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CLERGYPERSONS' EXPERIENCE OF VISITING

CHURCH MEMBERS IN PAIN:

AN ANALYSIS IN TERMS OF THE RELATIONAL THEORY OF PAIN

AND IMPLICATIONS FOR PAIN EDUCATION AND THE UCC

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CLERGYPERSONS' EXPERIENCE OF VISITING  
CHURCH MEMBERS IN PAIN:  
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AND IMPLICATIONS FOR PAIN EDUCATION AND THE UCC

A DISSERTATION APPROVED FOR THE  
DEPARTMENT OF EDUCATIONAL LEADERSHIP AND POLICY STUDIES

BY

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This dissertation is dedicated to my late parents, both life-long teachers

Zora Louise Killough Cunningham

and

Clell Ivor Cunningham

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## **Implementation Apparatus to Get Involved in Pain Policy**

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## **Abstract**

Using the methodology of narrative inquiry, the principal investigator traces, through her own narrative, the development and refinement of the relational theory of pain, a theory she postulated (Cunningham 1999). She describes how the refinement of the theory has been influenced by Lawrence Cremin's concept of public education (1976), Jane Roland Martin's concept of hidden curriculum (1976, 2002), and Michel Foucault's concepts power and resistance at the micro-level (Foucault 1977, 1990; Foucault and Faubion, 1994). Establishing that the harm of untreated or undertreated pain continues, and that no qualitative studies about clergy experiences of visiting church members in pain have been completed, Cunningham explains that she interviewed primarily United Church of Christ ministers because of the UCC's stated interest in social justice in general, and in health care in particular; because of their practice of developing lay and clergy educational materials; because they speak in terms of the relational nature of injustice; (but) because they have not been involved in the pain arena up to this time.

The author uses her relational theory of pain to analyze the interview data from fifteen ministers in four states, as a method of searching out hidden curricula and explicating how belief states such as the high value of endurance and the inevitability of pain can impede the communication of pain and establishment of the political value of pain. The author analyses the interviews, using the categories of factors that support or work against successful communication of pain, and factors that support or work against political validation of pain. The author provides another

layer of analysis by comparing the interpreted data with the fictionalized vignette of a chaplain who must decide how and whether to hear and advocate for a patient in severe pain. Cunningham suggests potential areas for further research by the UCC, potential ideas for curricula development, potential ways to involve ministers through sermons, and potential avenues of UCC policy development and implementation. She argues that other religious denominations can use this study to analyze their own assumptions and practices so that they might better protect vulnerable patients in pain.

## Preface

### **‘Methodology,’ or Hurting a Ten or a Zillion**

“On a scale from one to ten,  
With ten the worst,  
How much did your debridement hurt?”  
Said nurse to boy.

“A zillion”—said his mouth,  
A cowboy’s grudge against too much.  
She circled “ten” and moved along.

His parents looked.  
They thought of burns and death—  
Or maybe that it never happened—  
How much more he would endure  
Before the bronc gave one final throw.

They stood on Ellis Island, too,  
Where their parents had been processed  
In long queues and with inept questionnaires;  
Their boy’s nurse, an immigration officer;  
Each addressed the other in a foreign tongue;  
But only one recorded the event,  
Decided what the family’s proper name should be,  
And whether it hurt a zillion or just a ten.

I begin with this poem by Howard F. Stein (2000, 29) because it captures much of my motivation for undertaking this study of the experiences of ministers. Not only does this poem capture the agony of the patient, but also it also shines a bright light on the nurse, dutifully distant from the patient, and the parents as witnesses, wise in their understanding of fraud of naming involved, but unable to do anything about it. Since 1985, I have been involved in the Pain Movement, that is, the efforts of both healthcare professionals and lay persons—patients, family members, people in

government and patient advocacy groups—to improve pain assessment and management for all patients, especially those who are most vulnerable. (See Appendix 1 for a timeline of this movement. Marcia Meldrum (2005) has also developed a useful timeline.) This narrative inquiry study describes my intellectual journey through the development of a theory of pain. However, behind this journey is something more personal. When colleagues have asked about how I got into the field, I have answered that I heard about a situation in which a mother discovered that her premature baby boy had undergone surgery with a paralyzing drug but no pain relieving drug (Lawson 1988, 1990). Subsequent to my getting to know that mother and her work, as well as many of the professional contacts she had developed, I began my own involvement through research, writing, and teaching. I will refer to examples of these in Chapters 1 and 3. My training as an applied philosopher, with experience working on ethical issues in hospitals, made this subject a natural for me. But I was leaving part of the story out. After twelve to fifteen years in the field, I realized that events of unacknowledged, untreated pain in my own personal life were motivating me, too. (See Appendix 3.) For example, when I visited my mother in the hospital just after her hysterectomy surgery, I cringed and felt helpless as the nurse insisted that my mother cough. I will never forget her lips, white and trembling in agony, even as she was determined to comply. I believe that we all have stories like this. Ministers who visit their patients in pain certainly have their own stories about how it feels to be a witness to another's pain. The stories of fifteen ministers comprise Chapter 2. One of my stories as a chaplain making a hospital visit will begin Chapter 3, where I will offer an interpretation of both their stories and mine. However, partly because of the

educational efforts of the Pain Movement, and in spite of challenges to these efforts, *all of us*, including ministers, have opportunities to prevent or ameliorate instances of suffering because of pain. Most of the participants in my study are United Church of Christ (UCC) ministers for two reasons. First of all, as a member of the UCC, I know that one of their primary areas of emphasis is social justice. Secondly, I know that they have, through their Justice and Witness Ministry, as well as many other avenues, implemented a strong belief in lay and clergy education as a support to action that will help to counter injustice, particularly in the healthcare arena. For example, see their “Mission Statement on Health and Human Service: United Church of Christ” (United Church of Christ 2002). In other words, I interviewed UCC ministers because of the potential they, their parishioners, and the UCC policymakers and educators have for advocating for patients in pain. In Chapter 4, I will outline the current pastoral care literature on pain and a portion of the UCC’s current work in the healthcare field; then I will provide some suggestions to the UCC for strategies in pain education.

Before proceeding further, I wish to make clear what this dissertation mentions, but does not present as areas of *focus*: a) the experiences of hospital chaplains, physicians, nurses or other healthcare professionals when they visit patients in pain; b) the complex history, pragmatics, and current status of science and politics related to Schedule II drugs used for pain ; or c) a history and philosophical critique of the concept of autonomy within bioethics. Although each of these topics is related to the present study, each deserves extensive treatment on its own.

## **Chapter 1 – Pain as an Educational Problem**

### **Philosophy of Education and the Relational Theory of Pain**

Much of the philosophy of education is concerned with public schools—kindergarten through twelfth grade or institutions of higher education. Public education about pain has been non-existent in the public schools. In addition, until recently, relatively little pain education has occurred in medical or nursing school (Katz and Ferrell 1999; Fishman 2007). Rather than in public schools or universities, many of the improvements have been the result of educational efforts in what Lawrence Cremin (1976) calls “public education.” According to Cremin, John Dewey was wrong to describe education in schools as intentional and all other education as incidental. Instead, Cremin, argues, in “Toward an Ecology of Education,” that education occurs in many intentional contexts other than school. Cremin sets the terms of his understanding of education in the following way:

I have found it fruitful to define education as the deliberate, systematic, and sustained effort to transmit, evoke, or acquire knowledge, attitudes, values, skills, or sensibilities, as well as any outcomes of that effort. The definition stresses intentionality, though I am well aware that learning takes place in many situations where intentionality is not present. . . .It sees education as a process more limited than what the sociologist would call socialization or the anthropologist enculturation, though obviously inclusive of many of the same phenomena. And it recognizes that there is often conflict between what educators are trying to / teach and what is learned from the ordinary business of living. (27-28)

The definition also projects us beyond the schools and colleges to the multiplicity of individuals and institutions that educate—parents, peers, siblings, and friends, as well as families, churches, synagogues, libraries, museums, summer camps, benevolent societies, agricultural fairs, settlement houses, factories, radio stations, and television networks. (29)

Such deliberate efforts by professional organizations, lay groups, and governmental entities have occurred in many contexts in the United States. I detail below just a few of these.

Professional pain education began in 1973 when John Bonica and others founded the International Association for the Study of Pain (IASP), for the purposes of research, advocacy of patients, and education of professionals (Seymour, Clark, and Winslow 2005). A wide variety of professional groups have been instituted with these same aims, including groups such as the American Pain Society, the American Academy of Pain Medicine, the American Academy of Pain Management, and the American Society of Pain Management Nurses. Professional groups focusing education and research on specific diseases include groups, such as the Oncology Nursing Society, the American Academy of Orofacial Pain, the American Burn Association, and the National Hospice and Palliative Care Organization. The first formal educational response to the SUPPORT Study (Lynn et al. 1997) was Education for Physicians on End-of-Life Care (EPEC), established by the American Medical Association (Stratos et al. 2006), and the End-of-Life Nursing Education Consortium (ELNEC) funded by The Robert Wood Johnson Foundation (Sherman et al. 2003) . The American Society of Pain Educators was developed to train professionals to be the primary resource person in medical centers or other health care organizations. Other groups involved in teaching professionals how to teach the lay public include the City of Hope Palliative Care Resource Center, the Mayday Fund, and the Alliance for State Pain Initiatives.



In addition to providing educational opportunities for their professional members, many groups listed above also provide some education for members of the lay public and ways for patients and families to get in touch with education and support groups specifically developed for patients with pain associated with disease type or for pain in a particular body part. Groups for patients include the American Pain Foundation, the Arthritis Foundation, the National Fibromyalgia Association, the Vulvar Pain Foundation, and the American Cancer Society. Although the American Cancer Society was hesitant in the beginning to focus on pain because of the fear of drawing attention away from improving survival rates, it has published a book on specifically on pain for patients and families (American Cancer Society 2004).

Hospice use has increased 162 percent over the last ten years, according to the National Hospice and Palliative Organization (National Hospice and Palliative Care Organization 2007). Hospices continue to be an important source of pain education for the general public. Not only do hospice nurses teach patients and families about how to manage pain, but lay groups such as churches or social groups invite hospice representative as speakers. Part of this education by hospice representatives involves lessening fears of pain medications, fears which might be increased by the media, as the media discusses controversies such as medical marijuana or opioids for chronic pain.

In 2000, the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO), which is now called Joint Commission International, developed mandatory standards for pain assessment and management (Dahl 2000). These guidelines included not only requirements for education of hospital staff, but

also for patients and their families. This education was to begin with the posting of a pain patients' rights, such as the right to expect that one's reports of pain would be believed and that hospital staff would respond quickly to patient reports of pain (Joint Commission International 2001). Posted patient responsibilities included items such as the responsibility to ask for pain relief when the pain first begins and to tell nurses or doctors about worries or misgivings patients might have about pain medicine. (See Appendix 2 for the American Pain Foundation's "Pain Care Bill of Rights.")

Specific education from the government about pain began in 1992 and 1994 with the Agency for Health Care Policy Research's publishing of guidelines for pain care for cancer patients, for postoperative or other injured patients, and for infants and children (Acute Pain Management Guideline Panel 1992, 1993; Management of Cancer Pain Guideline Panel 1994). However, few physicians and nurses felt bound by these guidelines. The JCAHO Standards were more effective, though this was partly because of JCAHO's understanding that changes in pain care would involve not only education, but also structural changes such as changes in the chart and quality assurance documentation to include information about regular pain assessment and treatment (Dahl 2000). Through its website, the National Institutes of Health (NIH) Pain Consortium makes educational materials available to both professionals and lay persons. The Center for Medicare and Medicaid Services (CMS) includes requirements for organizational committees to improve and document "pain interventions." The purposes of the proposed legislation in Congress of the National Pain Care Policy Act and the Military Pain Care Act of 2008 include improved

research, clinical practice, and education (American Pain Foundation 2009; Capps 2009) .

The Pain and Policy Studies Group (PPSG), of the University of Wisconsin, has been more instrumental than any other group in educating state and federal legislators about how particular laws or statutes help to improve pain management or hinder good pain management, through the publications of their item-by-item analyses of each state's statutes (Gilson, Joranson, and Maurer 2007). In addition, PPSG assisted the U.S. Federation of State Medical Boards to analyze their guidelines for physicians. In 1998, they adopted the "Model Guidelines for the Use of Controlled Substances for Pain" (Federation of State Medical Boards 1998); in 2004, they revised these guidelines and began a nationwide training program (Federation of State Medical Boards 2004). The National Association of Attorneys General completed a two-year education program to help them to identify what their role might be in improving end-of-life care, including pain assessment and management (National Association of Attorneys General 2003).

In his "Toward an Ecology of Education," Cremin (1976) describes what he calls "configurations of education" as ways in which a "multiplicity of institutions" interact with each other and with society in general (30). According to Cremin, "The relationships among the institutions constituting a configuration of education may be complementary or contradictory, consonant or dissonant" (31). This can be seen in the pain field. For example, the American Pain Foundation works with groups such as the American Academy of Pain Medicine, and the Pain Policy Studies group to educate both professionals and lay persons about both the appropriate use of opioids for severe

pain, as well as the caution with which these drugs need to be used (Fishman 2007; American Pain Foundation 2008). Their work is consonant. On the other hand, some groups, at particular points in time, may be consonant with each other and, at other points in time, dissonant. For example, perhaps, the primary educational concept agreed upon by pain advocates of all kinds and the Drug Enforcement Agency (DEA) is the concept of “balance.” In 2001, these groups produced a joint statement supporting balance, which means preventing the diversion and abuse of prescription drugs, while making sure they are available for the legitimate medical purpose of preventing or relieving pain. These groups developed an educational document called *Prescription Pain Medications: Frequently Asked Questions and Answers for Health Care Professionals* in 2004 to make clear for physicians how they could act appropriately in achieving this balance, that is, how they could provide good pain assessment and care, without getting in trouble with the DEA (Drug Enforcement Agency Department of Justice, Last Acts Partnership, and Pain and Policy Studies Group 2004). However, the DEA abruptly withdrew its support of the FAQs because of what seemed to be its view that the problem of substance abuse due to prescription pain medications is a greater public health problem than unrelieved pain. Whereas the pain advocacy groups of the Pain Movement had worked very hard to teach medical professionals that fear of being “duped” by a drug addict was inappropriately reducing pain control for legitimate needs, the DEA appeared to want to reinstate that fear (Fishman 2005; Rowe 2006; Cunningham (in press a.)). Some of the dissonance in this situation was overt, and some of it covert. One of the primary aims of my work in pain arena has been to search for those activities, institutions, or systems, whose

educational consequences are in consonance or dissonance with the aims of the Pain Movement.

Kenneth Wain distinguishes between formal, non-formal, and informal learning (Wain 2004). Formal education is defined as that in which a teacher is involved in the learning context, and there is some intention for learning on the part of the teacher and/or student. Non-formal education includes "...those learning activities and processes, whether solitary or collective, that / are intended as such but do not involve someone in the role of teacher" (33-34). Cremin would call both of these categories education. Finally, with these last two distinctions, Wain is trying to catch hold of Dewey's idea that "living together educates" (33). Cremin would agree with Wain's use of the term *learning* here instead of *education*.

Jane Roland Martin, Michel Foucault, and Kenneth Wain are also concerned about learning in non-school contexts, particularly with learning that occurs when intentions of the teacher are hidden from the student or when learning states are out of the consciousness of the teacher or both the teacher and the learner (Martin 1976; Foucault 1977, 1990; Foucault and Faubion 1994; Martin 2002; Wain 2004). Wain designates as informal learning "unconscious experiential learning of all kinds on the learner's part" (33). Martin wants to add the situations in which curricula that teachers intend is not revealed to the students or situations in which students' curricula for themselves may not be revealed to the teacher. However, she also adds situations in which neither the teacher nor the student is aware of the curricula. She says, "[H]idden curricula can be found anywhere learning states are found" (146). Moreover, how and whether curricula come into being, go out of being, or change depends upon the

individuals involved, the environment, and the time. Martin (1976) associated the learning states of hidden curriculum with character traits or cognitive states, including belief states.

The learning states of a hidden curriculum can be states which we think of as character traits—for example, docility or conformity. They can also be cognitive states such as believing or knowing, states of readiness or of skill, emotional states, attitudinal states, or some combination of those and other sorts of states. (137)

According to Martin, “A hidden curriculum is not something one just finds; one must go hunting for it” (139), not only within schools, but also in non-school settings.<sup>1</sup> It is the source of a hidden curriculum that must be identified in order to make a change if the consequence of a hidden curriculum is harmful.

If our concern is not simply to discover hidden curricula but to do something about them, we must find out which elements or aspects of a given setting help bring about which components of that setting’s hidden curriculum. (141)

Once these elements have been discovered, they can be pointed out to the subjects of the hidden curriculum through “consciousness-raising” (148). After all, Martin says, “Resistance to what one does not know is difficult, if not impossible” (148).

*Docility* and *resistance* are the kinds of terms that Foucault uses in his explanation of power relations. “A body is docile that may be subjected, used, transformed and improved” (Foucault 1977, 136). One of the methods through which transformations occur is the examination.

[T]he examination in the school was a constant exchanger of knowledge; it guarantees the movement of knowledge from the teacher to the pupil, but it extracted from the pupil a knowledge destined and reserved for the teacher. (187)

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<sup>1</sup> In this way, Martin distinguished her theory from those of the vast literature on hidden curriculum of that period, which presumed that only public schools have hidden curricula.

Disciplinary power, in contrast to traditional power, is unseen at the same time that the subject is always seen. Moreover, the duty of surveillance, in a docile subject, will be taken over by the subject, herself or himself. As Arthur Frank and Therese Jones explain,

At the center of modern, disciplined society is surveillance, and Foucault understood most clinical work—family medicine, public health, and mental health—as practices of surveillance. The modern disciplinary imperative is that subjects must be observed, relentlessly and intrusively, to determine what forms of discipline they require either to remain or to be returned within the parameters of the normal. One of Foucault’s crucial insights is that society refines its claim that surveillance and discipline are for the individual’s own good. (181/182)

Martin’s understanding of the pervasiveness of a hidden curriculum is related to her acknowledgement of the pervasiveness of power relations, as described by Foucault. When Martin moves from the focus on pervasiveness of learning states and possibilities for hidden curriculum (Martin 1976) to focus on “multiplicity of educational agency” (Martin 2002, 37), she says this:

. . . I am reminded of the French philosopher Michel Foucault’s analysis of power. Foucault point out that we tend to imagine power as centralized: as coming from above and as being located in the hands of a sovereign. In fact, he said, power operates in all the nooks and crannies of society. . . . (37)

In other words, the educational effect, as described by Martin, is related to the political effect, as described by Foucault, in his view that every situation at every level is infused with power and resistance, which may be overt or covert, conscious or unconscious (Foucault and Faubion 1994; Marshall 1996; Scheurich and McKenzie 2005). Both Martin and Foucault say that it is important to study relationships and events at the micro-level, especially at the unconscious level, in order to see what is happening in order to have the possibility of resistance, especially against strategies

such as normalization or protection of the status quo. As explained by James Marshall, Foucault's "governmentality"

should be understood [as] a form of activity which attempts or aims at the conduct of persons; it is the attempt to shape, guide, or affect not only the conduct of people but, also, the attempt to constitute people in such ways that they can be governed. In Foucault's work this activity of governance could cover the relations of self to self, self to others, relations between institutions and social communities, and the exercise of political sovereignty. (112)

However, since the power relations within governmentality are not permanent, resistance is possible. According to Jana Sawicki (1996),

Foucault clarified the distinction between domination and power. Whereas 'domination' refers to a situation in which the subject is unable to overturn or reverse the domination relation—a situation where resistance is impossible—'power' refers to relations that are flexible, mutable, fluid, and even reversible. (p. 170)

Not only are there points of power everywhere, but also there are points of resistance everywhere, too. There is no one "great Refusal" (Foucault 1990, 96).

Instead there is a plurality of resistances, each of them a special case: resistances that are possible necessary, improbable; others that are spontaneous, savage, solitary, concerted, rampant, or violent; still others that are quick to compromise, interested, or sacrificial. . . .(96)

No doubt, such events as these might be underneath the consonance and dissonance of relations between institutions that Cremin (1976) describes. If hidden curricula can be "rooted out" (as Martin would put it) and resistance mounted (as both Martin and Foucault would put it), then this dissonance between or within institutions may effect changes in practice.

Sometimes a search for hidden curricula can be followed by a kind of public education. For example, I was able to determine early on that, even when safe ways to provide analgesia to infants in the neonatal intensive care unit had been developed,



physicians and nurses were provided by their hospitals or professional organization with few incentives to learn new techniques. So, the hidden curriculum was that they did not need to change. Parents were not aware of this situation; so, in an article for *Birth*, I listed a number of questions that parents or interested community members should ask their local healthcare institutions. One question was “What incentives are provided to assist physicians in learning techniques of anesthesia and analgesia administration new to them?” (Butler 1988, 40). Through this I was encouraging the kind of consciousness raising referred to by Martin (1976, 148) or resistance referred to by Foucault (1990, 96). It turns out that, before I learned about these ideas in educational studies graduate classwork, I was doing some research that is certainly complementary. In fact, one of my main contributions to the field is a theory about pain, a theory that enriches and is enriched by the philosophy, history and sociology of education. Moreover, because my study of ministers examines their thought at the micro-level of the hospital bedside, my theory can be used as a lens for analysis, at the same time that the theory can be enriched by the ministers’ experiences.

### **The Relational Theory of Pain – Its Beginnings and On-going Development**

This year, 2009, is the tenth anniversary of my publication of “Primary Requirements for an Ethical Definition of Pain” (Cunningham 1999). Although I had published a number of other articles prior to that one, “Primary Requirements...” has been most important because of its breadth and because it was where I introduced what I am calling *the relational theory of pain*.

No doubt, I began developing the relational theory of pain as I wrote my first article on the issue of unanesthetized surgery on infants (Butler 1987). In that article, I appealed to the American Nurses Association Statement on Ethics to show why operating room nurses, as members of the profession of nursing, could apply rules about fairness in order to change their standard practice of withholding anesthesia from infant surgery patients. Over the next ten years or so, I collected and created a number of ideas for the relational theory of pain. For example, in an article for *Bioethics*, I suggested that a culture's driving concepts could result in neglect of pain treatment (Butler 1989). The neonatal intensive care unit's (NICU's) driving concepts of saving lives, seeing patients as sets of mechanical systems, and focusing on the dramatic underdevelopment of infant patients could overwhelm an alternate concept of treating these patients as social interactors, who are attempting to cope with and influence their environments, including their caregivers. Under that first set of driving concepts, that is, within such medical, nursing and lay cultures, not only was pain unimportant, it was non-existent; under the second set of driving concepts, it becomes possible to see infants as communicators of pain, attempting to influence their caregivers.

It wasn't until I became involved with the issue of the definition of pain that I began, in a more formal way, to sketch out a theory of pain. Sunny Anand and Kenneth Craig provided the first challenge to the IASP definition of pain (Anand and Craig 1996) by arguing that, scientifically, it would make more sense to respect the developmental stages of infants by saying that the "newly born" will signal pain using non-verbal behaviors, rather than to say, if infants cannot use speech, then they don't

have pain (4). What was needed was more attention to the “communicational specificity of [infants’] biobehavioral response patterns during painful events,” according to Anand and Craig, reducing the need to depend on “compassionate feelings or ethical arguments” (5). A flurry of responses and counter-responses ensued (Derbyshire 1996; Merskey 1996; Wall 1996; Cunningham 1998; Derbyshire 1998). Finally, in 1999, *Pain Forum*, the journal of the American Pain Society, invited Anand, animal pain philosopher Bernard Rollin, and me, the infant pain philosopher, to publish as “focus” articles the papers we had presented to their 17<sup>th</sup> Annual Scientific Meeting at San Diego the prior year. In these papers, we all argued that definition of pain developed by the IASP (Merskey and Bogduk 1994) should be changed in order to include those who couldn’t talk.

I introduced my article by summarizing Anand and Craig (1996) and then saying, “I will argue that, while Anand and Craig were right that the definition should be changed, they were wrong to attempt to appease other members of IASP by reducing the place of ethics in this controversy” (Cunningham 1999, 93). This was an issue of ethics and of power, I would argue.

The theory of pain I offered in that article was an attempt to account for medicine’s authority over pain, its worry about loss of authority over pain, its ambivalence about pain’s existence, and its hierarchy of patients worthy of treatment of pain. In the nineteenth century, physicians had hoped to discover laws of pain such that particular kinds of injury in particular kinds of patients or body parts would result in a quantifiable amount of pain; they certainly did not see patients as experts on their own sensations (Burbick 1994). One part of the IASP definition of pain developed in

1994 was an admission that physicians had failed at discovering this kind of specificity, that there seemed to be cases in which patients claimed to have pain different from physicians' expectations. The solution for the IASP was to define pain in terms of subjective experience. "Pain is always subjective," but, the definition continued,

many people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons. . . . If they regard their experience as pain and if they report it in the same ways as pain caused by tissue damage, it should be accepted as pain. (Merskey and Bogduk 1994).

Each patient is an authority on his or her own subjective experience; if patients report pain, then that report should be accepted, according to the definition. However, I noted, one consequence of this move was to emphasize the objective nature of those not in pain, "unbiased and powerful in their objectivity" (Cunningham 1999, 95); in other words, the physician decides whether there is tissue damage, and, thus, whether the pain is just mental. According to the definition, while patients are authorities on whether they have pain, they are not authorities on why or what is the proper amount of pain. Moreover, if patients cannot provide verbal report that they have pain, no matter how much tissue damage they have, it might be possible that they have no pain. Consequently, a hierarchy of moral value has been created. In spite of the apparent rejection of specificity, I noted, when physiological damage is clear, when there is verbal report of pain, and when the damage seems to match the expected verbal report, patients will have higher moral status than they would otherwise, which means they are, "(1) more deserving of professional effort to hear communications of pain and (2) more deserving of professional effort to prevent or ameliorate this pain" (94). In other

words, the definition and values undergirding it support a policy of exclusion of particular classes from pain treatment.

