psychology and Psychiatry*, Volume 48, pp. 210-218.

Spikins, P., Rutherford, H. & Needham, A. (2010), *The Pre-history of Compassion*. San Francisco: Blurb Publishing.

Starfield, B. (2001), New paradigms for quality in primary care. *B J Gen Practice*, Volume 51, pp. 303-309.

Starfield, B. (2006), State of the Art in Research on Equity in Health. *J Health Politics*, Volume 31, pp. 11-31.

Starfield, B. et al. (2003), Comorbidity: implications for the importance of primary care in 'case' management. *Ann Fam Med*, Volume 1, pp. 8-14.

Stevens, R. (1966) *Medical Practice in Modern England: The Impact of Specialization and State Medicine*. New Haven: Yale University Press.

Stevens, R. (1971), *American Medicine and the Public Interest*. New Haven: Yale University Press.

Stockdale, A. (2002), Tools for digital audio recording in qualitative research. *Social Research Update (University of Surrey)*.

Stokes, G. (1993), *The Walls Came Tumbling Down: the Collapse of Communism in Eastern Europe*. New York: Oxford University Press, Inc..

Sumner, L. (2006), *An explanation of hospice and palliative care*, Alexandria, Virginia: National Hospice and Palliative Care Organization.

Taylor, S. & Bogdan, R. (1998), *Introduction to Qualitative Research Methods*. New York: John Wiley & Sons.

Temel, J. et al. (2010), Early palliative care for patients with metastatic non-small-cell lung cancer. *NEJM*, Volume 363, pp. 733-42.

Toce, S. & Collins, M. (2003), The FOOTPRINTS model of pediatric palliative care. *J Palliat Med*, Volume 6, pp. 998-1000.

Todaro-Franceschi, V. (2013), *Compassion Fatigue and Burnout in Nursing: Enhancing Professional Quality of Life*. New York: Springer Publishing Company, LLC.

Tripathi, S. et al. (2012), Pediatric palliative care in the medical home. *Pediatric Annals*, Volume 41, pp. 112-116.

Vincent, J. (1999), Forgoing life support in western European intensive care units; The results of an ethical questionnaire. *Critical Care Medicine*, Volume 27, pp. 1626-1633.

Voets, J. (2012), *Sunflower House*. [Online]

Available at:

<http://book.picturetank.com/v2/?module=site&action=displayContactSheet&randomId=ddc005310aa8b45423d1a3dedd04f091&lang=en&orderSet=a&publicLanguagesOnly=1>

[Accessed 30 June 2012].

Volf, M. (1996), *Exclusion and Embrace: A Theological Exploration of Identity, Otherness, and Reconciliation*. Nashville, TN: Abingdon Press.

Weisz, G. (2003), The emergence of medical specialization in the nineteenth century. *Bull Hist Med*, Volume 77, pp. 536-575.

Willard, R. & Bodenheimer, T. (2012), *The building blocks of high-performing primary care: Lessons from the field*, San Francisco: California HealthCare Foundation.

Wolfe, J. et al. (2008), Easing of suffering in children with cancer at the end of life: Is care changing?. *J Clin Oncol*, Volume 26, pp. 1717-23.

Wright, A. et al. (2008), Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*, Volume 300, pp. 1665-1673.

Wright, M. & Clark, D. (2006)., *Hospice and Palliative Care in Africa: A Review of Developments and Challenges*. Oxford: Oxford University Press.

Wrin, M. (2012), *No Child Dies Alone, Inc.* [Online]

Available at: www.nochilddiesalone.org

[Accessed 2012].

Zhang, B. et al. (2009), Health care costs in the last week of life: Associations with end-of-life conversations. *Arch Int Med*, Volume 169, pp. 480-488.