Here then is the theory, which begins to describe at which points exclusion or inclusion might occur:

Pain appears to have at least three categories of existence. The first category is the pain that is located inside patients. I will call it “contained pain.” It usually has to do with tissue damage in these patients, and it always has to do with subjective, mental activity within them. The second category of existence is the pain that is successfully communicated by patients to others. This type of pain comes into existence only when patients have certain abilities to communicate and potential caregivers have certain abilities to see and hear. . . .This category, what I will term “communicated pain,” is a / particular kind of communication event. The third category of pain comes into existence when the communication or the need for it is powerful enough to move potential caregivers to act on behalf of those in pain, or when those in pain can act to prevent or ameliorate their pain on their own. This is “politically validated pain.” (95-96)

Under this theory, the perception and experience of pain happens, whether or not it is successfully communicated. Contained pain means felt pain.<sup>2</sup> However, only certain patients will be able to communicate successfully, that is, bring the pain out of the container of the body. I explained, with a bit of sarcasm, “These patients are not too frightened; they are well-spoken and willing to use pain scales; they can follow directions; they are neither too brave nor catastrophic” (97). Infants cannot successfully communicate pain to people like Stuart Derbyshire (1998) because infants do not use language yet to describe pain; for Derbyshire, until a child can speak, the child does not have pain. According to the relational theory of pain, even when pain is successfully communicated, it may have little or no political value. It is not just that the communication of pain must be powerful enough to encourage advocacy, the communication of pain must work against forces such as stigma

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<sup>2</sup> I am grateful to Susan Laird for helping me to make this clarification.

(Lillrank 2003; Macdonald 2003; Jackson 2005).<sup>3</sup> Patients who have advanced cancer and a history of drug addiction may be able to communicate pain successfully, but be unable to get adequate treatment. In this way, I was trying to capture the relationality of pain. Whenever there is a witness, or whenever a healthcare system is set up to provide witnesses, pain is a relational event. Sometimes it is a relation of rejection. One solution to the grip on skepticism held by those in power would be to attend to the subjective experience of those not in pain by rejecting the binary of objective/subjective, that had been paired with the binary not in pain/ in pain. “Not only is pain a subjective experience, witnessing another in pain is a subjective experience” (96). In other words, it is possible that the diminished political value of the subjective experience of the person in pain might improve if the witnesses acknowledged that their experience of witnessing is subjective, too.

In addition to theorizing about relationality between individuals, I was working on why, at a larger professional level, the problem of pain might be like the problems of racism and poverty, in that the assumption of inevitability prevents change. I summarized Thomas Ross’s argument from *Just Stories* (1996) about how Supreme Court justices have justified retaining laws that will keep poor people poor.

[E]ither poverty is caused by moral weakness of poor individuals (establishing a clear difference from those who are not poor), something the justices can do nothing about, or...the phenomenon of poverty itself is too complex and multifaceted for the justices to begin to solve. (Cunningham 1999, 94)

As I mentioned above, since 1999, my work, as both student and teacher of pain education, has involved continuous attempts to revise, refine, and enrich this

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<sup>3</sup> I am grateful to Tassie Hirschfeld for pointing out the importance of stigma as a counter to culturally legitimized pain.

theory through example, counter-example or new theoretical lenses. For example, about one year after “Primary Requirements...” was published, I presented a paper entitled, “Proxy Consent Does Not Eliminate Infant Subjects’ Right to Withdraw” (Cunningham 2000). In this piece, I analyzed four different studies on infant circumcision pain (Lander et al. 1997; Taddio et al. 1997; Williamson 1997; Herschel et al. 1998) to see if they met research ethics requirements such as that of IASP (1995). I argued that use of placebo controls in these research studies did not meet the requirements of research ethics that subjects be guaranteed the right to withdraw from the study, to say, “Stop!” Here is the language from IASP: “In any pain research, stimuli should never exceed a subject’s tolerance limit and subjects should be able to escape or terminate a painful stimulus at will” (277). However, even though the investigators in the studies believed that the circumcision procedure was “excruciatingly painful,” (Williamson 1997), to give an example of languages used; and, even though the babies in the control group (with no pain control) behaved as if the clamping and cutting were excruciatingly painful during the procedure, no behavior of the babies counted as communication of intolerability. In other words, I was arguing, in the context of research, the communication of pain by the infants was damaged by the researchers’ responses to it. In addition, the pain that was communicated had no political worth.

In 2002, I made the problematic nature of this kind of thinking more clear in a paper entitled, “What We Owe to Those Who Won’t Remember: Pain Treatment Practices on Patients Under Conscious Sedation” (Cunningham 2002). I told the story of my neighbor, I called Lilly. During her eye surgery, she received a drug to relax

her, but inadequate pain control. Though she tried to let the surgeon know that what he was doing was hurting her too much, the sedating drug made it so that she could make noise, but she couldn't talk. Finally, the doctor gave her general anesthesia so that he could complete the procedure. Although most patients are affected by the amnesia part of the sedation drugs given during outpatient surgery and other procedures, Lilly was not. She said that she remembered and she "felt violated"; but her attempts to communicate pain were given no moral status because the surgeon assumed that she would not remember the pain. Her case was unusual. Most people don't remember, and, as far as many nurses and doctors are concerned, "if a patient does not remember a painful event, then, for all practical purposes, the painful event didn't happen" (Cunningham 2002, 5); in essence, the patients did not have the pain, professional caregivers may say (Rex and Khalfan 2005). What I argued was that, even if patients cannot remember their own pain event that they were witnessing at the time, the doctors and nurses *can* remember *their* witnessing of the event. And, even if the caregivers decline to admit remembering, the pain event still happened. I used the analogy of a tree falling in the forest.

If a tree falls in the forest, and there was no one to hear it, did it make a sound? This seems mysterious only because of the fallacy of equivocation.

Meaning #1 of sound: vibration of air

Meaning #2 of sound: transmission of vibrating air through an auditory nerve

If there is no ear within a certain distance of the falling tree, there *will* be sound in sense #1.

If there is no ear within a certain distance of the falling tree, there *will not* be sound in sense #2.

The fallacy occurs when people use the fact that there is no sound in sense #2 to confuse others into thinking that there is no sound in sense #1.



Can the tree example be used to explain how equivocation is involved in some thinking about pain?

Meaning #1 of pain: the negative experience someone has subsequent to injury of tissue

Meaning #2 of pain: transmission of this experience through the pain-interpreting mechanism of a potential caregiver.

If there is no such potential caregiver within a certain distance of the injured, perceiving being, the experiencer of pain, then there *will* be pain in sense #1. If there is no such potential caregiver within a certain distance of the injured, perceiving being, the experiencer of pain, then there *will not* be pain in sense #2.

The fallacy of equivocation occurs when people use the lack of pain in sense #2 to confuse others into thinking that there is no pain in sense #1. (6)

With the idea of a “pain-interpreting mechanism of a potential caregiver” I hoped to make more clear the relationality of pain, to show that the communication of pain depends upon the witness. Just because someone declines to acknowledge what they have witnessed doesn’t mean that there was no felt pain, no pain contained within the patient. Liesbet Goubert et al. (2005) suggest that not only does pain help to guarantee survival of a species, but also empathetic responses do, too.

As evidence accumulates on the interpersonal functions of pain, conceptualizations of pain as a predominantly sensory system are challenged. Adequate models of pain will need to account for the personal as well as the interpersonal processes that are mobilized in response to pain. (288)

Erich H. Loewy (1991) had argued similarly almost twenty years ago.

One of the first papers I presented as a graduate student was called “Explanatory Power of Embodiment and the Fear of Degeneration” (Cunningham 2006). In this paper I argued that part of the unconscious motivation in healthcare contexts can be fear of degeneration. As Christina Cogdell (2004) explains, while

evolution was understood in the 1930's as "progressive, ever-improving toward an attainable ideal" (21), "degeneration reversed this process. By definition, degenerate individuals were less suited to the 'civilized' world . . . [and, thus,] were perceived as producing a genetic and economic 'drag' on a nation's development" (22). Smooth functioning of individuals, as well as groups, machines, and institutions were understood as reflective of evolution. According to Joel Spring (2001) and Michael Apple (2004), fear of degeneration affected the white's treatment of non-whites throughout the country's educational history. One important method of guaranteeing the safety of the non-polluted was to develop testing materials to identify potential societal polluters (Apple 2004; Winfield 2007). This process helped to solidify the distinctions between the groups in the classroom, as well as in the research lab; it helped to solidify the binaries of researcher/subject of research, objective/subjective. I extended this analysis to the binaries of abled/disabled and not in pain/ in pain and specifically looked at the situation of colonoscopy patients, whom I identified as "temporarily iatrogenically disabled" (Cunningham 2006, 12). Sedation might remove patients' ability to talk, or the use of sedation might mean that the physicians would not take patients' verbal protest seriously; in other words, the communications of pain were damaged by the medical view of protests as merely potential interrupters of the smooth functioning of the colonoscopy suite (Waye 2002). Moreover, the physicians doubted the judgment of patients in pain (Ward et al. 1999). The hidden curriculum of the patient consent form involved instilling confidence in patients in the smooth, easy and very technical process of colonoscopy, without making clear the pain or the issue of not remembering the pain.

This process of continuing to develop my relational theory of pain has continued throughout graduate school. In Chapter 3 – Discussion, I will refer to ideas from other work, as well as to the philosophy of education, medical, and nursing literatures.

### **Continuing Harm of Inadequate Pain Management**

Although a great deal of improvement in pain assessment and management has been made in the last twenty years, many problems remain (Dahl 2004; Joranson and Gilson 2006; The state of pain care in America 2007; Stjernsward, Foley, and Ferris 2007; American Pain Foundation 2008; Boyd 2008). Inadequate pain care can be found in all age groups, from children (Anand et al. 2006) to the elderly (Teno et al. 2001; Chodosh et al. 2004; Teno et al. 2004; Duncan, Forbes-Thompson, and Bott 2008). Likewise, poor pain management exists for patients with many different kinds of diseases, including sickle cell disease (American Pain Society 1999), fibromyalgia (Dell 2007), heart disease (American Heart Association 2006), dementia (Morrison and Siu 2000; Herr, Bjoro, and Decker 2006), cancer (Davis and Walsh 2004; Gordon et al. 2005), and back pain (Glick 2005). Pain is often not well controlled in emergency rooms (Rupp and Delaney 2004; Probst et al. 2005; MacLean, Obispo, and Young 2007), in the procedural pain context (Brady-Fryer, Wiebe, and Lander 2004), in the postoperative context (Apfelbaum et al. 2003; Sauaia et al. 2005; Lavand'homme 2006; Leykin, Pellis, and Ambrosio 2007; Prowse 2007), or when patients are dying (Coulehan 2005; Johnson et al. 2005; Vallerand, Anthony, and Saunders 2005; Pollack 2006; Watkins et al. 2006; Rolnick et al. 2007). Gender (Wendell 1996; Berkley 1998; American Heart Association 2006) or ethnicity

(Sullivan and Egel 2005; Cintron and Morrison 2006; Palos et al. 2006) can be an important factor in determining who does or does not receive good pain assessment and management.

Not only should people from a variety of institutions be motivated by the unnecessary suffering that remains, they can make a difference. One of the institutions outside schools that educates, according to Cremin (1976), is the church. While pastors, members, or the organizations themselves may be subject to hidden curricula or networks of power, once they discover these, they can become exposers of hidden curricula and resisters against power. Similar studies could be done with healthcare professionals. The next step in this dissertation is to consider what qualitative research has been completed about the experience of pain. Have any of these studies focused on ministers' experiences as they visit their church members in pain?

### **Lack of Qualitative Research on Ministers as Current or Potential Advocates**

A number of qualitative research studies have focused on patients' experiences of being in pain. Studies in which the researchers themselves were the focus of study include examples such as an autoethnography of neuropathic pain (Neville-Jan 2003) and narrative inquiry/literary research study of cancer pain (Holmes and Chambers 2005). Examples of other studies focusing on patients' experience of pain include pain in elderly hospice patients (Duggleby 2000), pain in the general elderly population (Kumar and Allock 2008), arthritis pain (Sanders, Donovan, and Dieppe 2002), HIV/AIDS pain (Laschinger and Fothergill-Bourbonnais 1999), pelvic pain in women (Grace and Mac-Bride-Stewart 2007), and back pain (Glenton 2003; Lillrank 2003).

Generally these used a phenomenological method. Examples of qualitative research about professionals' experiences of working with or witnessing patients in pain include a clinical-interpretive study of doctors who experienced "difficulty whilst confronting a patient who was in pain" (Vegni, Mauri, and Moja 2005); an exploratory qualitative study of home healthcare nurses experience of barriers to good pain care (Vallerand, Anthony, and Saunders 2005); an interpretive phenomenological study of student nurses' experience of bearing witness to pain (Eifried 2003); and a phenomenological study of both patients' experience of pain and nurses' experience of inflicting pain (Madjar 1998). Although one research project (Burns 2002) involved interviews of ministers and analysis to determine "how pastors learn the politics of ministry practice," the published article provided no examples of experiences related to the sick call.

In answer posed to the question above, no qualitative studies have focused on ministers' experiences of visiting their church members who are in pain. This is not surprising. Janice Morse, editor of *Qualitative Health Research* delineated several categories of health research in "What Is the Domain of Qualitative Health Research?" (Morse 2007). The category of "caregivers' experiences" does not include ministers. However, the minister as part of a church organization might be considered appropriate for a category Morse calls "the context of care" (716). Although she mentions "small groups," "the institution," and "community organizations" (717), she does not mention religious organizations. However, I am arguing that ministers as both witnesses and potential educators in healthcare contexts should be included in the arena of qualitative research.

## **Narrative Inquiry for Pain Education**

The current study uses some of the premises of the methodological style of narrative inquiry (Clandinin and Connelly 2000; Chase 2005; Duffy). As I listened to the ministers in person, re-listened to them on tape, and transcribed their words, I was aware of participants as tellers of stories, as narrators, rather than as mere sources of information. As Clandinin and Connelly put it, narrative is “both phenomena under study *and* method of study” (4). There is an acknowledgement that both the participants and the researcher bring with them to the interviews a situated background and set of current aims, which each uses to construct meaning (Sandelowski 2004; Chase 2005). In the first part of Chapter 3, I provide some of the ministers’ situatedness as visitors to their church members in the section “Context of Visiting Church Members in Pain.” In the Preface, Appendix 3, and Epilogue of this dissertation, I have provided my personal situatedness; in Chapters 1 and 3, I include my philosophical situatedness. Although some research theorists refer to this situatedness as “baggage” (Thomas 2002, 249), this need not be the case. Researchers need to “bracket” their own experiences and feelings enough to be able to listen to those they are interviewing (Munhall 2007), but narrative inquiry is a relational method in that “Once we let the voice of another enter our psyche, we can no longer claim a detached or objective position” (Brown and Gilligan 1992). Narrative inquiry recognizes the constructedness of the researcher’s narratives; many phenomenologists do, too (Chase 2005; Munhall 2007). Not only did I construct the interview process to some extent by using some of the questions in the data collection instrument (see Appendix 4), but also in the themes that I heard in the interviews, and in my

subsequent decision to arrange individual speeches and categories of themes into sections of my relational theory of pain. It is not a matter of “themes” just floating up out of the data, as feminist epistemologist Lorraine Code (1991) and qualitative research theorist Margarete Sandelowski (2004) would no doubt emphasize. However, because I used parts of their stories, from a few lines to many lines long, I was able to construct the research process so that both the commonalities among participants and the uniqueness of each would be part of the analysis (Kearney 2001; Thomas 2002; Munhall 2007).

Although this study recognizes the importance of the narratives of the researcher, as well as the participants, it will not include some elements common to narrative inquiry projects. 1) Although each of my questions to the ministers was, in a sense, open-ended, during each interview, I was not asking for the stories of their lives. I kept the interviewees on task, so to speak. 2) I did not include in the consent form a responsibility on the part of the ministers to participate in the research by going over transcripts or interpretations of them. As Sandelowski (2000) explains, “Indeed, qualitative work is produced not from any ‘pure’ use of a method, but from the use of methods that are variously textured, toned, and hued” (337). For the specifics of my methods, see the beginning of Chapter 2.

### **Guiding Research Questions**

Many groups within the culture are involved in whether good pain treatment occurs. Ministers visiting their church members in pain are one of these groups because they are part of public education. No one has studied how ministers

experience their visitation to patients in pain, an experience that might include some type of advocacy of these hurting church members. Although Cremin listed churches as one arena where education occurs, he did not mention the possible consonance or dissonance between hospitals and churches. Because of the United Church of Christ's stated interest in social justice in general, and in health care in particular; because of their interest in and practice of developing educational materials for their clergy and church members; because they speak in terms of the relational nature of injustice; and (but) because they have not been involved in the pain arena up to this time, I have chosen to study how UCC ministers experience visiting their patients in pain and how their experiences may be illuminated by discussions and efforts within the pain field and the larger society.

1. How do the ordained UCC ministers participating in this study experience visiting their church members who are in pain?
2. What do they understand their formal and informal preparation to be for such visitations?
3. How do they understand causes of restraint of action on the part of all involved?  
How do they understand the possibilities of or reasons for action, especially advocacy toward better pain management?
4. How might the participants' stories understandings, questions or conflicts related to pain education be usefully interpreted in terms of the relational theory of pain, as a method for locating hidden curricula and bringing them out into the open?
5. How might the participants' stories reflect understandings, questions or conflicts related to pain education that occur within the professional field or the larger society?



6. What might be the educational implications for the United Church of Christ? In other words, what might be the value of the relational theory of pain for the UCC's further research, curriculum development for pain education, and involvement in pain policy?

## **Chapter 2 - Listening to Clergypersons' Experiences**

### **The Clergypersons and the Research Process**

For this study, I interviewed five ministers in the pilot, or what I will refer to as the first round, and ten ministers in the second round. The OU Institutional Review Board, as well as my dissertation committee, accepted the plan to produce one analysis of the total number of the interview transcripts, which turned out to be fifteen. The requirements for participation in the study included being 1) between the ages of eighteen and sixty-four, 2) ordained, and 3) not currently working as a hospital or hospice chaplain. I excluded ministers currently working as a hospital or hospice chaplain because I did not want experiences colored by the strict turf rules in the relationships between chaplains and medical professionals in that organizational setting. After the first round, I decided that I wanted to focus on the responses of UCC ministers; so, twelve of the fifteen participants are UCC ministers. However, I decided to include in my analysis stories and opinions from all fifteen ministers interviewed. Since the first round included all male participants, I decided to try harder to include female clergy in the second round; I was able to accomplish this with five men and five women. I obtained names of ministers to attempt to recruit from my prior contacts, from names suggested to me by these contacts, and from my use of the "Find a Church" feature found at [www.ucc.org](http://www.ucc.org). Of the twenty-five ministers contacted, fifteen agreed to participate, one was ineligible, and nine either declined or did not respond to a phone message. After reading the IRB-approved recruitment script, if the participant agreed, I made arrangements to meet with each subject. In eleven of the

cases, we met at the church where the minister is currently a pastor; in the other four cases, we met at other locations convenient to each clergyperson. These ministers are pastors at churches in four different states; three represent rural churches and twelve urban churches. However, many UCC seminary students do their internships in rural churches; in addition, some of the participants are now in urban churches, but they have pastored in rural locations previously.

Prior to the interview, each participant signed the IRB-approved consent form (see Appendix 4). The interviews lasted from 30 to 115 minutes. Although I had a general idea of the questions I wanted to ask and I had prepared a “Data Collection Instrument” for the purposes of the IRB (see Appendix 4), I was primarily prepared to hear their stories of their experiences. In most cases, the interviewees appeared to be grateful to tell of their stories, as if no one had attended to this side of their role as ministers.

Every person interviewed agreed to be taped, and I personally transcribed each taped interview. After this was completed, I listened to each interview a second time, in order to hear the voices again and to edit the transcriptions. By *edit* I mean that I made corrections to assure fidelity to the oral text; I did not change the grammar or remove instances in which participants changed direction in the middle of a sentence or spoke in incomplete sentences. The transcriptions included just over two hundred single-spaced pages of copy. The first organization of the transcript material involved determining a set of categories, which seemed to be evident in the ministers’ stories *and* compatible with my understanding of the health care context of pain. Here are the categories:

Finding out about someone in the hospital  
Feelings about hospital and nursing home visitation and reasons to do it  
Non-pain stories that provide context for visitation of patients in pain  
Private versus public  
Inevitability  
Distraction  
Providing comfort to those in pain  
Feelings about ministering to those in pain  
Resources most valuable for ministering to those in pain  
Advocacy- include statements about turf  
Trustworthiness of patient report of pain-subjectivity of pain  
Purpose of pain and its pointlessness  
Endurance  
Training for hospital visitation or the sick call  
Training for visiting church members in pain  
Other

Then I developed an outline, using as an organizing method my relational theory of pain, as discussed in Chapter 1, resulting in a data set organized into five main parts:

Context of Visiting Church Members in Pain  
Factors that Support Successful Communications of Pain  
Factors that Work Against Successful Communication of Pain  
Factors that Support Political Validation of Pain  
Factors that Work Against Political Validation of Pain.

Next I pulled statements from the sixteen categories from my first stage of analysis into the categories of this second stage, as each statement or set of statements appeared to be appropriate. Finally, then, I produced the narrative of Chapter 2.

Here are some notes on the presentation of the interviews. After each section of an individual's speech, I have included the page number of the transcript from which the speech is taken. If the speech extended from one page to another, I have indicated the page change with the symbol "/." In a couple of cases, I left my questions or responses out; however, in the vast majority of cases, I have made

available the entire interchange to preserve flow and meaning. Many times I have been able to provide examples of pastors' ideas and actions with shorter quotes from the interviews. However, sometimes only entire vignettes make the stories clear enough.

In order to preserve confidentiality, I have changed some of the details, such as names of cities, provided by the study participants. In addition, each clergyperson has a pseudonym. To make the narrative of Chapter 2 easier to read, I have referred to each minister as R (for Reverend) and the first letter of the pseudonym. Here are the abbreviations for the pseudonyms: RB = Rev. Bruno; RC = Rev. Calhoun; RE = Rev. Edwards; RF = Rev. Field; RH = Rev. Hayden; RJ = Rev. Johnson; RK = Rev. Kellin; RL = Rev. Lake; RM = Rev. Morning; RO = Rev. Osten; RP = Rev. Press; RD = Reinhold; RR = Rev. Rex; RS = Rev. Stone; RY = Rev. Young.

### **Context of Visiting Church Members in Pain**

To understand how the ministers' experiences might reveal why contained pain might or might not become communicated pain, as well as why communicated pain might or might not become politically validated pain, I had to come to understand at least some of the context in which each of the ministers sees patients. So, I asked questions which would fill out each pastor's story in terms of feelings about hospital visitation, routines for the visits, training for visitation, and some non-pain stories.

#### **Feelings about Hospital Visitation**

One of the primary feelings expressed by the ministers I interviewed was an acceptance of duty, with visitation very often described as an integral part of their role as an extension of the church.

RM: Well, it's a part of ministry, and I see myself more as a teacher in that area, so, um. [pause] I never really thought about it. It's just somethin' that I have to go do. . . . Um, I think it's important. I think it's an honor. (1)

RP: It's, it's needful. Um, although one would shy away from using this term, I would feel that it's my duty to do so. Um, it is a way of demonstrating that I care, that the church cares. For those who have an embodiment model of ecclesiology, in many ways it is the church extending itself to those who are ill or injured or homebound or in a long-term care facility, such as a nursing home. (2)

RH: My understanding of the exercise of my pastoral office is that I'm responsible for, responsible to God, first of all, but, but, um, the community and to the ecclesiastical bodies and things to exercise my office ethically and in the best way I know how. (15)

RB: Uh, I think visiting the sick is one of the most important parts of pastoral ministry and also the most difficult. It's important because people who are sick and people who are in pain need some assurance of hope and the presence of people who care about them and a minister, cleric, rabbi, priest has the opportunity to symbolize that, enact that. Um, so, part of it is, for me always, reminding myself when I go into visit someone that I'm there as myself, but I'm also representing the community that they're a part of. . . . And, uh, it's also important for them because it's one of those circumstances in life, especially if they're very sick or very much in pain, where they're looking for some comfort or support or some encouragement or hope from other people around them, and I can be most frequent, perhaps. [pause] So it's a very crucial ministry. It's also very, very difficult. (1)

While RR also described the work in terms of responsibility or duty, at this point in the interview, he said that it did not make him "uncomfortable."

RR: Uh, it doesn't make me uncomfortable. I'm not . . . I know a lot of people are very uncomfortable about just being in hospitals. Uh, that has never bothered me; nor has it bothered me to walk into a room where someone is sick or in pain. That's never been a problem for me. I think it's a pastoral responsibility of the ministry. (1)

Several clergy said that they enjoyed visiting their parishioners in the hospital because it is rewarding personally and because it provides a possibility for supporting people who are vulnerable. RK and RO are examples of this view.

RK: I feel very thankful to be a part of that. It's a wonderful ministry. I'm very comfortable doing it, and, usually, people are, are fairly open, vulnerable when they're not feeling well; and so they're more open to, um, my, anyone visiting, actually, but me also. . . . And these folks say, just right away, "Come." (2)

RO: I love to have it. Gets me out of the office, so it's kind of selfish. Um, but, especially with a hospital, actually both, with hospitals and the nursing homes, um, nursing homes generally having such a, in many places, a negative in our minds, a negative kind of connotation. Hospitals have a fearful, scary kind of connotation, for good reason. I like to go to hospitals, as long as I'm not the patient! [laughs] (2)

### Visitation routines

Both affection for their visitation work and frustration with it were revealed when I asked the pastors about their routines. RK carries just her keys and a songbook as she walks into the hospital.

RK: And I go up, just *really* trying to be open to the moment. Trying to not *have* too many set ideas on what I'm to do. And, um, I have found that really works pretty well. . . . But I do try and center and be at peace with / myself and my surroundings, so that, when I'm moving into their area, um, it's not a negative force, but a positive one, and one they feel they can hold on to. So, um, I am in prayer much of the day, and that is a preparation always. You know, we are to be in prayer always, as a process. (4-5)

Likewise, RJ spoke in terms of the connection between a routine of prayer and the ability to be more open.

RJ: I always pray just a little. I'll pray that Jesus will go ahead of me. I'll pray that God will make me open to what they need to say to me or what I need to perceive. Um, I'll admit that that's sometimes kind of on the fly in the parking garage at the hospital. [laughs] But I do try to prepare myself and try to get connected with God before I get started. Um, just so that I don't miss something obvious, *and* because that's, I feel that's what I'm called to do. (2)

RB spoke in the same vein about finding a quiet place to collect his thoughts about each particular visit. (1)

According to RF, he always has to be prepared for “false alarms,” where the situation turns out not to be as critical as it seemed when the family member first called about a loved one. (2) RL expressed frustration with the HIPPA rules that now make it so difficult for ministers to find out what is going on with a patient.

RL: Nowadays, with HIPPA , you see, there’s quite a different situation than years ago, where I could get diagnoses, I could get prognoses, I could get a lot of information for families from the nurse.

NC: Mm-hm.

RL: And that’s not true anymore. They can’t tell you anything about anyone. (5)

Often the recounting of their standard practices included something about calculations of the amount of time they should spend, planning to spend only five or ten minutes, but prepared to spend up to forty-five or longer, if necessary.

RP: So, I prefer to use short visits, short scriptures and short prayers, but frequently / . . . rather than wearying. Now, if the patient asks that I remain and stay, stay with that patient, I gladly do so; but, generally, if not asked, I will make it brief and then come back when that person is feeling better. (7-8)

RC described the motivation for short visits as attention to the patients’ vulnerability.

RC: And, uh, one of my chores is, though I’m to be attentive to the system, I’m there for the person—he’s the most vulnerable. And, so, I don’t want to stay too long. I invite them to talk about things. If they don’t, then I don’t oppose it because they’re held hostage, I mean they’re so vulnerable. . . . One part of my pastor’s training is to stand, don’t sit. (6)

Another important part of the ministers’ routines has to do with assessing patients’ needs. Although several pastors described this assessment process, RS explained this most thoroughly.

RS: I guess one of the things that I, um, kind of watch for is what kind of support system the person has. Are they there alone? Maybe there’s . . . maybe I kind of assess: Does it look like somebody’s staying with them *most* of the time, or just coming in *occasionally*, or do they have *no* support? So there is that kind of question. And, then, another is: How comfortable are they? Do



they seem like they seem like they need something, you know, physical or something like that. How able are they to really process information and communicate? On how deep of a level are they able to communicate? And then, then it just kind of depends on how serious the situation is. . . .Deep issues I probably tend to discuss first thing. If they're, if they're in for a short-term thing that they're going to fully recover from, that's different than if they're really in a process of dying, and everybody knows that. They may or may not know that. /

NC: Mm-hm. Mmm. You mentioned noticing if they needed anything. Are you talking something like: Do they need a drink of water?

RS: Well, everything: You know, how comfortable are they in the bed?

Does—it seems like there are less and less nurses that are available anymore, and so, unless a person has a pretty assertive advocate there with them, a family member or friend or somebody, who's . . . sometimes they even need, you know, clean sheets or just those kinds of things. It's really frustrating. But and then that goes all the way from that to how long has it been since anyone's talked to them? Maybe they were asleep when the doctor came in. Do they need more information, and then, sometimes it's things like do they need pain medication, you know, pain relief, you know, those kinds of things? What . . . how comfortable are they, I guess, physically? (1-2)

All the ministers I interviewed mentioned inquiring about how the patients were doing and offering reassurance.

RM: So, most of the time, when I go in to talk to a congregant, I'm just friendly and cordial, and ask them how they're being treated. And tell them they're looking wonderful and help them to change their thoughts from negative thoughts to thoughts of, you know, they're God's perfect child. Like the one individual I was talking about. She was just so embarrassed that I came to the hospital to see her, and she had, you know, the gown on. She's always dressed proper and prim and looking wonderful. And she was just like . . . so I had to let her know that, you know, that it didn't matter, you know, being all dressed up, which was a little bit of a concern. I mean, I'm sure that's a big concern for everybody—having their minister come in and seeing them in their jammies or not even their jammies. [laughs] So . . .

NC: She probably has jammies better looking than that.

RM: Probably [laughs] And so, and so, the first thing you have to do is to calm them from whatever ill ease that is and make them feel comfortable. (4)

All the pastors offered prayer at some point in the visit. Both RH (3) and RC (2) talked about how sometimes the ending prayer actually begins the meat of the visit because it gives the church member permission to cry or talk more freely.

### Non-Pain stories

The primary purpose of my interviews was to hear about the experience of ministers as they visited their church members in pain, and they recounted pain stories. However, how they react in pain situations needs to be understood in terms of their larger experience of ministering to the sick and dying. Some of these stories reflected on-going efforts to protect church members. RK's story about a widow in the hospital is an example.

RK: We have one lady that just got back from the hospital, and she said that she had sat on the toilet that they put in the . . . bedpan, I guess, that they put in the bed, for 45 minutes.

NC: Oh my.

RK: Oh, that angered me! That they had really—there was no reason to not take care of this little lady and she's real sweet. And, but that was in the past. Now that had happened the day before. She just wanted to let it out and to tell me about it. And, she said, "Well, there are reasons; there's always reasons," and then she started to be okay with it. And then I started to be real angry about it. [laughs] So I *did* go to the nurses' station and just asked for an update, just so they would be aware that the church was checking on this person. And I think a lot of times for our elderly, especially, those who are alone, who are widowed or have no children, I am a little bit more protective of them and do check on them, um, more consistently. (7)

Other non-pain stories revolved around the challenge of ministering to their church members in times of crisis. For example, two ministers told about working on ways to comfort families facing stillbirth. Others told about sitting with those who were dying or with relatives sitting vigil. They talked about how hard it was for them as pastors to deal with the deaths of church members who had become friends over many years. Two pastors recounted situations in which decisions about continuation of care seemed to be mired in hospital politics and problematic communications, and one spoke about particular elderly church members declining care out of fear of such a

thing happening. One discussed the challenge of ministering to Alzheimer's patients and their families when helplessness hangs in the air. Although most of the non-pain stories involved parishioners, some of those that were most emotion filled were those about family members of the ministers and about themselves. For example, RD ventured into the problematic nature of the cancer society's survivor walks.

RD: It is interesting, you know, with the cancer thing, the whole—I think I may have talked to you about this before was the survivor issue, when you go to the really pro-life. They have the survivors' walk and everything. For people that have lost their loved ones to cancer, the whole survivor issue is the tough one.

NC: Sure.

RD: It makes it seem like, somehow, they didn't try quite as hard as those who survived.

NC: Yeah. Yeah.

RD: You know, I just don't think, in my parents' case, that's not true. So, but, by the same token, you don't want the survivors to feel slighted, so . . . I can't think of a better term for 'em. (25)

It is within this general context that ministers come upon, witness, and make decisions about how to deal with patients in pain. With this in mind, I will continue now to the analysis in terms of my relational theory of pain.

### **Factors that Support Successful Communication of Pain**

As I explained in Chapter 1, I did not discuss my theory of pain with the people that I interviewed. However, I am arguing that it will be useful to use the theory as a lens with which to organize the ministers' responses, and that the responses can enrich the theory (which I will discuss in Chapter 3). In this section, I will recount instances in which it appears that contained pain, that is, pain experienced by an individual, successfully became communicated pain. I will do this by listing first some

instances of the ministers' discussions of pain where there appears to be no doubt that the patients were in pain. Next I will show some of the resources and strategies that the interviewees said that they use to minister to their church members in pain, including ways in which the ministers attempt to provide comfort to the congregants. And, finally, I will conclude this section by providing examples of feelings respondents said that they have when their church members are in pain.

### Criteria Ministers Use to Determine if Patients are in Pain

Sometimes pastors are present when patients are using a pain scale, and the pastors do not question what the patients are saying. RJ told a particularly compelling story about such a situation.

RJ: I have one in particular. I have a 90-or-so-year-old woman, who, you know, they wanted her to get out of bed. They didn't want her to just lie in bed because she might get bedsores and things. And, they sat her in the chair. And she said, "Oh, it hurts so much." And the nurse had been there, and she told the nurse, and the nurse, "Oh, we have given you this medicine and it will probably take effect soon." And I remember asking her, "What, on a scale of one to ten, how is your pain?" "It's a twelve," she said. It was just heart-breaking, and I felt helpless, and I prayed, and I felt like *this* isn't going to do any good! [laughs] I mean, there's the faith and hope! [laughs]

NC: [laughs with her]

RJ: It was just . . . and she was frail, and I could just . . . I could imagine those bones rubbing together, and, you know, a back that's starting to collapse. And she died about a week or two after that.

NC: Oh, my!

RJ: Yeah. She just . . . she just fell apart. She just said, "I can't live anymore." And I think she really just gave up.

NC: Mm-m.

RJ: And I don't know if medically they *could* have managed that pain better. I don't remember. I just remember that helpless and her saying, "It's a twelve!" But go! At least she *said* it! (10)

In other instances, a pastor may ask a parishioner directly about pain, though not using the pain scale. RC's story of a lady in his church who has back pain is an example.

RC: I was thinking, as you were talking, I think I'm more aware of pain among parishioners here at church than I am maybe in the hospital. Because in the hospital, you're, so traumatic going on, there are all kinds of issues, and I'm there for a short period of time. But here in the parish, here over time, I accumulate lots of information. One of our elders, she has serious chronic back pain. And so, I ask her about it, you know, usually on a weekly basis. And, you know, I'll touch her on her shoulder, and I'll say, "How's it feelin' today?" (12)

Sometimes patients need no prompting to say how they feel about their pain, or ministers hear sounds of pain coming from patients they are visiting (or patients in the next bed), and they don't question these sounds at all. RE told the story this way:

NC: When you are visiting a patient, who is, um, in pain, what kind of things does the patient say to you?

RE: You don't want to know. [laughs]

NC: Oh! [laughs with him]

RE: Um, it's not real pretty, a, if they are in real pain, you been a chaplain, you know, um. They want relief!

NC: Um-hm.

RE: They would sell their soul to the devil to get relief.

NC: Yeah.

RE: Um, no pun intended, I mean, when you hurt that bad, it's your screaming at the top of your lungs because of it, um, whatever deal you need to make, you're going to make it. (10)

In just as many cases, however, pastors rely on body language of some kind, or both body language and words, to determine whether persons they have come to see are in pain.

RH: But sometimes I would specifically ask about, um, their pain level, and how they were, um, experiencing that. Um, you know, and I would observe the responses, as well as listen to the words, you know, facial expression and, um, and so forth. (5)

Later in the interview, RH said that if a person in the next bed were "calling out in pain" or expressed pain through "obvious wincing," he would check with the nurse.

(7) As she described one of her church members under hospice care, RL related that it

was the behavior of “restlessness” that helped the family to know that the patient was in pain. (15) RO used the term *agitation*.

RO: Right. Sometimes, people will be in pain, but they don’t say anything. And the only way you know is if they are very agitated.

NC: Mm-hm.

RO: It took me a while to figure that out, but agitation often means pain. (17)

In other cases, ministers assume pain in patients because of procedures they are undergoing or because of the disease that the patients have.

RC: ‘Cause touch is also an important component of hearing and listening and I think touching in appropriate ways, and also in the hospital, you know, I usually touch people on the arm—not where they been stabbed.

NC: [laughs]

RC: Because so much of the touch in the hospital is painful. (12)

Three ministers talked about the pain of bone cancer. RR did not say what kind of cancer his friend had, but RR “knew he was in great pain.”

RR: I’ve had close friends, very close friends like my friend—a clergy colleague of mine just died of cancer. [His eyes tear up slightly here, but he keeps talking—no pauses.] And I spent some time with him, and, and, knew that he was in great pain. (6)

When she was visiting a patient who had HIV/AIDS, RS used the patient’s words, his body language, *and* his physical condition to determine that he was in pain.

RS: So, it was really a terrible struggle, his death. But, part of what happened is that he had, he had, a, rectal cancer, and he—*literally* the skin and muscles and flesh and everything from his whole backside were gone. You see his colon, you see all his organs. I mean, it was just *unbelievable* what his body was like. And it was absolutely just bizarre to think: Here’s this person who’s alive and talking to me, and they’re almost, I mean, their body is just falling apart literally. But, anyway, so he was in just tremendous pain. And, as it got worse and *worse*, and I was spending a lot of time there, and sometimes I would stay six, eight hours at night, late at night. And so I would *know* when he had last had pain medication. And so and rarely did the staff come in there, especially at night. And, I guess ‘cause if they knew I was there or some other volunteer was there, maybe they didn’t come in as often because they knew we were there anyway. But it was a real tiny room. There were flies. It smelled

absolutely horrible. It was just an awful . . . because of his body in this woundedness was open. But, anyway, he was in and out of consciousness, didn't talk a lot, but sometimes said some things that made you think: Yeah, he's still in there. He's still conscious, he still kind of knows what's going on. And I would ask him, "Are you *hurting?*" if he was awake and he was kind of talking or something. And he would just say, clear as, "*Yes, oh I hurt so much. Please, please help me!*" (3)

### Resources and Strategies for Ministering to Those in Pain

RO: If somebody's in great pain, um, I concentrate on that person, and everybody else has to wait. (5)

When the ministers I interviewed believe that a patient is experiencing pain, they use a variety of strategies, including distraction, praying and reading scripture, singing hymns, gentle touch, or providing a quiet presence. I'll begin with distraction.

RF: I can think of one time I had a young man, who was having a spleen removed; went and spent a good deal of time with him prior to the surgery. And, we put, this was at the children's wing of a hospital in Dallas, so they had these kind of wonderful like game rooms and stuff like that. So, we spent the time in there playing pool. And I think that helped to, you know, distract and calm him before he went into the surgery. (7)

RK described a group of women from her church who would dress up in silly outfits and sing songs to patients in their hospital rooms, as a kind of distraction. In addition, she would tell the patients little details of what had happened at church since they were last there, "kind of talking about the weather type of thing" (7). RE told about using his own experience as a patient to convince him that distraction can be an effective tool of pastoral care.

RE: [sighs] Number one, you pray before you walk in there, you're hearing screaming, know that there's nothing that the nurse can do anymore, whatever. You know, um, you just, I hold hands. I'll sit there and I'll hold their hands and I'll try to, again, use as much of the gifts that I have to let them refocus, um, on something other than the pain. But, it's hard. I mean, as I said, I had prostate cancer surgery and I had total hip replacement surgery.

NC: Oh, wow!

RE: And, um, and as much as I could distract *myself*, so I used my body as a living example of, hey, if it hurts, I don't like it.

NC: [laughs] Right.

RE: And what do I do about that? You know, so the one thing I've always found is that, if somebody would come in and visit me and would get me talking about something that was a hundred miles away from the hospital, then my focus was starting to move. It doesn't change that fact that I got pain. I *know* I got pain. See, I'm a person who doesn't like pain.

NC: Mm-hm.

RE: Okay, I don't—nothing to do with it. But, if I can . . . when my focus is away from that, then it somehow, even for a moment, dulls the pain. (5)

Not surprisingly, offering prayer and reading scripture are tools these ministers use to provide comfort for those in pain.

RD: You know, "Dad would like you have a prayer." Then you know that they at least want you there for the prayer. And then, it is awfully hard to talk to a person in that much, in that state of being because they have a hard time getting past their pain or whatever it is. But I do think there is some comfort there. And one of the things you can do, of course, is read the Psalms because the Psalmist, in several of the Psalms, is in it sounds like a lot of pain, you know, "My bones cry out to you! My bones ache!" Some people have said that it sounds like a person dying of AIDS. (10)

RJ: Which is why you have Psalms that say, "Oh, God, you've crushed all my bones" 'cause that's how it can feel to people. But that God *doesn't* crush our bones or hurt us or make us sick. Um, you know, that there is grace, that there's hope, that you . . . there's some kind of hope, whether it's learning to live with chronic pain or that your pain's / going to get better. So, those are real deep, kind of *basic* theological resources that are really, I mean, they're essential. (7-8)

In addition to touching and holding hands, ministers try to provide what RL referred to as "a healing presence" (2) or silence. Both RD and RK described using prayer and silence. Here is what RK reported.

RK: And, um, I think, if a prayer is said, and they can feel like they are participating and God's right there in our presence, which God is—where two or more gathered together. Usually it will be prayer that I would begin with, and then I am silent. I am not afraid of silence. There's nothing wrong with it, and so sometimes you need to just sit there and *be* with them, just be present there, silent . . . (7)



RY explained that she uses all of these methods—touch, prayer, and a holy presence through music.

RY: Um, you know, the way I see my role, above all, as a minister, is that I'm one of the few people, particularly if somebody is in the hospital, I'm one of the few people coming into the room who's not going to be sticking them or [chuckles]

NC: Yes.

RY: taking their blood or whatever. So, I just try to be there and to touch, hold hands, and, you know, at the prayer time, I ask what *they* want me to pray for. And then, I always include the Lord's Prayer, because then they like to join in on that part. Um, and I also sing a lot.

NC: Oh, good!

RY: I . . . yeah I heard Tex Sample say that a story about that one time. And I thought that was a good idea. So, I try to bring, especially when people are like towards the end and they can't talk and they're not very lucid, necessarily, um. I really try and sing, and, you know, there's some amazing stories about people who have been practically unresponsive and then they'll come out of it and just sing one of the old hymns. We had a fellow shortly after Christmas last year, um, who sang "Silent Night" in German. He was a / big . . . he loved to sing in the church. And he came out of it to sing "Silent Night" in German.

NC: Oh-h-h.

RY: Yeah. Yeah. So, that's really good, and I think people really like that because the music is comforting to them. (2-3)

In terms of specific education about ministering to those in pain, none of the ministers said that they learned about pain in seminary. Rather, the emphasis was upon psychological pain, such as "crisis ministry" (RP, 10), or upon general skills of "active listening" (RJ, 7; RO, 21). More than half of the ministers interviewed received clinical pastoral education (CPE) training as part of their seminary work. This training involves a regular schedule of visiting (usually) hospital patients, and a program of introspection and personal growth that comes from reflection with other seminary students and a supervisor about particular events of visitation. Three other persons interviewed described CPE-like training as part of their seminary's field education.

The seminary classes they took in pastoral counseling did not seem to them to transfer clearly to the hospital bedside. Moreover, in one case, it was clear that some seminary professors did not see the relevance of CPE.

RR: CPE was a required component of seminary when I was in seminary in the late seventies. I think it still is a required component. Clinical pastoral education, intervention in crises, dealing with people who are ill or dying. Um, how to listen, how to respond, how to be present in ways that are helpful and not harmful. I think it is a standard part of graduate theological education now; that's my understanding. It should be. It should be. It was always called practical theology, as if there is any other kind. Um, and it was always relegated to a sort of light-weight status in the curriculum. Like you take CPE, that's how you make the hospital visit and some things to avoid, and so on, and so forth. I can remember a strong prejudice against CPE by the "real" academicians, people involved in New Testament studies and systematic theology and social justice issues. They thought CPE was like driver training or auto mechanics; it was, it had to do with doing things, as opposed to just thinking about doing things. [laughs]

NC: [laughs with him]

RR: So, you know, there's this prejudice against, um, practical theology, as if we are learning theology for any other reason but praxis. A little philosophical aside. [laughs] (9)

RY agreed that, while pastoral counseling was a "fairly big emphasis" at her seminary, visiting people in the hospital was not. When I asked RS about what she learned in seminary about hospital visitation, she answered this way:

RS: I think the focus was on trying to help them feel God's presence in some way in the midst of everything that was going on in the hospital, and care for family members and other people involved in that in those circles. But, and, and, and probably some, a little bit of sensitivity training in not being a *pain* myself while I was there! [laughs]

NC: [laughs, too]

RS: But, a, not being irritating, avoiding certain things to not be irritating. But, just real, not much training at *all*, related to hospital visiting. [pause] (13)

A number of ministers did remember learning about turf issues in seminary. I will discuss those issues in the last section on advocacy below. Those who did take CPE in

seminary said that this helps them now only in that, during that experience, they became used to being up close to persons in pain. RK is an example.

RK: CPE, there you go. Thank you. Um, that was very difficult for me because I had never been able to handle anyone else being in pain. It just . . . I feel the pain, and took some healing touch courses, which were very easy and that I could feel the energy in the body and that sort of thing, so I had to kind of learn to iso- . . . or cut that off and so put a little bit of a wall of protection there because I *don't* want to feel the pain. I want to be strong for them, but I also want to be compassionate. I learned *so much* during that CPE time, but it *hurt* every day to go in and see those people in pain. I . . . it was the hardest thing; and, by the time it was over, I was, I really enjoyed visiting people in the hospital. I could say I truly enjoyed it. But I had shut off that empathetic wall, whatever it is that allowed me to feel . . . and I'm saying I truly, physically felt it. You know, if they were nauseous, I became nauseous. [laughs] Whatever . . . if they were having their leg operated on and I could see that there were wounds or whatever, my leg just ached like heck.

NC: [chuckles]

RK: So, um, I *did* learn to shut a lot of that off.

NC: Mm-hm.

RK: I think that's kind of self-preservation. (8)

Others did not recount this kind of problem, but they did speak of standing near even in uncomfortable situations. A much more significant source of education for the ministers I interviewed derived from their own experiences, especially with particular patients, with their own family members, and with themselves as patients. What their parents needed as patients in pain, and what they did or didn't get from the doctors or nurses or chaplaincy service had a special place in their hearts; and these experiences continue to influence their efforts for their parishioners. In spite of their training in CPE or course work in pastoral counseling, they seemed to be unaware of the discussion about this topic in the pastoral care literature.

#### Acknowledgement of Feelings about Ministering to Those in Pain

When I asked these pastors how they felt when they were faced with parishioners in moderate to acute pain, they generally responded soberly and thoughtfully. Though they appeared to be trying to be objective about their own responses to the patients' pain, their responses seemed raw around the edges.

RD: Yeah. But, of course, it's hard to be in the room with somebody who is yelling because of their pain.

NC: If you did go in the room, and somebody was yelling, um, what would be your response? You know, would you just be with them or would you talk to the staff, or what?

RD: I think I would ask them if it's okay for me to sit there with them. "Is it okay for me to sit with you through this?" And go from there. 'Cause they may very well not want you to be there.

NC: Mm-m.

RD: I have been with people who are dying, who can barely breathe,

NC: Mm-hm.

RD: and yet I got the sense that they wanted me there. And I didn't ask if they wanted me there. So, I guess that's an interesting question because, if they were yelling out in pain, I probably *would* ask because of my own uncomfortability being there. (9)

So much of the discomfort on the part of the minister has to do with being up close to the suffering but not know what to do next.

NC: Mm-hm. Um, when you're...so, are you saying, then, mainly you just feel helpless or . . . ?

RE: That's a good word for it. It's helpless and you're relying on the Holy Spirit to say, "Hey, you know, try this, try that." You know, God give me strength, you know. That's why I have a prayer before I go into the hospital room. I say, "God, get me out of your way so whatever, so you can do your magic and, you know, I'm not blocking . . ."

NC: Uh-huh.

RE: Because I honestly do not know . . . I've worked in the ministry, now, for 25 years. I don't *know* of a way to really *remove* pain from a person. (6)

Powerlessness was a common feeling.

RC: Well, it hurts. It hurts to hear that people are in pain, you know. A big part of ministry's there are lots of things that you can't do anything about. (13)

RL: Um, [pause] well, with early hip replacements and knee replacements, post-bypass surgery, accident victims . . . Yeah, I can remember . . . [pause] It's tough, seeing someone suffer and not being able to alleviate it. You know.  
(1)

In spite of their discomfort and helplessness, ministers retained determination not to abandon their parishioners. RK talked about needing to be prepared to accept patients even when they lashed out in their pain. (5,6) At one point in my interview of RP, I asked about whether visiting someone in pain ever brought up memories of the same kind of situation with himself or family members. He answered this way:

RP: Hm-m. [ long pause] Yes. I do see the similarities. Um, as far as its being overwhelming, no. Um, but I am conscious of the other situations and do see parallels. Um, and I think one of the ways that I'm able to keep it from being overwhelming in these situations is to realize that, that I am there in the capacity of performing a ministry. [Here, for a second, RP seems a little bit choked up.] . . . And that ministry calls us often into uncomfortable situations. Um, but, nonetheless, nonetheless, I go because how can one really say one loves one's fellow human beings if one is not willing to risk painful memory, risk being in a situation that might be uncomfortable physically or emotionally?...(10)

Because the ministers I interviewed responded to the relationality of pain, in the instances described, contained pain became communicated pain, and they developed a repertoire of resources and strategies to provide support and comfort as well as they could. However, as I will show in the next section, a number of factors can work against the communication event of pain. What the ministers said reveals an awareness of many of these factors which prevent or diminish the communication of pain. Some factors were out of their awareness, however.

### **Factors that Work Against Successful Communication of Pain**

A communication of pain event may not occur or may occur incompletely for a variety of reasons. Ministers may just not notice that their church members are in pain, patients may minimize or conceal their pain, or ministers may doubt the possibility or character of pain because of the subjective nature of pain, thus diminishing the effectiveness of the communication of pain.

#### Difficulty Remembering or Not Noticing Pain

A few of the clergy in the study had trouble remembering incidents of visiting parishioners who were in moderate to acute pain, at least at the beginning of the interview.

RF: I prepared for this interview, I kept trying to think of—there's *got* to be at least *one* incident of someone *really* in pain . . . and maybe they just all run together. (7)

As RK said in the section above, because patients in pain sometimes say ugly things that they don't mean, she tries not to remember about events of her parishioners in pain. (6) According to RL, pain management in her city's hospital has improved so much in the last several years, very few patients suffer from acute pain in the hospital. However, she admitted that she might not notice the chronic pain of those who come to church.

RL: I don't ever walk into a room and hear someone moaning and groaning and, you know, complaining. And I *always* ask if they're having pain.

NC: You do.

RL: Yeah. I always do.

NC: And then, how do they . . . ?

RL: Today, almost always, "Not much" or "A little bit" or "I have this little button here and I can push it" or "The nurse comes and will give me medication if I call for it." And, they do, and they get people going quickly. I think . . . actually, an experience / I've had is there's more pain pre-surgically, especially on replacements like knees and hips. And, a lot of times I won't know how much pain a person's been living with.

NC: Ah-h-h.

RL: And then they'll go in for replacement, and I'll say, "Are you having pain?" And they'll say, "Oh, yeah, but *nothing* like before I had the surgery."

NC: Oh.

RL: But, was I aware that they were suffering with every step? Un-ah. (2-3)

### Minimizing or Concealing of Pain by Patients

A factor that may lead to clergy's not noticing pain or their being unable to remember many times that they were visiting their parishioners in pain is the church members' deliberate attempts to conceal or minimize their pain. Although the clergy interviewed did not make this specific connection, it was clear that they were aware of patients' withholding of pain information.

RD: People just don't, they don't want to complain about their pain. And you really have to dig if you want to hear about it, if you want to find where the pain lies. (24)

Patients might conceal pain from people in general or, specifically, from family, from physicians or nurses, or from the ministers, themselves. In this general category, the primary reason, from the perspective of the ministers, is the high value of endurance and stoicism.

RF: And, what I have found, you know, when you kind of ask those questions at the / time, you know, "Are you okay? Are you in pain?" with a lot of them, you kind of get this sense of like, "Oh, yeah, but, you know, I'm going to push through." They're not going to go home and rest. They're here to do this other thing that's important for them. I guess they're just going to grin and bear it. (15)

RL: Yeah, there's some sense, "Well, I shouldn't be complaining, you know, people have it worse than me, and I don't want to be wimpy . . . . (2)

RH, like a number of other ministers, described this as a result of a kind of "socialization" to the idea that, "Well, I'm not supposed to complain" (6). However,

the ministers offered different sources of this socialization. One was the farming culture.

RD: Well, I know in this congregation, there is kind of a stoicism, and I think people might be hesitant to talk about their pain just because there is sort of a farming mentality that you don't complain. And even if you're in pain, you don't talk about it. You just say, "Oh, yeah, I'm doin' okay." (19)

Describing his own experience of growing up on a farm, RE described determination associated with farmers' identity as a motivator of endurance in the face of pain.

RE: That, you know, so that piece, you know, there were . . . us men decided we didn't want to deal with pain, so we didn't. / [What he means here is that the men decided that they were going to deal with pain by not getting sick. But just before this speech, he listed the illnesses of his father and brother.] We three males decided that we were never going to be sick. [He acknowledges the irony here.]

NC: Especially, I would think, because maybe the farmers spent most of their lives successfully ignoring pain . . .

RE: Um-hm, um-hm. Yeah, you don't—you go to work. You were taught you go to work, and so you deal with it. And to lay down and not be able to work, you know, is sometimes even more, um, degenerative than the pain you're having because all of a sudden, again, if you're not out there working, where's your value? So you've got all the pieces built upon each other. Yeah. I don't know . . . (16-17)

RK's description of an event while she was working on her parents' farm reflects the same sort of perspective.

RK: I've had a *lot* of pain in my life, so I am . . . I've sure experienced a lot. I had . . . when I was working on the farm, dropped a huge pipe. We were putting fence posts in the ground, this big metal pipe, and it land . . . and I was so exhausted and Dad was starting to get sick. Dad died in '96. And I was trying to do his work *and* mine, trying to do the work and not have to hire someone. And I was on my umpteenth fence post, and I threw—you have to throw it up and then bring in down *hard*, and up and hard. And I threw it up in the air, and I just didn't have the strength to catch it, and it came right down

NC: (gasp)

RK: on the middle of my head, and I thought my head would explode.

NC: Oh no!

RK: And I didn't go to the doctor. I just did *not* want to go to the doctor. Usually, but . . . I'd say I had about a week-long headache, so it was probably a



concussion or something, I don't know. But, I have *since* then had a lot of migraines and a lot of odd pains, kind of behind my eyes and things. So that's one. And then I've taken falls off horses, did things to my back, my back was curved a little. (12)

After telling a story about a church member who experienced an episode of "sudden excruciating pain" (4), RP expressed appreciation of the rural understatement "Boy! That sure got me!" (5).

Other possible sources of socialization included German ancestry and culture (RY, 3) or Midwest culture (RD, 24); but RR ascribed socialization toward endurance as a matter of American culture.

RR: Yeah. My experience is that most patients don't talk very openly or freely about how much pain they're in. There's almost a stoic quality that we've learned, that even if we're really, really hurting, we shouldn't say that because that just brings the other person down and that's a bummer. And so my clues about the level of pain someone is in usually comes from looking at the person and trying to figure it out.

NC: Mm-hm.

RR: Sometimes I'll ask a patient, "Are you in a great deal of pain?" And, if I broach the subject, then they are free to tell me how much they're hurting or how they're hurting. Otherwise, they don't seem to bring it up on they're own. That's my experience anyway.

NC: Mm-hm. Do you think that's part of the Oklahoma culture or . . .

RR: [laughs] I think it's part of the American culture.

NC: American culture.

RR: We're not supposed to complain. If we talk about ourselves, then we are being somehow selfish or self-centered. (1)

In contrast to seeing the source of socialization to endurance or stoicism as a matter of location of socialization, some pastors pointed to the importance of age. Older people are more likely to try to endure, they said. RD used the term "older mentality" (20) to describe what keeps people from complaining or encourages them to go on with life in spite of pain. RJ's recounted how difficult it is to get "older folks" to reveal their pain.

NC: Mm-hm. Well, um, what, then, goes through your mind, what happens, then, if you are there, and you can tell that the patient is having a lot of pain?

RJ: Well, I'll ask them. In fact, even if I don't get cues, I will often ask, "Are you in pain?" And, um, try to be, depending on how they answer, trying to let them know, "You can tell your nurse if you're in pain." There is a generation of people who were really taught to buck up. And saying, "The reason the nurses are here is to help you,

NC: Yes.

RJ: and maybe you *can't* have more pain medication, but *please* ask!" You know, "Don't assume or don't assume 'I can make it until they come.'" So, I try to be sensitive to that, especially in older folks,

NC: Yes.

RJ: who, for whatever reason, have been taught to be strong. [laughs]

NC: Yes.

RJ: Which is a good thing; you know, there are good things to this. Um, and sometimes they'll tell me, but I do try to ask. (3)

RC described this group as the "World War II generation" (13). When I asked RC about whether he thought his church members would make an extra effort to find out about pain control or insist on it, he responded negatively, saying that the World War II generation may complain about a lot of things, but they won't complain about their own pain.

RC: Probably a third of my congregation is 65 years old or older. Among that population, I would suspect that they don't know anything about pain management, unless the physician they happen to be seeing is attuned to that and thinks it's important. Because the World War II generation, generally, they, they're tough. They complain a hell of a lot, but they have this idea of "I have to get through it. Just the way it is." And those kind of dynamics don't lend itself to I'm going to knock on every door until I can find someone who can take care of us, or I'm going to network and talk. Because, you know, you bitch about the world, but you don't complain about yourself. You know, that's kind of the World War II generation. People in the church will complain about every rule, any change, but, you know, they show up. If they say they're going to do somethin', they do it. You know, they apologize, "I couldn't get here, I didn't feel well." Or they say, "I couldn't find anything better to do today, so I came to church..." [laughs] Cultural gap. (13)

In addition to reasons of socialization about endurance, another reason that patients might decline to communicate about their pain, according to some pastors, involves privacy or a kind of self-protection.

RL: And a parishioner just fell, just had two hips replaced and one knee replaced and fell and cracked her ribs.

NC: Oh, dear.

RL: I *know* she's in a lot of pain. What she does is stay home and not let somebody see her or . . . . (3)

Likewise, according to RE, when he was in the hospital recovering from surgery, the idea of being in pain in private was important.

RE: And, so, you know, just leave me alone. I want you [the nurses] to . . . when I ring the bell, I want you to be here. I want you to do what I want you to do, but leave me alone, please. (3)

RD described how it is difficult for him to minister to his parishioners who are in pain but not letting him know. However, he understands their reticence entirely in terms of a privacy issue, which, he explained, is related to an issue of safety.

RT: You know, talking about what kind of medication you're on is taboo to another person. We don't tell each other what kind of drugs we're using—anything, really.

NC: Hmmm.

RD: 'Cause I guess it goes back to the whole primitive idea you don't want to be seen as being weak.

NC: Ah-h. /

RD: I've read that animals, sometimes, if they hurt a foot will not limp because they do not want to send a message to other animals that they're in pain because they might get attacked or something. And I think that is probably still there. You know, we don't like to show that we've got a weakness, 'cause then, who knows? Our weakness might then be exploited or . . . You know, as a pastor, you don't want people to know that you've got—I don't go around telling everybody that I'm lactose intolerant. [laughs]

NC: [laughs]

RD: You know? Or other issues, you just, you don't want people knowing, which is silly, but I'm sure other people are the same way. They don't want people knowing everything that's wrong with them, which makes it hard to minister to people, who are not willing to admit that they're in pain. (23-24)

Although the ministers interviewed did not mention physicians, nurses, or healthcare systems and practices as sources of socialization to endurance, they often recounted events of patients in pain that could be viewed as events of endurance education. For example, RL described a church member who was in extreme bone pain when she arrived at the hospital; but pain medication was not provided until after the woman was x-rayed.

RL: And I don't think the nurses expected her to die because often they will tell me, "I think this is the end. Call the family." You know, and she said, "You know we gave her tests today and it's very painful just to be x-rayed and we made this brace for her and think the doctor's going to order something tomorrow. She's sleeping now." So, she wasn't in pain when I saw her; she was asleep. They had medicated her, and she died in the night.

NC: M-mm.

RL: But she had bone cancer! And her whole spine was cracking on her!

NC: Oh!

RL: No wonder she was in pain.

NC: Yeah.

RL: Horrible! (6)

In another example, RO discussed his own situation post-operatively after knee replacement. Although he tried to decline endurance, the system built upon the chart demanded endurance from him, taught him that it was the only choice at critical moments.

RO: And then, so all they had to . . . I mean, and it's, I'm sure it's not so easy for them either. So all . . . they would come in and ask me, "How's your pain level?" Well, it was a different person. And I'd say, "It's an 18." [laughs] Um, and they would look at the chart, and they'd only have the paper to go by. And, I would say, "The doctor told me I could have some pain medication in three hours, rather than four." And that person would say, "Well." The nurse would say, "Well, we only have four-hour increments here, intervals here on the paper." And, so, you know, [laughs] you're kind of a victim of the paperwork. *They* don't want to make a mistake, because *they* don't want to get in trouble. Um, in the meantime, yourself or somebody else, is in pain. And, they would

like to . . . and you're dependent upon that person, 'cause you can't get out of bed. [laughs]

NC: Mm-hm. /

RO: Or *I* couldn't, and most folks can't. Um, and you're dependent; so you're dependent on that other person to make that judgment. When they, first they ask you, "How are you feeling? What's your pain level?" you can say, "The doctor said I could have pain medication at 2:00." They say, "Well, you can't really have it until 3:00." And so you got another hour to get through, and so that's an issue in terms of pain.

NC: Mm-hm.

RO: Not being able to, even trying to manage it, yourself, having some empowerment to do that.

NC: Mm-hm.

RO: But yet being constricted by the chart. (8-9)

Even ministers, themselves, may encourage endurance, rather than more effective pain control. RP recounted one way in which he attempts to encourage patients.

RP: For example, if a patient has just come through surgery, of some kind, let's say orthopedic surgery, which, forms of is, such as patella replacement, it's very painful. Um, and the patient will be in distress, will visit with them, let the patient know that I am there. But also, in some form, communicate to them that, yes, hang on, this is a temporary situation. And although it's unpleasant, it will, in two or three days, you will be feeling much better. (3)

In addition to presenting reasons that their church members may have concealed or diminished their pain to a *general* audience, the ministers interviewed reflected a clear awareness that patients might prevent a clear communication of pain with *specific* audiences. One such group is the family. RC discussed this when he said that patients might "diminish" their symptoms in order to protect the family.

RC: So, it's a very complicated thing. But I think, with people who have serious diseases, and they've been in the hospital, and it's not all together that they are going to beat this disease, and a component is fighting for it, they can't let down with their family members. You know, that's a real struggle for people in the hospital, and that's real important to be able to visit with them alone, without the families. (9)

The two groups with whom patients might be least likely to speak candidly about their pain, according to that pastors, are healthcare providers—physicians and nurses—or the ministers, themselves.

According to RF, some patients will minimize their pain to their pastor because the patients see their primary role as provider of health status information for the minister to take back to the congregation. Another related possibility, according to both RC and RH, is that the church members will not talk about their pain because the minister has not given the members permission to do so.

RH: A, sometimes I would engage in some permission-giving around that. It's like, "Well, it's really okay, you know, to just acknowledge when something hurts." (6)

Although none of the clergy I interviewed holds the theological view that God sends pain to people as punishment or to teach people a lesson, a number of them expressed awareness that some church members have those beliefs, especially under the pressure of serious illness or injury. Giving permission to patients to express pain is important because of patients' possible concern that voicing pain to the minister will mean lack of faith.

RL: And, and I don't know whether people are this way with their doctors, but, I think maybe with their minister, at least with me, they try to put on a good face or a stiff upper lip or minimize what they're experiencing.

NC: Sure. Do you think they do that now? (1)

RL: Yeah. I think so. I think they probably have . . . there's some sense, "Well, I shouldn't be complaining, you know, people have it worse than me, and I don't want to be wimpy and I'm supposed to have faith, so, like, you know, if I don't have . . . If I show you too much of my pain, maybe shows that I don't have any faith." I don't know what goes . . . I never really stopped to think about what might be going through their mind. Um, [pause] But I still think that they want to be *good*, Christian parishioners. (2)

Later on in my interview with RL, she described a patient with chronic pain who did not want RL to visit because the patient did not want RL to see her in pain.

RL: She wanted me to love her, and she, I think, did have this idea that she maybe wouldn't be lovable if she was in pain. (11)

RD compared patient reaction to ministers and doctors, saying that the difference involves a related issue of authority.

RD: Usually, you have to try pretty hard to find out how they're really feeling before they'll really tell you that they're having pain. And it's kind of interesting to me that you've got to try that hard. I met . . . If it's that hard for a minister to find out, it's probably even harder for the doctor, because there is this old mentality that the doctor's almost God. You know, you can't criticize the doctor. I had to work with that with my parents. (19)

Patients withhold from physicians and nurses for a variety of reasons, according to the ministers I interviewed, and most of these reasons seem rational to them. Sometimes the reasons have to do with protecting the medical professional, sometimes with protecting the patients, themselves, and sometimes both.

RY: I often will find that. They just don't want to complain. They don't want to, you know, be trouble. (4)

RJ: I think they may occasionally perceive the staff as busy, but I don't know how much that's coming in. Or don't want to be a bother. The staff *is* busy. (3)

RL: So, I would definitely advocate for patients, should they not be able to do it for themselves or like you mentioned, they're holding back because they don't want to offend the nurse or the doctor or have a cranky nurse. I know how that is. You don't want to buzz for them, they were just here. You know, you don't want to be a bother, you don't want to be a bad patient. (3)

RL: I can see with women. I see it in myself, wanting to be strong when I go to the doctor, so I'm not surprised that women wouldn't, they might hold back about how severe the pain really is—they don't want to be labeled "a chronic, complaining woman." It's psychological thing. (9)

The very idea of trying to work with the nurses to find a better medicine for pain control may encourage patients not to voice dissatisfaction because making contact with the doctor can sometimes be so difficult.

RY: You know, sometimes, it's just that the staff can be so difficult to track down and trying to trace, you know, test out all those medicines can be difficult. (4)

According to RC, the entire context of the hospitalized patient might encourage reticence to voicing pain to healthcare providers.

RC: You know, and you're dressed in these gowns and all of these things, and so, and it's exhausting. People are poking you at 4:00 in the morning; you lose all sorts of privacy, all sense of control. And it's frightening, you know. You don't know what's going on and what they're going to do. And so, one of the things I do is, you know, I'll say things like . . . if anyone's been in the hospital more than three days, I assume that they're depressed because your sleep is interrupted, you've lost control, and a lot of times I'll say, "I was in the hospital once, and after three days, I got depressed." "Well, yeah, I'm depressed, too." I say, "And after about three days, I started wondering if I was ever going to get out of here." "Well, I feel that . . ." You know, and sometimes they do. It's a common experience, you know. And so, that's one of the ways I confirm their pain, or confirm and give them permission. 'Cause you don't want to complain in front of the doctor, because you need him or her to—you don't want to drive them away.

NC: So you find that, even if they think that some part of their treatment is not going quite right, they're reticent to say to the doctor?

RC: I think they don't want to disappoint the doctor.

NC: Right.

RC: And, well you have waited, you have waited twenty-four hours for the doctor and you get six minutes with this doctor. So this doctor holds your life in his hands or her hands, you think. And they do more than anyone else, and so you hang on every word and want to hear the very best of every word and so it's not really a time when you complain about what's going on. You know, when the doctor asks what feels wrong or what hurts, the patient wants to be as accurate as they can, but they also want to be getting better. You know, you want to diminish what your symptoms are. (9)

In another part of the interview, RC was more blunt in terms of why patients might be careful about appearing to criticize a care provider.



RC: They don't want to piss off the morphine nurse, you know! What if she won't punch it, you know, or if she will break it. It's serious business. (11)

RC is talking here about the mechanism that controls the patient-controlled analgesia (PCA) machine.

### Clergy Doubt about Pain

The ministers I interviewed expressed understanding that the communication of pain might be prevented or voiced inaccurately intentionally by their church members. In addition, a number of pastors provided other reasons why communication of pain might be adversely affected. Part of the experience of visiting their church members in pain is the feeling of doubt. Patients may not be able to gauge how much pain they actually have; patients may have some condition that prevents them from communicating truthfully or clearly; ministers may not have the skills to evaluate attempts of patients to communicate pain; and, because pain is a subjective experience, no one can truly know how much pain another is experiencing.

According to RO, one factor that makes it difficult for his church members to know how much pain they have is that pain gets mixed up with fear.

RO: One thing I'm saying is that it gets, um, it can get very complex. You know, if you're in a quiet room, with the family whose family member is, is really sick and close to death or, or even if it's a diagnosis, it's not going to . . . it gets real complex. People's feelings . . . emerge to the top. You mentioned / pain earlier, before we started taping this. And, really, that's, what I've seen in twenty-three years of this work. It's, um, pain is a great, pain and fear, you can't separate.

NC: Hm-m.

RO: You know, I don't think. And, they play on each other.

NC: Mm-hm.

RO: And, um, you can be feeling a lot of pain some place, and that might kick off fear of a previous experience or, um, a remembrance of somebody else's experience.

NC: Mm-hm.

RO: And, um, really gum up things, for lack of a more technical term. [laughs]  
NC: Mm-hm. Mmm. Yeah.  
RO: My point is that the pain the fear and the confusion, all if it, just gets merged together. (4-5)

RK and RP provided similar ideas about the relationships among experiences. RK described a book that she read in seminary.

RK: And it was on pain and your spiritual journey.  
NC: Oh.  
RK: And I found that fascinating. We talked about in the class how connected the mental and the spiritual and the physical all are, of course, intertwined. (11)

When I asked RP what kind of thoughts were going through his mind when he was visiting a patient in great pain, he answered in this way.

RP: [Pause] At the risk of psychologizing the situation, I would, um, the, the, first thing I would try to determine, at least for me, attempt to determine, is the, the source of the pain. Um. Sometimes a person is ill and sometimes that pain will bespeak more of, be coming from much deeper than a physical, um, discomfort and be speaking maybe a spiritual or emotional sense of abandonment. And I attempt to determine that in a variety of ways. (3)

In other words, RP would not automatically assume that the pain was physical. RP noted that he has to be careful not to confuse the patient about how much pain the patient is really having because he, himself sometimes finds the situation very confusing.

RP: Um, so, in situations such as that, I'm, I'm not certain. Again, let me reiterate. It does make me uncomfortable in those situations because I do not want, my fear is not so much because I'm, well I am distressed at someone else being in pain, but I also feel that I don't want to trivialize the pain.  
NC: [Murmur that says, "I see."]  
RP: But, at the same time, I don't wish to maximize it because I have known those who have unwisely focused the entire visit with the parishioner on "Oh, you must really hurt badly." That type of thing, and really the focus remains on that one event; and as great as pain is, and as much as we do not wish to trivialize it, I don't wish to maximize it either. (3)

RP went on to recount a story in which a church member was both grieving and having “geriatric minor complaints,” so that it was difficult to tell how much of the situation involved “spiritual abandonment or maybe emotional abandonment” (3). In a related way, RF explained that a patient’s pain and need for sympathy may be indistinguishable (3). At a later point in RF’s interview, he told about doubting an eighteen-year-old’s pain because teenagers tend to exaggerate (11).

RF: I, I can tell a story on myself.

NC: Ah-h.

RF: Not a flattering story

NC: Oh.

RF: related to a congregant’s pain. Um, we were on a mission trip, when I was youth minister, in a nearby state, in an area of great poverty, as a result of racial injustice and inequality. And, one of the young men who went on the trip with us was a young African-American, the only African-American in our group [tape ends] who was actually dating one of the girls in the youth group, so he was not a member of the church, not a regular. And he was eighteen, so he was, in effect, at adult, not one of the younger-age people. And, so, we had spent our first day of working in the heat and, of course, working to make sure everybody stayed hydrated all day long; that’s one of the goals of all the adults who were there. We had gone swimming in the afternoon. This is now about eleven o’clock in the evening. Just as I had gotten everybody kind of settled down into bed and was looking forward to bed, myself, he starts talking about being in pain and wanting to go to the hospital. And, so, having some experience with teenagers, you know, at times *exaggerating* certain things, um, I was skeptical. And so I started asking him a lot of questions. “Well, you know, what kind of pain is it?” [He said] it was muscle cramps and that kind of stuff. So, I said, “Well, do you think we could, you know, take a painkiller or some sort of, some sort of analgesic cream, you know, or other things.” I was like, “You know, maybe it’s you’re just not hydrated enough or...” And it just continued. And so then I went and woke up two of the other adults who were, who were mothers and said, “I need some mother help. I’m not.” I said, “I’m not . . . I don’t know if he really is or if he’s not.” And part of that I didn’t know the young man. And so they came down and they talked to him, trying to figure it out. And so, then, one of them finally called *his* mother. We didn’t have an under age consent form for him, ‘cause he wasn’t under age; but it was a policy I changed from . . . any other time I went on a trip like that even the people who were over age, of legal age, I had a fill out all the forms. So, so he gave us a number for his mother, who was in Las Vegas. And, so one of the other mothers called her. And come to find out the young man had sickle cell.

NC: Yeah.

RF: And, he didn't even really know that. It had been since he was child that he'd had a crisis.

NC: Ah-h.

RF: And so the mother from Las Vegas was like, "He's having a sickle cell crisis. You need to get him to the hospital immediately." And then, of course, we just all felt really / awful because the whole point of what we were there was to try to deal with racial inequality issues. And here we had our own blindnesses and had misjudged the situation.

NC: Mmm-hm.

RF: And it was a situation where the person had repeatedly told me, "I am in pain. I need your help." And I didn't believe them at first, so . . . (11-12)

Some ministers reflected an awareness that patients may have some condition that prevents them from communicating truthfully or clearly, or that the ministers, themselves, may not have the skills to evaluate attempts by their church members to communicate pain.

RE: But that's okay, too, he lived to be ninety-seven years old and, you know, it was like, he was laying in bed and he was going out of his mind with pain, and he was complaining that nobody had seen him in two days. I said, "Hang on." So, I went up to the nurses' station. I said, you know, "I'm Rev. E, I'm just visiting Mr. Smith in room 715 and he's in a heck of a lot of pain, and he said nobody's been in there for a couple of days. Um, is there anything that can be done to help him?" So, she checked the chart, "Well, nobody's been in there for a couple of days, but about five minutes ago he had a shot" or, you know, or something like this. So, yeah, I *will*, you know, go to the nurses' station and, not confrontive, but just trying to see what is really going on, what is reality? One thing I know is that, in any institution, reality [for the patient] does not exist because your normal reference points are gone. (7)

The implication for RE is that one of the reference points that gets lost in the hospital situation is the referent point of real pain, that is, the ability of patients to distinguish between pain that they have now and pain that they used to have. This realization came to RE after the nurse clarified the situation for him; that is, her view of Mr. Smith's pain was more accurate than Mr. Smith's view, according to RE. When RH described a patient with Alzheimer's, he seemed to be saying that such a disease may

both compromise a patient's ability to really tell if he in pain, as well as the patient's ability to communicate that pain, if it exists.

RH: Looking back on it, there was some challenge . . . I don't think, um, intentional ignoring of her pain, but the way she expressed her pain . . .

NC: Mm-hm.

RH: seemed to be a symptom of her Alzheimer's. There were some times she'd say, "They're killing me." Well, sort of after, with hindsight, um, she had some pretty significant osteoporosis, and I think she was in more physical pain, but what it appeared to be . . . but she also was, um, exhibiting some paranoia, that's, again, not uncommon, um, was in a new living situation, and having some challenge adjusting to it, and it appeared that she was communicating, but more like some things that she thought was happening. She was perceiving that, um, but there didn't seem to be physical evidence of somebody in her room hurting her, or something. But it may have been the way, more, um, the variation on the theme of "It's killing me" like a way you talk about pain, like when she would be . . . they'd move her in her bed, for instance. And then her Alzheimer's compromising her ability to communicate about that. (10)

So, RH seemed to believe, the patient's saying "'They're killing me'" did not gain the status of an effective communication event partly because of her lack of ability to use more realistic terminology, and partly because of his assumption of the paranoia that is sometimes a symptom of Alzheimer's. Both RE and RF described just not having the skills to know whether a patient is actually in pain. RE was especially concerned about ministering to his church members who are non-verbal.

RE: That's when I find my greatest weaknesses coming to the forefront.

That's when I have the best conversations with myself, trying to figure out just what to do, how to do, you know, how to know if I'm even making contact with the person, so. (14)

Likewise, RR expressed concern about lack of skills to interpret what might be an expression of pain. When I asked what he would do if he was visiting a parishioner in a nursing home and the patient was groaning, he responded this way:

RR: To wonder what my role is at that moment, whether I'm supposed to make a guess that that person needs immediate pain relief. I mean. What's a

groan mean? A groan. I mean people groan about very minor things. I mean. People make sounds in their sleep or, at times, and you think, well, I don't even know that I'm interpreting this groan correctly. This could be mild pain or moderate pain or excruciating pain. And I'm not their healthcare provider so I would wonder what I'm supposed to do. I mean I think that's the problem with pain in general, is that, the experience anyone is having of it is so inaccessible to you that you're always second-guessing yourself and wondering whether you're supposed to sort of throw yourself into that particular aspect. (7)

Of all the ministers, RR expressed the most uncertainty about not only being able to tell how much pain another might have, but also being able to tell if another is in pain at all. When I asked RR whether the family spoke to him about the pain of their loved one, he replied in the following way.

RR: Yes. Sometimes the family will say, "I think he or she is in a great deal of pain." Or, they may express confusion about how much pain they're in, because pain's one of those things that—it's kind of like having children. People who have children know certain things that people who don't have children . . . they can never communicate, there's this chasm, this gap. And I think pain is like that. The person who is having the pain has a hard time expressing to the person not experiencing that pain what it is that they're feeling. So, I think family members are often anxious about how much pain their loved one's in and don't know how to bring this subject up. You know, sort of to cross over this divide that seems to exist. (2)

The metaphor that RR uses to describe the uncertainty caused by the subjective nature of pain is the *gap* or the *divide*. A little later in the interview, RR explained that the subjective nature of pain means not only that one cannot claim to know what another's pain feels like, but also listening to a church member express pain does not mean that the expression of pain should necessarily be taken at face value.

RR: And I always felt like, when someone told me they were really in excruciating pain, that I'd best not pretend that I know what that feels like because we're all taught in CPE (clinical pastoral education) that the stupidest thing you can say is "I know how you feel." When, in fact, probably that's not the case. And it is better just to be present and to be listening to what that person is telling you and helping that person claim their own, um, you know,

need to manage the pain and communicate with the healthcare people in an appropriate way, so . . . (6)

RR seemed to be saying here that a communication of pain event more appropriately occurs when professional healthcare providers are the ones with the ears to hear.

Finally, when I asked RR to compare what he would do if he saw a patient in danger because of a safety hazard with what he would do if he saw someone in pain, he amplified the *gap* metaphor with the verb *separated*.

RR: To do something about it, to call. Yes, well, no, I think, if I thought that they were, that something might happen to them, when you talk about safe, I think you're, now you're getting away from pain per se to something that might be / hazardous, that, yes, I would alert someone about that situation more readily than I might alert them about pain. Because I might be able to see the hazard as in indisputable. There's a hazard. But I don't know that I can be as accurate in assessing pain as I might an issue of safety. You know, if somebody's IV tube had come unhooked or something or if there was something beeping and I didn't know if that was a warning signal or something, I think I 'd be much quicker to call the nurse than I might if someone were simply groaning or telling me that they might be very uncomfortable. Um, again, because I think we're separated by the inability to assess what pain is for other people, what level of pain is acceptable and so forth.

NC: Mm-hm. But if you thought that maybe the nurse should reassess the person with her professional skills, should reassess the pain . . .

RR: I'd be willing to ask that person to do that if I believed the patient was really in an unacceptable level of pain, whatever that is. If they were finding the pain, really, um, difficult and unbearable, yeah . . . (7-8)

Although RR could not imagine that pain might compete with an issue of safety, by the time he got to this last speech, RR seemed to be saying that, at a certain point, something a patient would say or do would give status to the communication of pain such that RR would be willing to ask a nurse to assess the patient's pain.

A final reason for doubt or uncertainty about pain consists of ministers' awareness of individual differences in pain responses or thresholds. To a question

about whether patient would let him know about pain, RH first said that he would inquire of the patient about the pain; but then he told a story about different pain thresholds. The idea was that the parents and the doctor could not tell how much pain the child had, not because of her unwillingness to tell them (he assumes), but because she had gotten so used to the pain that it was less than the adults would have supposed.

RH: Um, the doctor asked her if her throat hurt. And she said, "No." And he said, "Well, it's killin' me just to look at it." Well, what we learned about that was [our daughter] didn't know anything, um, but . . . I mean that, that, apparently, this level of inflammation and the pain that accompanied it was kind of her life experience.

NC: Ah-h.

RH: And so it was not, it was kind of like what she had gotten used to. Um, at least that's sort of the way we interpreted it. And I think there's something to that. I mean some people live with a level of pain over time, and you kind of accommodate it and get used to it. It's almost like, um, you don't know how bad it hurt until it stops. So, I mean, I / really do think people manage, cope, deal in a variety of ways. And I think people, some people are just more sensitive, um, just kinesthetically, tactically, tactile responses and things, and so that there are things that are, um, what may seem a minor irritation to one is a pretty big problem for another. (5-6)

One way of looking is to say that the pain is the same in a variety of cases, but the responses are different. RH seemed to be saying that the accurate communication of pain by patients may be prevented by the length of time the pain has occurred, the coping skills of the patients, or the sensitivity of the patients. However, another possibility is that the difference in thresholds means that the coping ability makes the size of the pain different. RD and RR also expressed uncertainty about this question.

RD: But, there again, you know, one woman will go through mastectomy and not complain about the pain a lot, and another woman will just have a lumpectomy and complain endlessly about the pain. And I always wonder if it's the person's pain threshold? Or if it's their attitude that is the determining factor of how they're going to deal with that pain. (9)



RR: And every once in a while, I will have a family member say, “I think she is in a lot of pain” or “I wish I knew how much pain she is in. I wish I could figure out how much pain she’s in.” My suggestion is always that they ask. But, then, of course, the pain threshold’s different for different people, too. So, it’s really all very confusing and awkward sometimes. (1-2)

### **Factors that Support Political Validation of Pain**

As I noted in Chapter 1, “politically validated pain” is the category that “comes into existence when the communication or the need for it is powerful enough to move potential caregivers to act on behalf of those in pain, or when those in pain can act to prevent or ameliorate their pain on their own.” So, I am going to look at the ministers’ reports of their activities which show that they actually do advocate for, by getting help for, the patients, or they encourage the patients or family to do this for themselves. Secondly, I will mention factors which support this possibility of advocacy, including the issue of turf.

#### Clergy Willingness to Advocate for Those in Pain

All the ministers I interviewed said that they thought it is important to advocate for their church members in pain. However, they offered a variety of views about whether patients and families should be encouraged to advocate for themselves first, before the minister actually requested help from a professional caregiver. Whether patients are able to advocate for themselves or families are able to advocate for their loved ones depends both on the vulnerability of those involved and on their beliefs about both advocacy and pain. RR reported that his primary response to the pain situation is to encourage patients to advocate for themselves.

RR: Have I ever had a patient say to me, “I don’t think they understand how much pain I’m in”? [pause] Um, that may have happened, actually, a few

times. And I think I have said to the patient, “Have you told them that the pain management’s not working for you?” And I think they’re response has been, “No, I haven’t.” And my question was, “Why not?” (5)

RR continued that he thinks it’s most appropriate for the patients to advocate for themselves. RF also focused on self-advocacy. He recounted a story about this in which he was emphasizing this to his mother.

RF: And I’ve had to repeatedly tell her, “They do *not* [laughs] know better than you do how you feel or what you need, that you need to be a better advocate for yourself.” (6)

RL told a story about insisting to healthcare providers that they provide better pain control for her dying mother, and she said that she would encourage other families to do the same thing; but in most situations, she preferred to encourage self-advocacy in her parishioners.

NC: Other than that situation with your mother, did you ever talk with a healthcare provider about the pain control for a patient? I mean [for] someone who was from your church?

RL: [ long pause] I can’t recall, um, direct intervention like that or, um, pretty much, I’ve just talked to the patient, themselves, to make sure that they knew that they *could* get relief if they needed it. But they all seemed to understand that they could have it, and now they have things on the timers, push-button. You see that a lot, the IV, rather than just taking pills. (6)

For RL, this encouragement of self-advocacy included encouraging patients to talk to their doctors about alternatives to opioids if the patients know they are alcoholics. (7)

RB and RJ expressed a willingness to advocate directly to the nursing staff, but a preference for encouraging patients or families to do the advocating.

RB: Um, I have been an advocate on the patient’s behalf a couple of times. Um, and mostly what I try and do is encourage the patient to look at the options that they have. And, sometimes, I’ll also talk with the family and encourage them to advocate for the person that’s sick. (3)

After RJ told about encouraging patients to ask for better pain control and being frustrated because of the patients' tendency just to try to endure, I followed up with a question about what she would do next.

NC: Yeah. Well, um, if the patient is reluctant to advocate for himself or herself, then what do you do? Or how do you respond?

RJ: I think I would continue to encourage them. If there's . . . I would ask, "Do you have" you know "is there . . . is your son coming in today? You might want to ask him." Because sometimes if they tell the son or the daughter or the friend, the friend will advocate for them. And, um, especially, I think older folks, particularly, and certainly pain is for *all* people, but feel, probably, rightly so, that they're not at the center of power. So, you know we've had all these medical advances. They don't understand these machines; they don't understand all these medications. Their *children* often are middle-aged people, who *do* feel that they're able and willing to advocate. So, that's unfortunate, but certainly, "If you won't tell the nurse, would you tell your husband? Would you tell your daughter?"

NC: Mm-hm.

RJ: I don't think I have, I'm trying to think if *I* have ever advocated directly. I think I have occasionally asked a nurse, not on a regular basis, though. I don't generally talk to the staff.

NC: What are you thinking when you're making that decision?

RJ: That's a good question. Well, I think I'm always trying to empower the patient *first*, and then feeling that a family member is a *closer* empowerment of the patient than *I* would be. For better or worse, I'm yet another professional in that team, even though I don't exactly see myself that way. So, if they can, they can advocate for themselves or have someone really close to them advocate for them, I think it's more likely to help them when I'm not there to do it.

NC: Um, are you ever thinking about, worrying about crossing turf lines?

RJ: [laughs] Maybe I *should* be. No! And, when I did clinical pastoral education, as a student, there were definitely turf lines, and they would give you a hard time. And I was just like, you know what? We're dealing with a patient, we're dealing with a human being here, and I'm sorry if the charge nurse doesn't like it. Um, no, I'm, I'm very willing to cross turf lines and to bother them when they're busy if it really needed to happen.

NC: So, for example, if the patient said that a son was coming in later on that afternoon, but the patient really appeared to be in pretty drastic pain . . . (5)

RJ: Oh, yeah, if it were drastic pain, absolutely, I would advocate. I think I would encourage them, "Well, let's call the nurse and we'll talk together," rather than going out and talking to the nurse's station. But, oh yeah, I wouldn't not for serious pain. If it's kind of this chronic—"Well, I *always* have a sore back"—then it might be able to wait until the staff's coming in.

Fortunately, I haven't had *too* many experiences with people in really drastic pain. (5)

So, even though RJ is willing to cross turf lines, she still wants to assist the patient to be the one to ask for help.

Although RD expressed a willingness to advocate directly for patients, he also discussed the difficulty or, perhaps, inappropriateness of forcing patients to self-advocate when it comes to pain. First, I'll relay his story of direct advocacy.

RD: You know, I think, probably, you know, with other people I've asked, and I'd have to say, in the hospital, in some of the rooms, if somebody was crying out in pain, sometimes I wouldn't go in there. I would just go get the nurse and say, "Hey, so-and-so is in a lot of pain" [laughs] "and deal with, you have to deal with 'em!" And that was probably the best thing for their comfort that I could have done.

NC: Mm-hm.

RD: Spiritually, I don't know if I did a good job. Sometimes in the hospital setting, I think, the best thing you can do is be the patient's advocate, and be their voice, you know. If they're not being heard—sometimes I don't understand how the staff can't be hearing them! [laughs] But, if they can't be heard, you have to be their voice and say, "Hey. Can they have something?" And sometimes it's not the nurses' fault. You know, a lot of times they're understaffed and they have too many patients to care for. And so the patients go in pain, not knowing what button to press. (11)

With respect to self-advocacy, RD indicated that sometimes the patients are declining because they would see such a move as criticizing the doctor, which they don't want to do; and, RD said, he must respect this point of view.

RD: And most people don't think, "Oh, I have to be my own advocate." They think, "I'm being taken care of because I'm going to a hospital." I think it's probably a newer mindset. I hope it's a newer mindset, that people are learning to be their own advocates.

NC: Do you think you would ever feel like it is part of your role to be . . . to encourage them to be their own advocates, where they might be holding back?

RD: Sure. Yeah. I do sometimes. The interesting thing there is, there's also sort of a respect issue. /

NC: M-mm.

RD: You know, I have to respect their worldview.

NC: Yes.

RD: And I don't want them to feel like I'm belittling their attitude, their perspective, by saying that they should be more critical of the doctor because they might feel like, "Well this young upstart"—part of it's an age thing—"thinks that my perspective is wrong." It just . . . the whole health care thing is very thick, as they would say in seminary.

NC: Mm-hm.

RD: Pastoral care is very thick [smiling]

NC: [laughs] Yeah. (19-20)

RY described her efforts to try to improve communication between patients and doctors on issues including pain; however, she also said that she bumps up against patients' resistance.

RY: . . . Like I said, I try to say, "If you are in pain, you can ask for more medicine. And you need to let them know that. And if you don't like the side effects, you tell them that, too, you know." Because I think people often tend to just they're frightened and they just defer to whatever the doctors say, even though they don't understand anything that they're saying, you know, so . . .

NC: Mm-hm. Mm-hm.

RY: So I try to facilitate some of that, I guess, between patients and doctor or staff, I suppose.

NC: Yeah. Yeah. So, if, if the patient were there by himself or herself, and, obviously, in great pain, would you ever consider contacting the staff?

RY: Yeah. Yeah. Yeah. I do. I'll go and I'll talk to the nursing staff. I've done things like left notes. Um, now I don't know whether they get through, but sometimes, you know, if the patient has a particular question that they're not getting answered, and the nursing staff can't help them with it, I'll write the note down and say, "The doctor needs to talk with her about this issue," you know. But, whether that gets communicated, I don't know, but, you know. But, yeah, I've gone and talked to staff and grabbed them, if like, you know, somebody is in pain or try to get some other questions answered or try to find out when the doctor's coming or something like that. (6-7)

RO is more likely to focus on direct advocacy for the patient in pain because, as he explained, the overall situation in hospitals requires patient advocacy.

RO: And, I'll, I will encourage the family or the patient to ask questions they have written down. Or I'll take the questions, and I'll say, "Look, if you don't want to do this, I'll do it." And take it to the . . . find the social worker or the right person, the appropriate person, and say, "Look, this family in room such-

and-such is part of my church.” It’s kinda like being a lobbyist on Capitol Hill, you know. [laughs]

NC: Ah-h. Mm-hm.

RO: People need advocates, and they need lobbyists on their behalf. /

NC: Mm-hm.

RO: So, um, so often that’s the situation, and that’s my job when I get there. (2-3)

RO: [A]gain, empowering is, is the whole, is very much the thing, but in the hospital, all the power rests with the hospital. And, um, and it’s sometimes a really formidable institution, and just, for instance, the sounds . . . /

NC: Mm-hm.

RO: You know, the person in the next room is yelling and screaming, and all kinds of things.

NC: Sure.

RO: So, I don’t know if I ever, when I get into a hospital room, I don’t use the word *empowerment*, but that’s what I’m trying to do, is give the family and patient some say, understanding and some say in the situation. (3-4)

When I asked RK whether she would encourage a patient to call the nurse to ask for more pain relief for a patient, at first, she said, “No, I feel like the nurses have done their work” (7). However, then she said that, if the patient told her about the need, she would go out and ask the nurse for help.

RK: I have, a time or two, asked for pain from the nurses, a, painkiller, drip, drip, whatever that is. I’ve gone out and asked for that when they have said that they are needing something; but usually they just express it to me.

NC: Mm-hm. But you would feel *comfortable* advocating on the patient’s behalf to the nurses?

RK: Absolutely. Absolutely, yeah. I think we need to do that for our elderly, as well as those who are sick and more vulnerable.

NC: Mm-hm.

RK: I know the nurses are way overworked, but, um, sometimes it does make a difference to speak up. (8)

RS told the longest story about her attempts to advocate for a particular nursing home and hospice patient in pain. (I have quoted part of this story above.) When her attempts were unsuccessful, she encouraged the patient’s mother to advocate also,

thinking that the doctor might be more likely to listen to a relative; but the mother was unable to do this.

RS: And I would ask him, “Are you *hurting?*” if he was awake and he was kind of talking or something. And he would just say, clear as, “*Yes, oh I hurt so much. Please, please help me!*” You know, those kinds of things. And, so then I would say, I would go out to the desk and I would say, “You know, he’s really, he’s really complaining about pain. He needs pain medication.” “Oh, okay, I guess, you know, we’ll check and see if it’s time for more.” And, then, maybe two hours would go by and I’d go back out there. “Wait, we were going to check. Oh, okay, okay.” You know, and then, bring him *pills*, which he had a really hard time *swallowing* the pills, even sitting up enough to drink the pills, to drink something with the pills. But, so this was what it was like, day after day after day. And so one time when the hospice nurse happened to come in while I was there, I asked her, “Can’t they do something more for his pain?” “Well, he can’t be on a morphine pump if he’s here.” I don’t know. That’s what she said; I don’t know if that’s true or not. And, over the next few days, she and I began to kind of, I was kind of pushing her a little bit. And, at one point, she got *really* angry with me, and she said, “There’s a legal limit as to how much pain medicine you can give.” And I said, “So are you saying he’s getting the maximum amount he can get?” “Well, I’m not sure.” I mean, she didn’t even say, “Yes, he is.” Clearly, she didn’t really *know*. But, so she kind of said something like, “Well, I’ll talk to his doctor” or something. I was just horrified, and she was really, really angry with me, and the staff then started getting kind of angry with me. I was getting signals from the nursing home staff, from some of them, that they really agreed with me that he needed more pain med- . . . something different. But, and then, the, the hospice nurse said to me, “Well, if you give him any more, he wouldn’t / be conscious.” And, I thought, “Well, *who cares!*” [laughs] “He’s just in *agony*.” I tried to talk to his mother at one point, when she was there. I just said, “You know, a, if you, if *you* would talk to the hospice nurse or the doctor, I think they could give him more pain relief.” And I don’t know whether she ever did that, or, or not. But I think she was, like I said, I think she was really intimidated and bewildered; and I’m sure she was in grief and shock and everything, too, so she wasn’t functioning very well. So, there really was no advocate for him at all, except there were a couple of other volunteers with me who were . . . and I don’t mean to criticize. Some of the nursing home staff were really, really very caring and tried to help take care of him. But I guess they can only do whatever the doctor says, so . . . I was awful. (3-4)

In this situation, RS appeared to see herself as unable to provide the kind of political validation that would change the pain management situation for the better, at the same

time that she saw herself as a pest to the staff. When RS was explaining later in the interview about how she deals with pain advocacy in general, she mentioned that she at one time had the same attitude as families and patients, that surely the medical staff is doing all that it can.

RS: I think I've gone through a learning process over the years, probably five or six years ago, or six or seven years ago, it didn't even *occur* to me that I needed to do that. I, you know, like so many others, I just assumed that we would count on the hospital people to do all that, that that would all just be taken care of. And, then I went through a phase of starting to just wake up to fact that *somebody* has to *ask* for pain relief, the patient or other people, and sometimes they have to keep asking, and sometimes they have to say, "Well, this isn't working; let's try something different." And they have to be pretty persistent. And sometimes, I think, so I came to recognize that, as a pastor, sometimes *I* needed to talk to the family member or the patients about that, to help educate *them*, / because *I* didn't know that before, and *they* don't know that. And so I think that's part of my role as a person trying to be a caring presence. And then, in some cases, if they, if they aren't able to or they don't have a family member who's able to, I feel like *I* need to talk to the doctors and nurses and say and *ask* about their pain relief, and say, "Well, he just told me he's in pain." And then the nurse'll say, "Are you in pain?" And I'm thinking, well why didn't they ask that before? [laughs] (8-9)

To summarize this section, then, the ministers I interviewed are participating at least part of the time in the process of political validation by directly asking for help on behalf of the patient or by encouraging the patient or the family to do so. Next I will consider statements that pastors made about factors that support the position of advocacy.

#### Beliefs that Pain Can and Should be Relieved

One of the primary factors in support of advocacy is the set of complementary beliefs that pain should be relieved and that it can be relieved in most cases or in this particular case. RL, RJ, and RS all learned about this from their contacts with particular experiences with professionals in the medical field.



RL: I had a doc in my church some years ago—she was a palliative care specialist—so that’s who I learned, you know, my idea that you do not need to suffer, that there are plenty of alternatives and ways to help people manage their pain. And she was absolutely adamant about it. (12)

RJ: I firmly believe that, if pain can be controlled, it should be. And I *also* firmly believe that it *can* be almost all the time. And that comes from CPE, too. Doing / oncology, I was really amazed at how well, and there had been such advances in the last years, that they really were maintaining, they were really controlling cancer pain quite well. (10-11)

RS: But [one of my relatives] is a doctor; he treats patients who have cancer, and he always tells them that he will make sure they are comfortable. So, I know it can be done.

Experiences with hospice convinced RC and RE that pain control is not only possible but the right thing to do, especially at the end of life. RC explains.

RC: One difference is this; once people experience hospice care, once they experience that, it’s like a whole world. Well, yeah. These doctors, they’re trying to keep me from dying; it’s their whole focus. The pain management thing, it’s not that it’s not that important, but it’s not as vital. Keeping you alive is what is vital. Then you get in the hospice environment and you get a social worker making suggestions about pain management, the chaplain, and the nurse and the doctor, and it’s usually a huge relief. You know, you give them permission to manage that, and that’s as important as the other aspects like the disease progression. Once people experience it, then it’s a transformation. It’s a conversion experience, I think. (13)

An end-of-life situation makes acute pain especially pointless, according to RL and RS. RL told the story of having to insist on better pain management at the end of her mother’s life.

RL: It’s been quite a while since [my parents] were gone. It was 1989 and ‘93, so, um. No, it doesn’t usually . . . It’s hard to watch. Just . . . especially when you *know* they’re going to die. And I did have that experience with my mother. Um, and she needed more morphine and they, the nurses, were reluctant. And I said, “But she has come to die, so it doesn’t matter. Give her what she needs.” And I had to call the doctor and get, you know, the order changed, because they allowed her to suffer for a while before they would alleviate it. I think they were afraid of liability issues if they gave her too much or something. I said, “It doesn’t matter. She not living much longer.” “We have people who

say that, but then, they don't really want to let them go." I said, "Well, we're here so she can go on, and she's ready and wants to go, and you cannot let her suffer like this—it's *needless, it's cruel.*" So, we did get it fixed, but it took a bit of a battle. (4)

Part of the belief that pain should be relieved, as described by the ministers interviewed, is a theology that does not support suffering for purely redemptive purposes. Here are some examples. When I asked RO if his church members ever gave him theological reasons for thinking about their pain, he answered in the negative, but then jumped immediately to his own theology of social justice.

RO: No. I often think of justice reasons. Now I see a lot of injustice, especially in nursing homes, where people are treated like junk, or people are ignored . . . . You know, it's, well, it's . . . yeah, in terms of justice, it *is* a justice issue. We often in the UCC, you can find justice issues to, you know, picketing Dole pineapple, or something, but this is an issue, but, so is, so is the reformation of nursing homes, and, and reclaiming human dignity in those situations. I don't think we, I *know* of it as an issue. It's just an overwhelming. I'd just like to walk down the halls of the hospital and say, "You better take care of my people!" [laughs]

NC: [laughs with him] /

RO: You know, "Because I'm stayin' here until you do!" And, it's exhausting sometimes, and

NC: Mm-hm.

RO: but, again, it's a social justice, Gospel justice, issue, and I can be pretty theological about that. (20-21)

In a similar manner, I asked RH what he would do if a patient declined pain management, citing as the reason that Christ suffered. Though I didn't say it out loud, I was thinking about my own uncle who said this kind of thing when he was in a battle with colon cancer.

RH: And, certainly, to the idea of redemptive suffering, it was for some purpose. I mean, if, if someone were, you know, the kind of Father Flannigan story—he ain't heavy, he's my brother—well, somebody suffering something and there's some purpose, I mean, that it, whether or not it had to be that way, if it was accomplishing something that had some, um, accompanying good, um, that's different from suffering for suffering's sake, so . . . .(14)

RH continued that, when someone is in extremity, it might not be a good time for theological education, but he would at least “invite reflection” on the subject with such a patient in case it would be helpful. RL answered my question in a similar manner.

RL: Well, that would certainly be something I’d watch for. If I were in a situation where the person felt that there was some redemption in suffering, um, I would certainly enter that discussion. [laughs] I *do* believe that God suffers *with* us when we are suffering, but that we are not meant to needlessly suffer. Suffering . . . I really do think in today’s world, we do have ways of relieving pain that should be available to everyone. We have to be careful with how we administer, but, um, let’s just be careful and let’s not make people suffer. I would definitely hope never to perpetrate the idea that God wants us to suffer, that there’s some nobility in being strong and muscling through. (10)

When I interviewed RR, he not only rejected the idea of redemptive suffering, he also rejected the idea that God uses pain to get people’s attention or to punish people. From RR’s perspective, the theological idea that God uses pain to get people’s attention and/or to punish people is not just a theology of Christianity, but perhaps of the larger culture.

RR: Well, I suppose that there is always some element of the old notion that if I’m sick or in pain, I’ve done something wrong. I’ve done something to deserve this, you know. Or, that weird thing—“This really hurts, but there must be something redemptive about that.” [laughs] You know, “The pain will make me stronger”; or, a, “if I get through this, I can survive anything. Um, I never knew what pain was until I had this, and this is going to make me a better person or something.”

NC: If somebody says something like that to you, how do you respond?

RR: I usually say that I don’t think the pain is the result of any thing they’ve done wrong, just that it’s the result of whatever illness or disease they’re suffering from, and that the best thing would be for them to try to find a way to be in less pain. Because, I mean, you know, there’s that Catholic priest Fulton Sheen, who said once. I’ll never forget this. I was watching him on TV and he said, “*Pain is God’s megaphone.*” (2) [RR lowered the pitch of his voice here, but increased the volume and slowed the tempo for this quotation.] /

NC: [laughs and smiles with RR]

RR: And I thought, “That is really an interesting idea.” I think, I think there’s a strong strain of that belief in American culture, that God’s trying to get

through to you, through this pain. And that if he can't get through to you any other way, he will get through to you, he will get to you through the megaphone that is pain. Now, I don't know if you've ever heard that before, but I think that is revelatory of, of a sort of cultural approach to pain, that there must be either a) a reason why you're in pain, and so you're to blame or b) you're going to be taught something through the pain. I don't personally feel that way. I just think pain is something that, if we can reduce, it would be a compassionate thing to do. (2-3)

To summarize, RR said that this theology is "weird," but common, and he does not agree with it. In my interview with RJ, the theology we discussed had more to do with the general idea of God's being in control of the situation. Under some circumstances, according to RJ, this might be an understandable perspective, if not necessarily a reasonable one.

NC: Have you bumped into somebody who, um, might have a theology which makes them accept the pain and not try to lessen it?

RJ: Mm-m. Not real overtly. Um, you know, the pain, they're sort of giving up the pain to God, as a sacrifice, or that kind of thing? Is that sort of what you mean? I haven't run in to Christian Scientists.

NC: Oh, no, I say that sort of like the line of whatever's happening is supposed to happen.

RJ: Uh-huh. Um, let's see.

NC: And so, if my pain is an eight on a scale of one to ten, well, it's supposed to be that way.

RJ: I don't think I've run in to that. I've certainly run into people who say, "Oh, I must be supposed to learn something from this."

NC: Oh-h.

RJ: But, not to the point where they would refuse medical help. Now whether, where that line is of actually *refusing* it and, and not asking for it . . . I mean, there are people who are not asking for it because they think this must be God's gift to me to help me learn. I don't think I've run in to that, but I've certainly, lots of people make sense of the world by saying, "Well, this is happening for a reason. I must be . . . there must be something I'm supposed to go through to learn what I'm supposed to learn."

NC: Mm-hm. But that wasn't part of your UCC training?

RJ: Um, UCC training . . . UCC training is almost an oxymoron, but [laughs]

NC: [laughs with her] (9)

RJ: You know, don't quote that! [laughs] It's like UCC beliefs. Well, it's a big tent.

NC: [laughs]

RJ: Um, you know, I would say that's something we're ambivalent about

NC: Ah-h.

RJ: as liberal Protestants. Um, we're . . . we don't like going there because we like, we like being in control. We really believe that God gives us the medical profession and education and government to help the world. Um, but, but, on a lot of levels, I don't, I'm not sure that it's unhealthy to say, "Well, this illness is going to teach me something. It must have happened for a reason." I'm not willing to just throw that out completely.

NC: Mm-m.

RJ: But, you're right, it does push against . . . I don't know. But I've heard a lot of people say that very sincerely and in a very simple faith, and I'm, you know, willing to honor that. I could see using it, myself! [laughs] (9)

None of the ministers held the theological belief that suffering physical pain, by itself, is redemptive, although there might be circumstances where this is the case. So, in this sense, that is, not holding a belief in redemptive pain might make it more likely for these ministers to politically validate their parishioners' pain. However, they indicated that they knew that some of their parishioners hold this belief, and the ministers would not force people to change this belief.

#### View that Professional Boundary Lines May Sometimes be Crossed

The last factor I will consider in this section is the issue of professional boundaries, or "turf" as a possible support to advocacy. Although a number of ministers emphasized that it is important to distinguish clearly between the responsibilities of the clergy and the medical caregivers, the general willingness to advocate for patients in pain may mean that the turf lines are not so strict. These clergy are not merely providing spiritual care. For example, RC, RE, RO and RR described working to make sure that their parishioners understand their medical situation, that is, what the doctors are saying.

RC: You know, I don't, since I don't know anything about medicine, I wouldn't know if something is plugged in or not or working or anything. And

I'll ask people . . . I'll usually ask, "How's it going?" or "How are you feeling?" And then that way they can talk about the medical stuff if they want, or they can they talk about spiritual stuff or family stuff or whatever they are . . . But at some point I always ask, "Now what are they doing for you?" That way, I hear what the patient understands is their problem and whether they know what the treatment is or not. Just, it gives you kind of a mental state. How clearly are they thinking? Some of my parishioners really know what's going on, some don't. Some will express anxiety, "Well, I don't really know what they're doing." Well, that's a big red flag for me. You ought to know what's going on, and so I'll encourage them to talk to the doctor or I'll talk to a family member. (10)

RO explained that he tries to support understanding by suggesting that the processes be slowed down if the emergency atmosphere is no longer necessary or by getting the doctors to explain certain issues using simpler terminology.

RO: Um, I know that there are emergency cases, and you have to move quickly. But, if there's, if there's not a necessary, not a necessary urgency

NC: Mm-hm.

RO: for speeding, I try to slow things down. "Wait. Let's, let's stop for a minute." And I can do that through prayer. I can just ask a doctor to slow down.

NC: Mm-hm. (4)

RO: But, um, if I can help a family and a patient answer some questions, just to give them some peace of mind and some understanding of what's going on .

. .

NC: Mm-hm.

RO: And not necessarily in a medical sense, since I'm not a medical person, but . . . and most of the medical people that *do* come in, you know, rattle off

NC: Mm-hm.

RO: the language that they know. It's not very helpful to anybody. So, I can serve as a kind of translator

NC: Mm-hm.

RO: and say, "Wait. You know, if *I'm* not understanding what you're saying, I *doubt* if anybody else here is." [laughs] /

NC: [murmur]

RO: "Is there any way to bring it down to our level?" (16-17)

In another part of the interview, RO made clearer some of the separation of duties or difference in kinds of support he as a pastor makes.

RO: I can be with the person in pain and listening, you know. I don't want to ask [chuckles], "Is your pain level . . . where is your pain level between one and ten?" It's not my question to ask. (6)

RE indicated that, because he has learned some of the medical terminology through continuing education at the hospital, sometimes parishioners think he knows more than he does; but he tries to correct this view with "I'm sorry, I'm not an MD" (21).

In contrast to RO and RE, RR described the importance for clergy of knowing something about medicine in order to be able to actually interpret a medical situation for church members.

RR: I feel strongly that clergy should have, at least be cognizant with, some dimensions of medicine and be familiar with the physical, recovering model which prevailed well into the modern period of clergy being also persons who were acquainted with, if not also practitioners of, the healing arts. Um, the church is doing better now with the parish nurse programs and so on, but I really feel that the clergy have a long way to go. Um, I'm no paragon of virtue, certainly, but I know it has really helped me, my scientific training, to be able to understand, to know and even to be an interpreter to patients or parishioners, when asked about something, about their particular course of treatment. That has really served well; it also, I think, serves to diffuse anxiety and so on, on the part of the patient, and certainly it does orient one when one knows what is occurring. Philipp Melancthon always advised the theological student that there's some things in theology that one cannot understand without first understanding anatomy; and I feel that's very true. (12)

RR went on to explain that he feels like a fellow professional with physicians and is comfortable using this "partnership model" (13).

Although RF received specific training in seminary about professional boundaries, he said that he has "fuzzed a lot of those lines" (14) in order to do his job carrying out the gospel. RJ, RS, and RL seemed to say that they were not concerned about the turf lines.

NC: [Are] you ever thinking about, worrying about crossing turf lines?

RJ: [laughs] Maybe I *should* be. No! And, when I did clinical pastoral education, as a student, there were definitely turf lines, and they would give you a hard time. And I was just like, you know what? We're dealing with a patient, we're dealing with a human being here, and I'm sorry if the charge nurse doesn't like it. Um, no, I'm, I'm very willing to cross turf lines and to bother them when they're busy if it really needed to happen. (5)

RS expressed more concern about boundaries with the patients than with doctors.

RS: I don't really care about crossing boundaries when, when it comes to—I mean, there's a difference between the boundary with the *patient*. If I, if I knew that my parishioner didn't want pain relief, I would not try to encourage them to do something they didn't want to do.

NC: Mm-m.

RS: But, if I, but if, if it comes to the boundary with the *hospital* staff, I don't care about that at *all*. I just, um, and I guess that's one of the benefits of being the personal pastor and not the hospital chaplain, because *don't* have to care whether those peo--, what those, what the hospital staff think of me. (9)

When I asked RL if she has concerns about crossing boundaries when she speaks to a healthcare provider to check on a patient in pain, she answered with a smile, “Should I be?”

To summarize this section, then, the ministers I interviewed described situations in which they do or would participate in providing political validation of successfully communicated pain. In addition, some told about these instances in the larger context of their continuing advocacy, their theological views, and some of their attitudes toward turf. Next I will show how some of the narratives by these clergy might make advocacy for or politically validation of patients in pain less likely.

### **Factors that Work Against Political Validation of Pain**

So far in this chapter, I have provided what the ministers said that would illuminate the general context in which they experience church members in pain, their



understanding of supports for communication of pain or barriers to this support, and their descriptions of support for advocacy. Because advocacy for persons in pain is difficult without successful communication of pain, all of the issues given above that reduce or eliminate this successful communication will reduce the possibility of advocacy. For example, patients who do not want to appear to criticize their doctors or nurses, who do not want to upset their families, or who believe that a good Christian endures pain may decline to communicate and, thus, prevent or reduce the possibility that their ministers can be advocates for them. Ministers I spoke to put some of this in perspective in the next section I am calling “the role of cheerfulness.” In the second, larger part of this section, I will consider the factor of the assumption of the inevitability of pain. Finally, I will consider the ministers’ feelings of powerlessness that diminish the possibility of their advocacy.

### The Role of Cheerfulness

One factor that may prevent political validation of pain, according to some of the ministers I interviewed, has to do with what might be called giving low status to pain. Although the clergy recognized that patients have a number of reasons for concealing or diminishing their pain in front of a number of visitors, including the clergy, themselves, pastors acknowledged that they might be participating in this overall understanding of duty toward cheerfulness. I refer back to RR.

RR: We’re not supposed to complain. If we talk about ourselves, then we are being somehow selfish or self-centered. And, when a person has come to visit us—in this case a minister—we don’t want to burden that person with our / problems. And pain would be considered one of “our problems.” So we don’t share that information very readily. (1-2)

Later in the interview, RR explained some of this in terms of his understanding of the role of clergy.

RR: Pain . . . it was almost like I didn't really have the right to go there. That's what the medical people are supposed to do, so I'm there on other business. Pain is in the medical category, so I don't, I don't do pain. That's, I think that's, actually, I haven't thought about it until just now, but I sense that I'm not the person that's supposed to be dealing with those issues, interestingly enough. (7)

RL showed this recognition in the following part of her interview, but she ventured that the clergy should deal with this cheerfulness carefully.

RL: So, how she deals with it on her own, I don't know. If I say to her, you know, "How're you doing? Does it still hurt?" She says [using a cheerful tone of voice], "Yeah, but I'll be okay!" You know, just flip it to the sunny side.  
NC: Oh-h-h. How does it make you feel when they do that? Flip it to the sunny side?

RL: Oh, I guess there's a couple of reactions. One is like, "Well, good, then I don't have to deal with it," you know. [laughs] That's normal. Like, "Okay! [laughs] We can go on." But, you know, when I'm being a better pastor, um, I can stop and try to explore that with them. (3)

When I asked RB about this issue of the pastor as visitor and cheerfulness, he agreed with RL that sometimes this cheerfulness goes against the minister's primary role.

RB: I tend to think that too many people who visit the sick try to cheer them up and not enough people who visit them—family, friends, whatever—are there for any kind of sharing or allowing the person to express themselves. And that's one of the dangers of going in as a minister, a clergyman, is that people expect, when you walk in there that you're there to cheer them up. That's his job—he's supposed to come in and say nice cheery words and say a prayer and then leave. And, what I . . . you know, it's kind of interesting. Lots of other people will do that; very few people, in my experience / anyway, when I have been there, very few people come in and say, "How are you *really* feeling?" or, if a patient brings up some problem or something or wants to talk about pain, they will find a way to change the conversation. One of my roles, especially if there's family present, but even if just the patient, is to allow [discussion of problems such as pain] to happen. If the family's present, to try and encourage that to happen, simply because the family may need to listen to these issues. (1-2)

RB continued with a story about a teenager with non-Hodgkin's lymphoma, for whom he served as a listener partly because her friends abandoned her after it became clear that good cheer was not going to make her well.

RD described both the temptation to participate in this atmosphere venerating happiness and the opposing responsibility of the church community to get shoulder to shoulder with those in pain.

RD: I think our s- . . . it's kind of . . . our society views it quite negatively to talk about your pain, 'cause we're supposed to be all happy and joyful and fine. Everybody's supposed to be fine. So, that's really kind of a criticism of our church communities, that we're not more honest with each other when we ask each other how we're doing. We just say, "Fine." And oftentimes, I end up asking again. A lot of times people will say, "I'm okay." And I'll say, "You're just okay? How come you're just okay?" And then, sometimes, they'll continue, "Well, you know this is going on and this is going on." But, still, if I hadn't have followed up their "okay" with another question, they would have just left it at that, and I never would have known that their aunt just passed away or they're having heart problems, you know. I don't know. (23)

Then RD mused about the clergy's responsibility to suffering persons and the possible rejection or neglect of this responsibility.

RD: I mean, there's certainly enough about pain in the New Testament. And one of the things we know about Jesus is that he was an amazing healer. And, I think there's no denying that. That's partly why his fame developed, why he was so popular was because he was a healer. /

NC: Mm-hm.

RD: And so then the question becomes, "What does that mean for *us*?" What is our role in helping people deal with their pain? And you could attack it from that theological perspective. You know, how *are* we helping to heal our community? And how are we helping our congregation deal with their pain? You know, we are told to cry with each other.

NC: Mm-hm.

RD: And heal each other. It's in the [chuckles] New Testament. [tape ends] It's a personal issue. You know, there isn't really anything more touching than pain, more poignant. (21-22)

RD: It's funny that we don't think more about it. I don't think most pastors spend a lot time thinking about it. We like to think that we're focusing on healing. We don't like to think about pain.

NC: Ah-huh.

RD: We are in the healing industry, and that doesn't include caring for pain. We like to think we're moving people away from pain. And so caring for the pain wouldn't be our job. At least that's how I think about it. (26)

The issue of whether to support endurance is clearly related, partly because underlying such support may lead patients to feel that they must shoulder a great deal of responsibility about whether they have pain or not. Thus, sometimes clergy support of cheerfulness or endurance will result in missed opportunities to advocate for good (or better) pain management for patients or to help them to advocate for themselves.

#### The Assumption of the Inevitability of Pain

Ministers may hesitate to get help for patients in pain or to encourage patients to insist on better pain management as long as ministers or patients believe that some amount of pain is inevitable or that this particular pain is inevitable. One common reason for the assumption of inevitability has to do with patient safety. People often think that pain has a purpose or that alleviating pain includes some element of danger, more danger than the pain itself. Another common (and related) reason for the assumption of inevitability is the belief that the medical staff has done all that they can do for the pain, either all that they can do safely or all that can be technically done with the science that can be applied so far. I will start with what some of the pastors said about purpose and safety.

RR and RH both expressed awareness of concerns about how pain communicates that something is wrong with the body, and reducing the pain may prevent finding out or even treating what is really wrong with a person. Although they

seemed to indicate that these are the views of others, not themselves, they expressed some uncertainty or ambivalence also.

RR: I think there's also the feeling that there's a kind of folk wisdom that pain is a warning so that if you dull the warning system, you are short-circuiting the process by which the body is trying to tell you something, trying to tell you something important. This hurts because, it's like waking up with a hangover, you know, oh, then I shouldn't have gotten so drunk. So the pain is the price I pay for indulging, overindulging in alcohol. And, if I did something to treat the pain, I'd be treating the symptoms and not the disease, if you will. I think that laps over into all our understandings of pain, that there must be something redemptive about it. [laughs] And, maybe in some cases, pain can serve as a warning. I mean I think that's not an untrue medical statement, that your body hurts when something is wrong as a way of telling you that something is wrong. But, once you're into disease treatment and you've diagnosed the problem, it's not a question of you need the pain to tell you you're sick because you know you're sick. [laughs] So there's an initial response to pain that may be very positive—I need to get something checked out—and a pain management problem, which is a different sort of matter altogether. (9)

RH: I think there's also, there may be amongst some a resistance to, um, helpfully responding to the pain by, you know, "I want to, you know, I really want to know what's going on, my body, so I don't want to mask symptoms" or, you know, there's something wrong with . . . I should just, you know, grit it out, you know, grit my teeth and just, you know, get through this. (13)

Later in the interview, RH acknowledged that he may have some of these beliefs, too.

RH: And I'm just realizing maybe one of those misconceptions that I still carry around, not so much related to the danger of addiction, but I'm thinking of some people that would have a suspicion and maybe one that I sort of unconsciously have more than / I, that, that sometimes pain medicine is given in a way that may be over-prescribed to treat the symptom, but not with adequate attention to the cause? Like, if you're in pain, you just try to mask the pain, rather than ask, well why are you in pain? I don't . . . I guess that's . . . I'm saying that more in the form of a question, but also maybe an acknowledgement that I'm, I think there may be some, there may be some, you know, may be something to that. (20-21)

RE was more direct about claiming the belief in the purpose of pain for himself.

RE: And Edwards's Theory also says that there's a reason why you have pain, if it's nothing more than to get your attention that there's something wrong.

I'm a living example of that, so I can tell you, I can tell you the modernization of what I see in hospitals. As I say, they go so far.

NC: Mm-hm.

RE: Then, after that, somehow, I don't know, maybe it's, it's a pain is a way of one of those dinosaur things we have to remind you of that hurts, maybe you have to deal with it, or maybe, as my mother used to say, "If it hurts, that means it's healing." My mother was a registered nurse. (8)

Notice the relation between these views and the theological view that RJ mentioned, which was something like: whatever is happening should be happening. It is true that pain is a kind of warning system under some circumstances; however, as RR indicated, that fact about some pain may be unrelated to the appropriateness of providing pain control in a particular case. RR and RH expressed doubt about when to apply that knowledge.

Likewise, a general knowledge that sometimes pain medicine may cause side effects or even be dangerous, can contribute to a view of the inevitability of pain. Both RO and RY discussed side effects of pain medicines as difficult to work with, maybe not worth working with. When I asked RF what he thinks of when he hears the word *painkiller*, he said this.

RF: Oh, I worry about addiction. Um, I worry about, you know, covering up some things you're not aware of what is going on in your body, and, but I also think, um, you know, ease and comfort. (8)

Later in the interview, RF relayed a story about a congregant who was taking Oxycontin and had "volatile mood swings," where RF suspected that there was a relationship, though he acknowledged that he did not know whether the pain or the medicine caused the mood swings. RH described a patient who experienced hallucinations, as "the by-product of pain medication" (8). RM told of his experience visiting patients who were "on morphine."

RM: They don't like feeling weirded out. I don't know if you have been in a hospital and talked to somebody or in hospice and they're on morphine and their eyes are all glassy. And you go to talk to them and, um, it creates, the drug, itself, creates all types of fears. (6)

RR expressed concern that increasing morphine to deal with pain might "compromise [a patient's] recovery in some way" (8).

Sometimes the concern about pain medicine occurred in the context of overuse of medicine in general.

RM: Yeah. And so what happens is that, is that, the morphine and the stronger drugs that they use for healing to help stop the body actually can do more harm than good. And especially with [unclear], if you're not used to using the drugs. I don't use any kind of medication at all. I don't even use aspirins. Um, and if your body is not used to using any type of medication, um, it doesn't take as much to push you over into a psychotic case. And that's what I've seen in my congregants and a lot of times the drugs are overdone and pushed. (6-7)

After RY noted that some of her parishioners express concerns about the side effects of pain medicines, she expressed dismay about medicines in general.

RY: [laughs] You know, I have ambivalent feelings about medicine in that regard, 'cause I've just seen too many people who got sick from the medicines because they were being doped up on so many different things. (4)

RO told about the difficulty of handling situations when there was an allergy to pain medicine (11-12). For RD and his mother who had bone cancer, both the pain and the drugs were hard to bear.

RD: I think it sounds like a person dying of cancer because my mom died of breast cancer. I know how much pain *she* was in, you know.

NC: And what year was that?

RD: 2000

NC: Oh!

RD: That was—oh, terrible a thing to see. Breast cancer can be terribly deforming

NC: Mm-hm.

RD: once it gets in your bones.

NC: Yeah.

RD: Anyway, it certainly doesn't seem to have anything to do with how good of a life they have lived 'cause my mom certainly didn't deserve to die such a horrible, painful death. It was awful to see that.

NC: [sympathetic murmur]

RD: But that's where the pain medication does come in. I mean, she was able to be drugged to the point where it was tolerable.

NC: Mm-hm. /

RD: But she was drugged. She said, "I never thought I would have to be this drugged at the end of my life." (10-11)

More than overuse of all medicine, the relationship between the use of morphine and euthanasia was on the mind of some of these pastors. RL had described the efforts to get good pain medication for her dying mother. Later in the interview, she added this:

RL: And that's an interesting thing to explore and see what those factors are, particularly with terminal cases, I mean, it's temporary situation, then you do have to be very, very careful, not to accidentally kill somebody with pain medication. That wouldn't be good. [laughs a little] But, if a person is going to die anyway, you know, I'm not saying that you shouldn't be careful, because then you would be euthanizing people. You know, but, still, why should they be suffering? (17)

After RS described a family in which an elderly, dying woman refused pain medication because she was afraid of addiction, RS talked about how it used to be even more common that people were afraid to discuss increasing pain medication at the end of life for fear that it would hasten death. RS had recounted a situation in which someone she knew wanted physician-assisted suicide because of what he assumed would be the pain and other sources of loss of quality of life with the progression of his disease, though she knows that it is possible to provide adequate pain control at the end of life. Here she continues that story:

RS: Sometimes there is a theological issue about endurance and the importance of suffering; but the person I was telling about didn't want that suffering. *I don't want the suffering. I don't want it for my dog! My dog is really, really old. She has been kind of a co-parent for me. It comes up every day, about how much pain she is in. Some days she can hardly get up because*



it's so painful. Some days it's a little less. A quality of life thing. In some ways it's not like people at all, but in some ways, it is. It gets all mixed up with the euthanasia thing, even though there are other kinds of pain. (16)

Finally, RD talked about how he had had conversations with nurses who said that they had provided pain control at the end of patients' lives, which probably shortened the patients' lives. This made RD wonder if the reason his father died before RD could reach the hospital was the effort to keep his father comfortable.

RD: But I wondered if they were giving him morphine—I wouldn't be surprised—for his pain. And it probably shortened his last few hours. And, which made it so that I couldn't say good-bye to him, you know while he was alive. But, I'm okay with that. You know, if they did that to keep him comfortable . . . he probably didn't have much more time left anyway. And, it's too bad that that happens, but I'm sure it happens. [laughs a little bit] And, that's okay with me, you know. It's all about . . . for me, it's all about the patients' comfort and I think the tough part of it is I don't think nurses usually ask the patient. They might say, "Do you want something for pain?" You know, the patient would probably say, "Yes." The patient may not know that this is going to shorten their last few hours; but, at that point, they're in such pain, I think the most loving thing to do is probably to give them the morphine. But, know it's the whole Dr. Kvorkian ethical issue. Do you actually give 'em something that's not causing them harm—it's easing their pain. [pause] I don't know. It's a tough issue for me. I . . . and I was surprised when I got into the hospital to find out that it does happen, you know. Nurses give morphine, knowing it's probably going to shorten their last few hours, but . . . (15)

As he recounted this situation, RD appeared to be revealing ambivalence, regret, and longing. The implication here is that pain is inevitable unless life is shortened with pain medicine. RD, like other ministers, seems to be unaware of the wide variety and combination of medications, as well as alternative modalities that can be used to manage pain at the end of life.

Another part of the assumption of inevitability of pain is the belief that the doctors and nurses have done all that they can, that they are limited by the person's particular body or by the available medicine or technology. It did not occur to the

ministers that some caregivers have more knowledge about how to provide good pain control than others or that other professionals in other hospitals might use more effective protocols or procedures. However, in the context of the patient-controlled analgesia (PCA) pump, the ministers expressed some skepticism. But first, the idea that caregivers are doing all they can.

RE was the most vocal about the inevitability of pain. When I asked him how he felt when he walked into a room where there was someone in a great deal of pain he said this:

RE: [sighs] Number one, you pray before you walk in there, you're hearing screaming, know that there's nothing that the nurse can do anymore, whatever. You know, um, you just, I hold hands. (5)

RE told a story about a woman who had bone cancer, saying that there was not much that could be done about that kind of pain. When I asked him if he had noticed any improvements in pain care over the last twenty-five years, he mentioned the introduction of the PCA pump, but talked in terms of limitations.

RE: Well, I know what you're saying. Oh, there's also, through the computerization, you know, we've now got, um, the little morphine shots we can give ourselves, and those type things. But, when it comes down to deep, severe pain, I don't care what gimmick you have, medicine, doctors, nurses, technicians, um, they can go so far. That's their theory of life, and there's a point that you're not going to manipulate the body any more than the body wants to be manipulated. (8)

I refer back to RJ's story about the 90-year-old lady whose bones were rubbing together, but the staff had her sitting up, in spite of a pain level of 12. RJ said, "And I don't know if medically they *could* have managed that pain better" (10). Later on in the interview, we had this interchange.

NC: Do you have any awareness or have you ever felt like there is a situation where there are a lot of professionals in the world who would know what to do in the case of this pain, but these particular ones don't have the knowledge?

RJ: I haven't run into that yet. I, I've always assumed that the ones I was dealing with knew what they were doing and were able to take care of it or find out the resources if they couldn't. But for, that's interesting though, because then when you ask for a family member, yes, I'd be on the phone to another hospital! (11)

RO said that, while he would not necessarily assume that all that could be done was being done, he was certain that his parishioners would assume this, that they wouldn't question their doctors (6).

The closest any of the pastors I interviewed came to saying that maybe the pain management could have been better was when they talked about the PCA pump. Although there might have been a hint of understanding that the nurses and doctors might have done something different, the focus was primarily on the technology, with the idea that something might be wrong with the machine.

RB: I've certainly been there when patients have had self-administered pain control and there's too long a wait between the time they can press the button. (3)

RO brought out the skepticism of some of his church members.

RO: A lot of times the patient doesn't know how to, um, manage their own pain, for instance. If they've got a morphine drip [question on his face]

NC: PCA pump?

RO: with the button?

NC: Yeah.

RO: They wonder, "Why should I push it? It's not going to work anyway. (6)

RH remembered a patient who said, "Well, it only comes out every half hour, or something like that" and RH thought maybe "the pump was a kind of placebo effect" (8-9).

The overall belief in the inevitability of pain can influence a patient's or a visitor's view of the inevitability of a particular instance of pain, thus making political validation of pain less likely. RJ did not demand help for the 90-year-old lady, for example. RO didn't encourage his church members to ask the nurses to change the setting on the PCA pump. According to those I interviewed, one of the most common feelings when a patient is in pain is the feeling of powerlessness.

### Clergy Feelings of Powerlessness to Change Pain Care

Even if pain is successfully communicated and ministers as witnesses have the wish to do something about it, they may decline to try because of a sense of helplessness. RC described his feelings about ministering to those in pain this way.

RC: Well, it hurts. It hurts to hear that people are in pain, you know. A big part of ministry's there are lots of things that you can't do anything about. So, most of the time, that's the first, immediate response. This person is in pain and I don't want them to be in pain. And that's always a part of my response, I think. (13)

In one case, RS described a patient who was dying and conscious, but whose doctors appeared to be ambivalent about removing the respirator.

RS: So, so *then* what happened was it was a couple of *weeks*—like two weeks!—that he was on that ventilator. And just *so* uncomfortable in the bed, and they had to put tape and they had it real tight to keep that thing in his mouth, and his lips were all swollen and, course he couldn't talk or anything. And, it was just, it was just *awful!* It was just absolutely *agonizing*. (6)

In recalling that story and two others, RS described here frustration at not being able to change the situation.

RS: But also I think about, it just makes me realize maybe there's a whole aspect in which there's a theological issue that we, that I, that we tend to avoid that has to do with suffering, I guess. Because I think most of . . . I think it's, it's, it's one thing to accept death. I don't find that that hard, actually. But, *suffering, pain*, um, and especially in situations where it's on-going, is, it's

pretty hard to a respond in any helpful way. I feel, I guess I feel a lot of powerlessness about how to respond in any helpful way to that. And, course, when I think about my parishioners and their needs, I want to be able to fix things and respond in helpful ways! [laughs] So . . . (15)

When I asked RS if she thought it might help for her to know more about pain, for example, that acute pain can be damaging to the body, she was skeptical.

RS: Well, yes and no. I mean, because, on the one hand, intuitively it seems pretty obvious to me that that's true. But, to try and go up against the doctors and nurses? It's so *intimidating*. It's *so hard*! And, yeah, I mean, I feel a lot of powerlessness and frustration if it comes to really locking horns with the healthcare professionals. Pretty much if they're in the hospital, I feel like, well, there's not much I can do.

NC: M-m. [Oh.]

RS: So . . . I mean, I guess what I'm saying is I, I can imagine myself trying to use that kind of an argument with a doctor or a nurse, but when I think about that, I just, my assumption is that they'd blow me off. (10-11)

As part of his seminary training, RF was taught that turf meant that there were certain boundaries he should not cross. “[There’s] nothing we can really do as far as the medical situation” (2). So, he wanted to know, “Or are we just kind of blowin’ in the wind if we go try and help?” (13). When I asked RB about the turf issue, he recounted a story in which he encouraged family and friends of a patient to take advantage of the grievance procedures at the hospital to handle the poor treatment of one of the church members. However, the authority of the physician in a little rural town stood, and the friends and family would not complain primarily because the doctor’s patients had to live with him over time. He was a church member, too (4).

### Summary

While these clergypersons did describe a number of instances in which they believed that they were able to hear the communication of pain by church members, the clergypersons did acknowledge many reasons why pain communications might not

occur. Likewise, while they provided a number of instances of their own advocacy for their patients or their support of self and family advocacy, they acknowledged the challenges to advocacy. In Chapter 3, I will discuss some of the results of the interviews in terms of my own experience visiting a patient, research from the medical literature, and research from the philosophy of education literature. At the end of the chapter, I will discuss how I might now amend my relational theory of pain.

## Chapter 3 – Hidden Curriculum

I begin my discussion of the ministers' stories with my own story of a bedside event that I experienced when I was working as a chaplain. I compare my experience and thoughts about it with what the ministers experienced to see both the similarities and the differences. The similarities present themselves because of the shared experiences of things like active listening to the patient and deference to the healthcare providers. The differences come, I think, because of my other experiences in the Pain Movement. In order to make clearer my thought processes, I have turned what I remember of the event into a fictionalized vignette, which I present now.

### Procedural Pain

When I arrive in the hospital room today, Mr. J is reading a hardback book. Mr. J is a sixty-one-year-old Native American, who has come to Mortimer Hospital because of peritonitis associated with his peritoneal dialysis catheter. During my initial chaplain's visit, Mr. J explained that he is a Baptist minister from the eastern part of the state. Yesterday, he had surgery to remove some infected tissue.

"Well, Mr. J, I'm glad you're here today. I didn't catch you yesterday. How are you?" I say, walking up to the left side of his bed.

"Oh, I'm okay. I'm sore today, but I'm fine." *Sore* can be loaded with meaning. In my vocabulary the word is the epitome of downplay.

“That’s great. What are you reading today?” Maybe I am playing along, maybe not. I go right on by the pain, but I acknowledge that he is someone besides a patient. I sit down, facing the patient.

“It’s a book about Revelations.”

“Well, what do you think of it?”

“Oh, this author is a good writer. I’ve read some of his other books. He’s done a lot of research. But, there are lots of different views on Revelations,” he says, his eyes bright, yet calm.

“It’s a pretty complicated book,” I respond, appreciating his thoughtfulness, acknowledging to myself that I know almost nothing about the book. The UCC definitely does not emphasize study of this book.

“Yes, but I think John was divinely inspired. He was lonely on that island, but God came to him.”

We both look up as a professional in a white coat walks into the room and stands at the end of the patient’s bed. “Mr. J?” she asks pleasantly enough, but with an air of all business.

“Yes.”

“I have come to remove your packing.”

I know what that means, and I want out of here. “Shall I come back a little bit later?” I try to offer with an air of innocence, leaning forward, about to stand.



“Oh, no. This won’t take long, and I would like for you to go ahead and visit, distract him a little bit.” She gives him a wide smile, and then she steps back over to the wall to get some gloves.

Have I been invited to stay or ordered to stay? I wonder what Mr. J wants. What am I saying? He is Rev. J, not Mr. J. Does that make any difference? He answers.

“Okay. I was just going to tell the chaplain about the books I found at a garage sale.”

“Great! Now, let me explain what I am going to do. Your incision was only sutured in three places. See here?” She has pulled up his pajama top and pointed to the four-inch incision on his stomach. “The surgeon didn’t sew you up all the way because he didn’t want to allow the infection to fester and grow. After I pull the packing out, your incision will just ooze for a few days and sort of push the infection out. Does that make sense?”

“I think so,” responds Rev. J, uncertainly. What does any of this have to do with sense-making?

“Okay. I’m going to grab the packing, which is a piece of gauze, really, and you just keep talking to the chaplain. Don’t worry. I want you to know that I am very gentle,” she says in a slightly softer voice.

I know what she is *not* saying. Already I have the picture in my mind of the gauze of debridement, meant to stick to the wound to help pull off dead skin during the process. The problem is that the dead skin is stuck to very live skin.

Rev. J looks over at me. “I have quite a library at my house.”

“What kind of books do you collect?” I ask, the last word interrupted, taken over by his grimace.

“Oh, Mr. J, I know this tape is pulling on your hair here. I’m so sorry. I don’t want you to think I’m not gentle. I’m really gentle.” She continues on. It’s not just pulling the hair; it’s pulling it out, I growl to myself, though, of course, I don’t look.

“That hurts,” this preacher says. Plain and simple. No number for the pain. Just, *that hurts*.

“We’ve almost got it here.” We are all in this project together. Did you hear the first person plural? Yes, but only one person is in charge.

Finally, she says, “There. Go ahead with your discussion.”

“You were telling me about the books you collect,” I say, continuing in this co-project of distraction.

“Oh, yes. Religious books, of course. I enjoy finding out what other people think and preach about. I don’t agree with all of them, but I want to understand different perspectives,” he offers gamely.

“Sure.” I appreciate so much his openness, but his appreciation is cut short.

“In fact.... OH-H-H!” Rev. J squeezes his eyes closed in pain and grips the bar hanging above his bed.

“That really hurts, doesn’t it?” the wound specialist says, with surprise and a little confusion in her voice.

“It’s excruciating!” he responds, breathing hard, letting his hand drop from the grip.

“I’ll try to go more slowly.” She pulls again.

He winces again, explaining, “That hurts way down deep inside.” Again, no number, but patient report of pain clear as a bell.

“Is there a local that could be used?” I ask softly, knowing it is not my place to ask, but unable to contain my alarm, all the same.

“No, a local would only get the top layers deadened,” she responds, making perfect sense from the medical point of view. I want to counter that preventing half the pain might be enough for the patient, but I decline.

“Mr. J, how about if we rest for a minute?” Minimalism in pain control.

“Okay.”

“Gosh! I can’t imagine how hard this must be for you!” I exclaim. Does he hear me saying that this is hard for me, too? Who all is requesting bravery from him?

“This is a tough one,” he answers with careful understatement.

“Are you ready?” She has about three inches of bloody gauze wrapped around her fingers. “I’m going to pull again.”

“OH-H-H! That hurts so much!” he wails and then whispers.

“Well, I had no idea that the sutures would be so tight. Usually it’s not this hard to pull out. I’m going to get the surgeon and see if we can get something for your

pain. I'll be back. Can you stay here with Mr. J, Chaplain?" Ah, so the pain is from the sutures, not from her pulling with all her might against injured flesh.

"I can if Mr. J. wants me to." I look at Rev. J. His eyes are closed. "This is a pretty drastic, intimate time to have a stranger in the room with you."

"Especially a white woman. But I would like for you to stay. Maybe we can go on with the distraction." I didn't know the half of the privacy issue. The wound specialist has left. A circle of red gauze lies limp across the suture. The patient lays one hand on each side of the incision and pats his stomach a little bit.

Perhaps, distraction has moved on from being a tool of the wound specialist to a little blanket for us both to grip. "Okay. I don't know where we were, but let's assume we were at the part about the garage sale."

"Oh, yes. I believe that God led me there. I saw in a box a Jerusalem Bible and a Scofield Bible. So, I said to the man, 'How much do you want?' He said 'Three dollars.' So, I got out my money. This was a steal. 'For the two books?' 'Oh, no. You can have the whole box.' The whole box! The Holy Spirit was with me that day."

"Wow!" The Holy Spirit at a garage sale. Is that Holy Spirit here now?

"Are you a preacher?" he seems to ask on cue.

"No, I was sponsored as a lay person from my church."

"Well, officially, my church doesn't go for women preachers. But I think God sends the gift of preaching to women and men both. I don't agree with keeping women

out. I think there's just-- what do you call it?—a macho thing going on there. Some people call me a liberal for saying this, but I'm not a liberal.”

Before I can respond, the surgeon appears in the doorway, sporting gauzy cap, coat, and shoe covers. “Mr. J, this really hurts, huh?”

“It's excruciating,” he says flatly.

“Well, you're a big, strong guy. If this hurts you, it would hurt anybody. I'll order you something. Are you allergic to morphine?”

“No.” Thank God! The surgeon disappears. Maybe mere complaints of pain turn into real pain if the patient is a big strong guy. I wonder if this patient would have shrunk had the surgeon had heard the conversation about the library, the garage sale, and the Holy Spirit.

“Are you expecting family to be coming by today?” I venture.

“Yes. My wife should be here any time.”

“Gosh! I wish she could be here with you!”

“Me, too!” She belongs in this private scene.

Soon, then, the nurse appears on the other side of the bed with a syringe. “I'm going to push this morphine into your IV,” she says to Rev. J. She tries, pushes hard. No luck. “It won't go in. Let me try again.” She tries. “No, it won't go. Do you have any other veins, Mr. J?” She searches his other hand, the one that has a big black and blue lump on it.

“No, they just took the other one out this morning,” he says, thinking she’s asking about another IV port.

“Let me try one more time.” She speaks in consternation now. “No, the morphine is leaking out the side. Let me go get another butterfly, and I’ll just put in a temporary IV, just long enough to get the morphine in.” She leaves with determined step. I wonder what is more important to her at this moment, to relieve the pain or to carry out the doctor’s order.

“This must be one of the longest afternoons of your life,” I offer, describing myself.

“It’s all right. I’m going to be all right,” he reassures us both.

The nurse arrives back at his bedside. “Okay. Here comes another stick.” Rev. J winces. *Stick* is a pitiful word to describe an IV insertion. “I’m sorry. It’s in now. I’ll go find the wound specialist.”

“Uh, why don’t we give this morphine a little time to get into his system?” I ask unreasonably, forgetting that morphine is not like lidocaine; it’s lidocaine that takes time.

“Do you feel anything yet?” the nurse asks.

“A little bit,” he answers softly. See.

“It will start working right away,” she states.

As she leaves the room, Rev. J closes his eyes. “It’s making me foggy. I hope it’s like the medicine they gave me last night. I felt so relaxed. Finally, I could get some sleep.”

“I’m back,” says the wound specialist as she pulls on a new set of gloves. “This time we’re going to be able to finish this up. Are you ready?”

“Just go ahead,” he says in a tone I can’t describe.

“There! I got it!” she says with satisfaction, as Rev. J squeezes his eyes closed eyes one more time. “There wasn’t that much left. I bet that you don’t believe that I’m usually gentle. Those sutures were just so tight!” She looks at me. “You have been great! I was so glad that you could stay here to distract Mr. J. Thanks a lot! Good-bye now, Mr. J.” Now there is just empty space where she stood.

“Are you all right?” I ask, knowing that he has survived, but he is not all right.

“I’m glad it’s over,” he says in indirect agreement, I imagine.

“How about a prayer?” Chaplains are to offer every patient a prayer. Should I have offered this earlier?

“I could use one,” he sighs. He reaches for my hand.

“Dear Lord, as you know, this precious child of yours has been through the ringer this afternoon. You have given him strength. Now we ask that you comfort his bruised heart, heal his injured flesh. Lord, we are grateful for his family who will be here to comfort him, too. Show them how best to love him in the minutes and days ahead. We give you all the praise. In your name we pray. Amen.”

“Thanks. I feel better now.” I know that this might be obligatory gratitude. So many obligatory statements today.

“I need to go on down the hall now. But I will keep you in my prayers.” And in my memories forever and ever. Amen.

### **Rooting Out Hidden Curriculum**

As Martin explained, “There can be no doubt that when the hidden curriculum we find contains harmful learning states, we must try to root them out. But this is sometimes easier said than done” (Martin 1976, 145). She says that we must look for the source of the hidden curriculum. Part of the purpose of my relational theory of pain, as I said above, is to determine where hidden curricula exist so that resistance might be possible.

It seems to me that what this story and the ministers’ stories have in common are four primary, interrelated themes—endurance, doubt, inevitability, and what Susan Wendell calls “the cognitive and social authority of medicine” (1996, 117). All of these work together to reduce successful communication of pain and to reduce political validation of pain. As I compare this narrative and the pastors’ narratives, I will include references from the medical literature, which might also be called narratives in a very specific form (Charon and Montello 2002).

“Procedural Pain” is a story of endurance education. Before and during the episode of pulling on the tape stuck to Rev. J’s abdomen hair, the medical resident expects Rev. J to endure the procedure. Likewise, she expects him to endure the



pulling out of the gauze. In fact, her image of herself as gentle reinforces this expectation. In addition, when the resident gives the technical explanation to Rev. J about why she is doing the procedure, the very reasonableness and, perhaps, slight mystery of the appropriateness of an oozing, open wound, reinforce the expectation that Rev. J will endure whatever pain happens. And, finally, it could be that Mr. J's gender influences how long it takes for the resident to consider the possibility that the expectation of endurance should be relinquished. When the surgeon comes to the room, he seems to further this possibility by saying, “Well, you're a bit strong guy. If this hurts you, it would hurt anybody” (95).

In Chapter 3, the discussion on endurance can be found under the general category of “Minimizing or Concealing of Pain by Patients” (52-61). In the interviews, the ministers mostly viewed the sources of the church members' beliefs in the value of endurance as the farming culture, German ancestry, the older mentality of the World War II generation, or maybe just part of the American culture. What they did not point to directly was the endurance education provided to the patients, as well as to patients' visitors, by the doctors and nurses, or by the organization of the healthcare system. This is an example of Martin's “hidden curriculum” (Martin 1976, 2002) or Foucault's “disciplinary regime” (Foucault 1977). However, certain *events* that the ministers described could be termed endurance education by the medical and nursing staffs. For example, one patient who had bone cancer was x-rayed before getting pain control. (46) In another example, when RJ described the situation of the 90-year-old woman who was made to sit up in the chair, in spite of her pain, she quoted the nurse as saying, “Oh, we have given you this medicine and it will probably take effect soon”

(30). Until the medicine took effect, the elderly lady was expected to endure her pain. I described RO as someone who had tried to decline endurance education, but failed. As he recounted, RO tried to advocate for himself after his knee replacement surgery, by telling the nurse what the doctor had said about getting pain control in three hours, instead of four. (57-58) He may have been receiving Demerol. Though the prescriptions for it are generally written for use every four to six hours, the action of the drug is over at three hours. But RO's nurses declined to give the medicine at three hours because the change in prescription (by a doctor who may have known more about Demerol) was not written in the chart. The educational message in these three cases was, "No matter how you describe yourself on the pain scale, rules are rules." Medical and nursing authority was not just held in them as professionals, but also in the system of prescription writing *and* in the cultural practice in that institution at that time in which no one was accountable for getting all the healthcare providers on the same page or for making sure that the patient did not have to endure pain at a level of eighteen. Patients receive a double message in this kind of situation. On the one hand, they are taught that they should number their pain because pain matters and should be relieved. On the other hand, they are being taught that their pain matters only to the extent that it does not bump into individual caregivers who don't agree with that pain matters or into a system that can't accommodate good pain care. In cases like this, the message reflecting pain management tradition has more power than the one reflecting the Pain Movement. Not enough has changed in endurance education since the mid 1980s when Dax Cowart, a terribly burned patient in Texas, was debrided against his will for months. The message of his endurance education from the doctors and his

mother was that no amount of pain could be described as beyond endurance, in spite of his protestations to the contrary (Kliever 1989).

In fact, within the pain research literature and in certain pain clinics, the opposite of endurance is a diagnosable condition called *catastrophizing* (Sullivan, Bishop, and Pivik 1995). According to Michal Granot and Sari Goldstein Ferber (2005), “catastrophizing has been defined as an exaggerated negative orientation to aversive stimuli that involves rumination about painful sensations, magnification of the threat value of the painful stimulus, and perceived inability to control pain” (439). The idea is that endurance preserves autonomy, whereas catastrophizing ruins it. An association is made between self-efficacy and endurance (Miller and Newton 2006). So, the prescription is to teach patients how not to catastrophize (Kugelmann 1998; Nelson and Tucker 2006). However, what has happened here is that what has been just individuals’ own way of coping has been turned into a symptom of a condition, that results from the decision to normalize particular pain behavior and pathologize other behavior (Rose 1990; Frank and Jones 2003; Cunningham 2008; Miller and Rose 2008; Cunningham (in press b)). Foucault (1965) describes the same kind of situation in *Madness and Civilization*.

[From] the acknowledgement of his status as object, from the awareness of his guilt, the madman was to return to his awareness of himself as a free and responsible subject, and consequently to reason. This movement by which, objectifying himself for the Other, the madman thus returned to his liberty...” (274)

In a paper entitled “Exploring the Educational Value of Endurance in the Context of Acute Pain,” I had asked, “When does the attempt at growth through endurance and coping with difficult and complex situations become mere acquiescence to the status

quo of social injustice?” (Cunningham 2008, 8) Who is the slave and who is the tyrant? Care providers in the Pain Movement want to define self-efficacy in a very different way from the researchers who study catastrophizers. Autonomy and self-efficacy, from the Pain Movement’s point of view mean admitting pain and getting help (Berkley 1998; Sun et al. 2007).

Very much related to the question of endurance is the status of patient report, or who is the expert on the patients’ pain? As I noted in Chapter 1, the IASP definition of pain appears, on the one hand, to say that the patients are the experts; on the other hand, if the reports of pain do not match the physicians’ physical diagnosis or expectations of what is normal, then the pain is merely psychological. In “Procedural Pain,” Rev. J uses the terms “sore,” “excruciating” and “that hurts.” And, at different times, he uses the body language of grimacing, gripping the bar, and crying out. The resident does not ask for a pain number. Although it appears that she hears the communication of pain well enough, she describes herself more than once as “gentle,” as a way of doubting the current situation. “This patient doesn’t seem wrong about his pain, but his reaction does not match how I understand myself, so he might be wrong,” the resident may be thinking. In addition, she seems to be focusing on contending with the tight sutures more than with the experience of Rev. J, thus, damaging her ability, for a time, to get help for the patient from the surgeon.

From the perspective of the ministers in the study, there are a variety of reasons to doubt patients’ pain. For example, RO noted that pain may be impossible for the patient to distinguish from fear (62-63), and RP expressed a fear of maximizing patients’ pain (63). According to the medical and nursing literature, it is common for

professional caregivers to rate patients' pain lower than the patients do (Byrne, Morton, and Salmon 2001; Anderson et al. 2004; Sauaia et al. 2005; Wilson and McSherry 2006). Moreover, some pain researchers work hard, for example, to show that patients mistake anxiety for pain, thus making the patients' pain reports untrustworthy (Keogh et al. 2004; Pesut and McDonald 2007). As Code (1991) would describe it, in a context like this, masculinization of reason includes the idea that "dispassionate observation and scientific objectivity promise control over unruly emotions" (50). Emotions need to be cleanly separated, the researchers believe. If they are not, then patients make mistakes. For example, Joel Katz, Tom Buis, and Lorenzo Cohen (2008) showed in their research that women who scored higher on an "impact of event scale (IES) measuring intrusive thoughts and avoidant behaviors" (88) were more likely than others to "make excessive demands for postoperative intravenous-PCA morphine during lockout intervals" (88). From these researchers' perspective, these women were carelessly and unreasonably not treating current, real pain, but attempting to avoid future pain. A bedside nurse who took this research to heart might well educate patients that they should only use the button when they are having moderate to severe pain. But one of the main ideas in the reform of the Pain Movement is that pain needs to be prevented so that it doesn't get out of hand; patients are not to wait until the pain is severe to use the medicine.

The same kind of situation happens with research on anxiety. Anxiety is described as something that confuses patients about the amount of pain that they have (Reiss et al. 1986). On the other hand, from the Pain Movement perspective, not only might anxiety motivate patients to get help for their pain (American Heart Association

2006), patients might actually be right! For example, Madelon L. Peters and colleagues (Peters et al. 2007) studied 625 patients who underwent elective surgery to see who might be most likely to have the worst outcome in terms of function and quality of life in the six months after surgery. “The most important predictors of unfavorable outcome were duration of the operation and high levels of acute postoperative pain” and “preoperative fear of surgery”(487). In other words, their fears and anxiety were right. According to Paul Svedman, Martin Ingvar and Torsten Gordh (2005), if caregivers know beforehand that patients are particularly anxious, and that this anxiety might interfere with the effectiveness of pain control, then analgesic therapies should be directed “...towards being prophylactic and continuous...rather than reactive and intermittent” (4).

A third part of this complex issue has to do with what I call the inevitability of pain. When the resident in “Procedural Pain” comes into the room, she does not provide preventative morphine in the IV; nor does she attempt to remove even some of the pain through a local anesthesia; nor had the surgeon ordered seventy-two hours of lidocaine infusion into the wound. All of these were possible (Lavand'homme 2006) ; however, prevention is not a controlling systems requirement in a system where pain is understood as inevitable. As I noted in the introduction to the section on inevitability, “Ministers may hesitate to get help for patients in pain or to encourage patients to insist on better pain management as long as ministers or patients believe that some amount of pain is inevitable or that this particular pain is inevitable” (89). A better way to state that idea would be to say that ministers or their church members or the caregivers may believe that *because* some amount of pain is inevitable, *this*

*particular pain* is inevitable. The ministers described two main reasons for this belief: reducing or preventing this pain might be unsafe or the doctors have done all that they can. The question of safety arises partly because of the worry about respiratory depression as a side effect of morphine, due in part to the public education they had received about euthanasia and physician-assisted suicide. RL says, "...you have to be very, very careful, not to accidentally kill somebody with pain medication" (93). RD described his own theory that his father died sooner than he might have because of morphine. Used correctly, morphine does not do this (Portenoy et al. 2006), but the fear remains. Moreover, this fear of morphine spreads out into other arenas where morphine might be used, such as emergency care (Rupp and Delaney 2004; Probst et al. 2005; MacLean, Obispo, and Young 2007), creating inadequate pain care in the emergency room.

But whether the care is safe and whether all that *can* be done *is* being done are related issues. This is shown in the arena of patient-controlled analgesia. Patients are often self-surveillant; that is, they use less than they can with a PCA pump because of fears of morphine (Shiloh et al. 2003; Chumbley 2009). On the other hand, they may use less than they can because, when it doesn't seem to work, they just give up (King and Walsh 2007). RB, RO, and RH (96) all express doubt about whether the PCA machines really work. However, they seem to be tying the problem to inadequacy of the machines, themselves. What they *not* appear to know is that the problem may be how the human caregivers set the machines up to work or how the caregivers prepared the situation. As Gillian Chumbley (2009) makes clear, sometimes the machines are set with doses too small or too far apart, or patients may be in the

situation of not having a loading dose. In other words, in the recovery room, the patients are supposed to be given an effective amount to start with, so that what the patients do back in their rooms by punching the button, is to *add* to the original dose for the purpose of maintaining good pain control. If a loading dose was *not* given, it may be hours before the patient can catch up. (167)

Ironically, a diagnostic instrument called the “Barriers Questionnaire II (BQ II)” (Gunnarsdottir, et al. 2002), which attempts to ascertain in patients correct or incorrect beliefs about pain or pain medication, includes a section called “fatalism,” meaning that patients believe that pain cannot be controlled, and that, therefore, ““good patients’ do not complain about pain” (388). This belief was certainly evident in the ministers’ church members. According to the scoring system of this questionnaire, patients need education if they are fatalistic, if they believe that pain cannot be controlled. The questionnaire does not include questions about events that actually have happened to the patients or their family members and friends that would assure them that pain could or could not be controlled. The hidden curriculum here is that those events in which pain control was inadequate shouldn’t count in the rational decision-making of patients or their visitors. In other words, although there are many reasons why inadequate pain control remains, including the lack of knowledge on the part of physicians or nurses, or a problem in the system (Dahl 2004; Sun et al. 2007), particular patients’ belief in this inadequacy is diagnosed as a barrier that needs to be removed through education of the patient. This is the case even when the articles about patient barriers include references to studies that show contributions to undertreatment



of pain by medical professionals and healthcare facility systems (Gunnarsdottir, Serlin and Ward 2005).

The chaplain in this fictionalized vignette *did* try to advocate for the patient by asking if the patient might have local anesthesia at the site of the incision, and then asking if the resident could wait to begin again until the pain control could take effect. The chaplain *did* hear the communication of pain, and she *did* try to advocate. Likewise, in a number of instances in the study, the ministers described how they have asked the healthcare providers directly about more pain control, or how they have encouraged the patients to do this. However, these attempts at advocacy by the chaplain in the “Procedural Pain” are surrounded by her acquiescence to the resident when the resident asks her to distract the patient. In the study, RF and RK mentioned their use of distraction, but RE was the most vocal about the usefulness of distraction. (44-45) However, the cheerfulness, about which some pastors showed concern (86-89), might be considered a part of this effort at distraction. Sometimes participation in cheerfulness might be a method of supporting the regime of inevitability, which encourages ministers not to advocate for the patients, or to wait too long to do this.

### **Alterations to the Relational Theory of Pain**

While the theory, as I originally stated it, captured much of the relationality of pain, four areas need strengthening. First of all, what I did not explore originally was the extent to which the patients, themselves, might be involved in creating unsuccessful communication of pain. This was partly a result of the fact that most of my focus at the times was on patients who are unable to talk, especially infants.

However, in addition, I did not include originally reasons why patients might withhold communication of pain. My study of Foucault and the idea of self-surveillance has helped with insight. The ministers in this study have provided a wealth of reasons why communication of pain may be unsuccessful or successful.

Secondly, I need to add more to the relational theory how the practice of normalization, described by both Foucault and Martin, overlays and infiltrates the micro-situations at the bedside. In spite of doubts about the measurability of subjective experience, patients are asked by medical professionals to rate their pain. Ministers reported watching this or experiencing this, themselves. However, the hidden curriculum within professional responses is that patients will be marginalized when patients communicate pain outside the expected normal, or when they ask for pain medication outside the normalization contained within hospital routines.

Thirdly, my theory needs to include more about how the assumption of inevitability of pain, by patients, professionals, and visitors, can adversely affect both communication of pain and political validation of pain. RR, RH, and RE were right to say that, under some circumstances, pain has a biological purpose, for example. As Clifford J. Woolf (2007) explains, “The unpleasantness of pain originated and has been elaborated and retained by evolution because it has survival value” (28). But there are many circumstances in which that biological purpose has already been served, and withholding pain control now may just damage the patient both physically and psychologically. The emergency room is a good example of where this occurs (Rupp and Delaney 2004; Probst et al. 2005; Duignan and Dunn 2008).

Finally, I need to add more to the part that educational institutions outside of schools play not only in preserving the status quo, but also in making a difference in change. In Chapter 4, I will begin this effort by discussing how clergy and the institutions they represent may make a difference or not.

## **Chapter 4 – Implications of This Study for the UCC**

“Conflicts and opposition to unjust societal arrangements and cultural practices are not only the stuff of novels or the province of special people with unique personal qualities. It is the stuff of everyday life”(Turiel 2008).

While the clergypersons in this study did describe a number of instances in which they believed that they were able to hear the communication of pain by church members, the clergypersons also acknowledged many reasons why pain communications might be damaged or not occur at all. Likewise, while they provided a number of instances of their own advocacy for their patients or their support of self and family advocacy, they acknowledged the challenges to advocacy. How might the UCC be involved 1) in supporting what UCC ministers already do to advocate when they are visiting their parishioners, and 2) in helping to change the situation of inadequate pain control? The UCC has the possibility of being fully engaged in the Pain Movement through clergy and lay education, as well as policy development. But, first, it is important to understand what is currently in the pastoral care literature and the UCC literature.

### **Pastoral Care Literature Related to Pain**

The pastoral care literature includes a small number of articles about considerations that clergy might take into account when they are serving patients in pain. Although authors of these articles generally acknowledge that pain assessment and management are inadequate, they are likely to give advice to chaplains and ministers about how they can help patients in pain to advocate for themselves.

Significantly, few discuss the responsibilities of healthcare professionals to bring about better pain management, the involvement of systemic problems, or direct advocacy by the clergy. Jacqueline Cameron, for example, noting that emotions can affect pain, encourages women to follow the example of Teresa of Avila, a sixteenth-century mystic, who found strength in her identification with a suffering Jesus (Cameron 2005). Although Cameron notes that "...pain researchers have found that a single episode of severe pain from trauma, disease, or other injury can lead to irreversible changes throughout the nervous system that result in continuous and debilitating pain" (174), *she treats this pain as if it is a given, rather than a kind of pain that might be prevented*. Cameron says up front, "My guiding question is more along the lines of 'Given that pain and suffering exist, where and how might we find healing and hope?' rather than 'Is all this pain really necessary'" (168). Likewise, David Zucker treats pain as a given and suggests that clergy teach nursing home residents to advocate for themselves by taking back responsibility for themselves (Zucker 2006) through "reaching past their personal pain to care for their fellow residents" (405). In other words, he is saying that patients should take responsibility for their pain. This author lists no references to studies documenting the undertreatment of pain in nursing homes.

Ralph Underwood acknowledges the epidemic of chronic pain, but he sees the part that clergy can play primarily in terms of acknowledging patients' pain, assisting them to be hopeful yet realistic about their pain, and making sure that patients do not feel isolated (Underwood 2006). In a section called "Mental Habits," he notes that patients may exaggerate their pain, citing research about "catastrophizing"; their pain

may be increased by a “pre-morbid condition” like substance abuse; and that grieving may make pain worse (6). In this section and one on “Pain and Identity,” in which he describes situations where patients’ only identity is as persons in pain, Underwood tries to show that clergy can help patients become more realistic about their pain if they can see how they are contributing to it. In a similar manner, Timothy Ledbetter analyzes the situation from the perspective of an assumption of patient autonomy, which merely needs to be supported by clergy (Ledbetter 2001). He says, “The primary way others aid and support the coping of a person in pain is through *professional interventions*—medical/surgical, orthopedic, nursing, pharmacological, psychological, chiropractic, and homeopathic, among others” (384). *Yet* Ledbetter details none of the difficulties of obtaining the interventions, and he focuses on ways to support patient autonomy by determining the patients’ “intentions,” whether they are seeking relief, survival, or improvement (383); depending upon these intentions, patients can be assisted to move toward “outcomes of managing pain” of recovery, adaptation, or integration (386). Here again, patient responsibility is the key; however, patient autonomy is not described in terms of the patients’ insistence on better pain management.

Phyllis Brooks Toback and Purdy describe ways clergy may assist patients at the end of life when the issue might be suicide or assisted suicide because of pain or other suffering (Purdy 1992; Toback 2006). Toback says that education is needed about how to be respectful of self-determination around issues of withdrawal of treatment. Clergy especially need to be good listeners. Toback also acknowledges the inadequacy of pain management; she says, “Our knowledge of pain control needs to

be increased. Practice continues to linger behind available resources. Recent studies indicate that patients are often significantly under-medicated, because of some inappropriate concerns about addiction” (31). However, she adds, “There needs to be more encouragement of alternative approaches to pain” and follows by pointing to “a Hindu festival in Singapore called *Thaipusam* where hundreds of people feel no pain from being skewered and pierced by steel” as an example of “the impact of emotions and spirituality on physical well-being” (31). Such an example might make those patients who are upset by the fifth attempt at insertion of an IV with no pain control feel that they should keep quiet.

Purdy (1992) sees the problem of pain on a continuum. No pain medication or severe undertreatment is on one end of the continuum, while so much pain relief that death will be hastened is on the other end of the continuum. Purdy says that patients on the undertreatment end of the spectrum may believe that they are accepting God’s will or that they should use Jesus’ suffering on the cross as an example, and he suggests that the patients may be convinced that they do not need to replicate the suffering of Jesus or that pain is not God’s will in the form of God’s wrath. At the other end of the spectrum, patients may “want to try to control pain by ordering the process of dying” (16), according to Purdy, because patients cannot see that their suffering has any spiritual purpose. Clergy responses to this situation can be as “witnesses to the dialogue” or helpers to see that “patients arrive at an acceptance of their powerlessness” (16). *He makes no mention of the possible power of patients, families, or clergy to improve pain management in a situation like this.* However, at least in contrast to the clergy authors discussed so far, Purdy says that the situation of

no or little pain treatment may be caused by professional attitudes, as well as patient attitudes.

Doctor hesitancy to prescribe pain drugs liberally may have to do with unconscious feelings of failure and denial—because the doctors have given the best possible care, how can it be possible that the disease is not in remission? Admitting that the patient has pain is in a sense acknowledging that medicine has been inefficacious. The more the pain, the more bitter the defeat. (13)

However, Purdy makes no suggestions about communicating to the doctors about their possible inner feelings. Margaret Morhmann seems to provide some contrast to this view with her insistence that, in order for pain to be “productive of the endurance that strengthens character and engenders hope . . . [it] must be unavoidable” (83). and it must not be so great that it only crushes the patient (Mohrman 1995). Moreover, she notes that patients need advocates “in the face of inexpressible pain” (50). Still, she does not acknowledge anywhere else the lack of adequate pain management or the possibility of systemic reasons for it; her focus is on the relationship between patients and caregivers.

Wayne and Charles Oates do mention the fact of inadequate pain management as a failure on the part of physicians (Oates and Oates 1985), noting a study in which physicians ordered less pain medicine than appropriate and explaining that PRN (as needed) administration of pain medicine may well result in patient fears of addiction and poor pain control due to the “peak and trough” of each dose’s effectiveness (81). However, this small section comes only *after* the authors describe how pain works, emphasizing the patients’ responsibility to perceive their own pain accurately, cooperate with efforts at distraction, accept physicians’ diagnoses of the cause of their pain, and comply with physicians’ “therapeutic instructions as a form of prayer” (19).



The primary role of ministers is to refer patients to physicians appropriately for issues such as depression and to make sure that patients do not feel isolated. Ronald Ropp notes in his review of this book (Ropp 1986), “The tone I received from the book is that pastors need to be very sensitive to medical leadership in the whole area of pain management but that they have unique and critical roles. Very little room is given for the pastor as one who confronts the rest of the ‘team’ in behalf of the personal and human needs of the patient” (85).

Only James Lapsley states that clergy have a specific responsibility to advocate for patients by directly asking physicians whether patients with dementia might need more pain control (Lapsley 2002). Lapsley notes a specific study of persistent pain in nursing home residents (Teno et al. 2001); then he explains how a focus on autonomy in bioethics can lead to a neglect of those no longer autonomous. Lapsley argues for a search for causes of pain both for those who cry out and those who are mute, even at the risk of “...upsetting those in charge, or even becoming *persona non grata*” (324), though, usually, he says, healthcare professionals will welcome the interest that clergy take.

Finally, Edwin Lisson (1987) agrees with the other, that “the meaning of suffering is redemptive only if it is freely and voluntarily accepted” (656), but he is the only clergyperson who describes several systemic reasons for poor pain management, arguing that “it is in the context of care that the ethics of pain control must be examined” (650). According to Lisson, ways that systems contribute to inadequate pain care include laws and regulations; the refusal of pharmacies to stock adequate pain medication due to poor pharmacist-physician communication or fear of pharmacy

theft; lack of physician and nursing education about pain, including the focus on science and technology that leaves out pain; the “mythical ‘Pain Book,’” (657) which specifies the pain treatment for the normal (or ideal) patient, in contrast to treatment for individuals; the lingering view that nurses should respond to patients’ complaint of pain by assuming that the real problem is anxiety; and the myth that the main responsibility of the nurse with the keys to the narcotics is to keep the box locked, rather than to open the box when patients need the medicine. Although Frederick Schmidt does not produce an equivalent list, he would appreciate Lisson’s list (Schmidt 2001). He notes that “in complex ways, some theologies of suffering have, in the past, helped to preserve institutions that were the engine of suffering” (33). He continues, “Theologies that preserve a destructive status quo . . . can short-circuit the energy that might otherwise be devoted to the / reduction of suffering. Working to reduce suffering can also sensitize us to the ways we inflict suffering on others” (33-34).

### **UCC Literature Related to Health and Compatible with Opportunities to Improve Pain Management**

Two aspects of this literature search are significant. One aspect is that the United Church of Christ (UCC) has reflected on on-going interest in and commitment to providing a positive health ministry, and to playing an active role in social justice issues in the healthcare arena. The other is that they have not focused much on pain management.

Through its Council for Health and Human Service Ministries (CHHSM), the UCC operates “359 facilities that range in size from small care facilities to large hospital networks” with the following vision statement:

CHHSM **envisions** itself as an organization that provides leadership for its own member ministries, the UCC and the interfaith community of health and human service ministries that, together, we may:

- Live out our understanding of human service as an enterprise grounded in faith-bound compassion;
- Advocate boldly and effectively in the public arena for the right of all to have access to a high quality standard of health and human services;
- Promote a comprehensive view of health which includes all dimensions of the lives of persons and communities;
- Uplift and celebrate the values of faithful servanthood and stewardship at the core of health and human service ministry. (United Church of Christ 2009)

While CHHSM lists a number of public policy advocacy partners, none of these is a pain advocacy group. It could add to this list groups like the American Pain Foundation, the American Academy of Pain Medicine, and the Alliance of State Pain Initiatives. The CHHSM provides a list of current public policy issues that does not include any related to pain, but it could add issues such as disparities in pain care.

Since the UCC General Synods began, 46 resolutions related to healthcare have been passed. During the most recent synod (in 2007), one resolution that passed states that seven different groups within the UCC will study the issue of physician assisted suicide (United Church of Christ 2007). One line of this reads: “Whereas, medical technology, pain management and palliative care have made great advances, yet some persons still face intolerable suffering during a terminal illness” (§6). The UCC Science and Technology Taskforce has produced “A Word to the Church on End of Life Care: Theological, Spiritual, and Ethical Reflections,” which emphasizes the relational nature of suffering (Epperly and Mills 2009).

Human life is profoundly relational. There are no isolated, self-made individuals. We are made for relationship and find fulfillment in healthy and life-supporting relationships and communities. We are part of the body of Christ, in which our joys and sorrows are one. (4)

Autonomy is balanced by interdependence in all ethical settings. Our lives are ultimately relational...Although there is a bias toward autonomy in medical decision-making, autonomy is contextual and relational, not absolute. (4)

This understanding of relationality is important, but it does not include an understanding of the relationality of pain. Another reflection that the task force included involves attention to the vulnerable. “Ethics has a bias toward care for the helpless and vulnerable” (4). The “Mission Statement on Health and Human Service” (2002) offers a similar statement. “Thus, an essential part of the Church’s commitment to health and human service ministry is advocacy on behalf of those who are oppressed or disadvantaged” (3). Describing persons as vulnerable or oppressed is not a way of describing just them; it is a way of describing relationships. The UCC has an opportunity to attend to the special vulnerability of those in pain and to the relationships which make possible or prevent successful communications of pain or political validations of pain. “A Word to the Church . . .” mentions that part of the decision-making that patients do at the end of life includes a fear of poor care, or what they believe is the best that institutions can now do. “Patients also fear unrelenting pain and debilitation in institutional contexts committed to the prolongation of life” (5). Many patients are right to have this fear (Coulehan 2005; Rolnick 2007). Partly because of the growth of hospice and the field of palliative care throughout the life span, good pain care is almost always possible at the end of life (Seymour, Clark and Winslow 2005); further discussion of care at the end of life could include this kind of

information and resulting opportunities for advocacy. According to Rev. Barbara Baylor, the Minister for Health and Wellness, Justice and Witness Ministries, (personal communication, 18 February 2009), the plan of the UCC is to continue this study in the 2009 General Synod and produce an educational document for churches that includes the issue of pain management.

The UCC has encouraged its member churches to get involved in the social justice issue of access to health care through two different adult educational resources, *Vision and Voice* (Neale et al. 2009), and *Health-Care Reform* (Walling 2008). While these study resources tackle a number of general access issues, the specific issue of access to good pain care is not mentioned, though it could be. For example, the Health Care Justice webpage of the UCC includes a request for “personal stories of health care injustice” (<http://www.ucc.org/justice/health/>). The request might include stories of disparities in pain care also.

This look at the UCC literature that would be compatible with the relational issue of pain is just a beginning look; however, it suggests that the UCC might well have bases for consideration of further efforts toward pain advocacy. According to Rev. William Johnson, Vice President for Member Relations at CHHSM (personal communication, 9 July 2009), one method of moving ahead on this issue would be to put together a working group in order to insure “buy-in from all the relevant groups before the project begins.” Johnson suggested that participants in such a working group might include Justice and Witness Ministries – Health and Wellness, CHHSM, the UCC chaplaincy group, the International Parish Nurse Resource Center, UCC health care ethicists, and the UCC Physician’s Network, the UCC seminaries, the UCC

Council for Higher Education, and Local Church Ministries. Activities for such a group might include further research, curriculum development, and policy actions.

Within each of these kinds of activities, efforts can include attention to both overt and covert curricula. When I asked ministers in this study if they had heard of *Pain Control: Understanding and Managing Cancer Pain* (American Cancer Society 2004), none had, but they agreed that it might be a good addition to their church library shelves, and this public document might be a good reference for future UCC curricula about pain. This book is up front about the inappropriateness of mere endurance, and it says that most cancer pain can be well-managed. On the other hand, when the UCC studies its own practices or makes decisions about what to include in pain curricula, it might want to attend to its “rationalities” (Foucault 1994) that are yet unexamined. For example, in seminary class discussions about turf, what are the unexamined assumptions about endurance and the inevitability of pain? Is there an awareness of professional caregivers’ tendency to rate patients’ pain lower than the patients do (Byrne, Morton, and Salmon 2001; Anderson et al. 2004; Sauaia et al. 2005; Wilson and McSherry 2006), or that many studies have shown that patients receive less than adequate pain care even when it is technically possible to provide adequate care? (See the section “Continuing Harm. . .” in Chapter 1). If there is awareness of this literature, how is this awareness used? If not, why not? Once these assumptions and decision-making processes are analyzed, each UCC group can decide whether hidden curricula are supportable and it wants to keep them, or whether they are not and the group wants to “root” them out, raise awareness about them, and

change practices (Martin 1976) through appropriate resistance (Foucault and Faubion 1994).

### **Potential Areas of Further Research**

If the UCC were to develop a working group, one move might be to conduct research, preparatory to curriculum development or policy involvement. A number of research questions might be relevant. I offer a few examples below.

1. What else in the UCC literature might be supportive of or compatible with attention to the issue of pain and the importance of the role of witnesses to pain? The UCC makes available the booklet “Holding on...While Letting Go: Reflections in Times of Grave Illness” by Joan Hemenway. Does it encourage people to accept unacceptable pain management at the end of life, or does it encourage people to advocate for better care? Perhaps, Margaret Mohrmann’s book *Medicine as Ministry: Reflections on Suffering, Ethics, and Hope*, published in 1995, could be updated with more current information about pain assessment and management. It would be especially important to include an analysis of a variety of cultural sources of the value of endurance, including the medical or hospital cultures which may encourage endurance using hidden curricula.

2. Would the UCC literature about social justice in health care be compatible with the pain and ethics literature? For example, would the UCC agree that with the idea of pain management as a fundamental human right? (Rich 1997; Farmer 2003; Brennan, Carr, and Cousins 2007; Fishman 2007; Human Rights Watch 2009) What do rights say about relationships?

3. Have the developers of other UCC curricula made particular decisions about whether to include material related to physical pain? If so, what was the context of these decisions?
4. What have been the UCC parish nurses' experiences of pain in the church members they have visited? Does this group's training involve particular CEU's about pain assessment and treatment?
5. What have been the UCC chaplains' experiences of pain in the patients to whom they minister? Did their chaplaincy training include specific material about patients in pain, and the relationships among patients, medical professionals, and systems, as they may affect pain communication or advocacy?
6. What do UCC missionaries report about the status of pain care at health care institutions where they are located?
7. What is taught in UCC seminaries about physical pain? Do pastoral counseling courses learn about possible psychological consequences of episodes of severe, unrelieved pain in relation to issues of trust, for example? (Shapiro 1996) The ministers in this study all said that they learned only about psychological pain in seminary. If pain is not part of the curriculum, which courses might be the most likely ones to accommodate this discussion? It was when I mentioned articles about disparities in pain care due to age, race, disease condition or ethnicity (i.e., Bonham 2001; Cintron and Morrison 2006) that RF told his story about the young man who turned out to have sickle cell disease. What do students in UCC seminaries learn about turf issues, when it comes to making a sick call at a hospital or nursing home? How might the clergy stories in this study provide a basis for discussion? How might



assumptions from the past about the inability of lay persons to understand medical information and a sort of gentleman's agreement about areas of expertise prevent ministers from providing advocacy where it might be appropriate? RC, RO, and RE made specific reference to the fact that they are clergy, not doctors; but that fact need not prevent all advocacy for better treatment.

8. What are UCC healthcare institutions doing to provide the best assessment and treatment of pain for their patients? The Joint Commission provides guidelines for pain care, including requirements for staff and patient education. Under what circumstances do patients receive this education? For example, do all birthing classes include information about the possible forms of pain control for circumcision, as well as studies showing the consequences of using or not using pain prevention or amelioration methods? If patient barriers questionnaires are used, are they used to elicit patients' stories of their experiences with pain? Under what circumstances do staff members receive pain education? What are their incentives or disincentives to get the education and then to apply the principles they have learned? Are there regular analyses of systems barriers? For example, what is the protocol for establishing responsibility for pain care during transport from the recovery room to the patient's room on the unit? If a patient says that his or her pain is a twelve, eighteen, or a zillion on a one to ten scale, what does the care provider write down in the chart?

### **Potential Ideas for Curricula Development**

Lawrence Cremin listed "benevolent societies" (1976,29) as institutions beyond the school that educate, but he was not considering education related to health

care. If he had, he could well have included activist healthcare organizations like the Alliance of State Pain Initiatives, the American Society of Pain Management Nurses or the American Pain foundation, as well as religious organizations. Using this alliance, a number of educational strategies are possible for the UCC. The purposes would be, first, to use the relational theory of pain as a conceptual map for analyzing current actions and policies, and second, to raise awareness of hidden curricula which help or hurt pain assessment and management.

According to Rev. William Johnson, mentioned above, Rev. Michael Schuenemeyer, Executive for Health and Wholeness Advocacy, and Rev. Dr. David McCurdy, Director of Organizational Ethics, Park Ridge Center for the Study of Health, Faith and Ethics, the UCC process of curriculum development is very much a collaborative process among groups within the UCC. As Rev. Schuenemeyer put it, “The more issue-oriented a topic is, the more collaboration there is” (personal communication, 10 July 2009). He continued by saying that “collaboration helps to “maximize the learning experience and provide various levels of facilitation.” Thus, when I explained to Rev. McCurdy that, out of respect for the UCC, I would not be including a curriculum in this dissertation, he expressed appreciation for the reason for this decision (personal communication, 15 July 2009). However, Rev. Johnson said that identifying some of the main components of curricula that might be appropriate for a variety of church groups would be helpful to an education working group. So, I offer some topics that might be included in some curricula, with the idea that the present study would provide one part of the set of resources used for curricula development.

1. Include some studies from the literature that reveal common misconceptions about pain. For example, RE told a story about his daughter, where he assumed that she had become used to her pain. However, according to Woolf (2007), “we do not habituate to pain; if anything, we increase our sensitivity to it” (30). In another example, although some ministers in the study expressed uncertainty about whether it is possible to determine if persons with dementia are in pain, a wide variety of pain assessment tools do exist, and professionals can be taught how to use them (Herr, Bjoro and Decker 2006).
2. Introduce some healthy skepticism about the idea that pain is inevitable because all is being done that can be done. Include studies that show how pain is underassessed and undertreated (Byrne, Morton and Salmon 2001; Won et al. 2004). Include also descriptions of ways that complicated pain can be treated with complicated methods—success stories in treating pain. In “Procedural Pain,” the patient’s pain was not inevitable; it could have been prevented or made less by providing pain control before the procedure started.
3. Include a section on the UCC’s understanding of the relational nature of health care, along with a companion section of the relational nature of pain, as described in the theory in this dissertation, and applied in the discussion of the interviews of the ministers. For example, church members may not voice their pain accurately if they believe that the only appropriate attitude during a minister’s visit is an attitude of cheerfulness or hopefulness.
4. Include examples of hidden curriculum within institutions. For example, if an informed consent form for colonoscopy downplays the pain that a patient will feel in

the recovery period, is this a normalizing effort so that patients will be self-surveillant and decline to advocate for themselves even if they are experiencing pain in the recovery period?

5. Offer some practical steps toward advocacy. For example, during a number of the interviews with ministers, I asked if they had heard of the Pain Patient's Bill of Rights and Responsibilities, and if they knew that many hospitals put these in the admissions packet. While one had heard about the Pain Care Bill of Rights, none knew that it might be in the patient's drawer. It is here in the Pain Care Bill of Rights that timeliness is promised. "You have a right to have your pain thoroughly assessed and promptly treated." (See Appendix 2.) If a patient is holding this document in his or her hand while discussing pain treatment, it can help. Rev. McCurdy had developed a list of questions that clergy might use to help "stimulate reflection and promote clarity" when patients and their families are thinking about making end of life decisions (McCurdy 2008, 7). Perhaps, a similar list could be developed for patients and families dealing with pain, except that it would be more assertive in questioning the necessity of painful part of some procedures, for example.

6. Include something about the history and politics of pain care in the United States. For example, a number of ministers in this study described their church members' fear of addiction to opioids. Many organizations agreed, as early as 2001, that, although use of opioids is complicated, it is nevertheless possible and necessary to provide good pain relief for many patients (*Promoting Pain Relief* 2001). While the members of the Pain Movement have struggled with the Drug Enforcement Agency over the years about this issue (Cunningham (in press a.)), new efforts have been established to get

the various groups to work together so that more people can get the relief that they need (Fishman 2007; American Pain Foundation 2008), since these drugs can be given safely.

7. Include some activities about advocacy at the national and international level. For example, all church members can go to the Pain and Policy studies Group webpage <http://www.painpolicy.wisc.edu/> to check with *Achieving balance in federal and state pain policy: A guide to evaluation*. 5th ed. (Pain and Policy Studies Group 2008) to see how their states' laws either do or do not support good pain management. Or, they may look at efforts at the international level to bring about pain care justice (Joranson and Ryan 2007; Human Rights Watch 2009).

### **Potential Involvement of Ministers through Sermons**

When I asked the clergy about whether they ever did sermons on pain, some said that they did. But these sermons were about the inevitability of psychological pain from difficult situations and how this kind of pain must be endured with the help of God. They would not be surprised by a nursing qualitative research study done by Wendy Duggleby (2000), which concluded that nurses should help elderly hospice patients to “adjust” to their pain by supporting the patients’ use of faith (825).

Although she also said that “pharmacologic and non-pharmacologic strategies for decreasing pain” (830) should be used, Duggleby did *not* discuss how support of adjustment to pain might prevent communication of pain, making it less likely that other strategies would be used to reduce or prevent pain. None of the ministers I interviewed had ever done a sermon about when physical pain should *not* be accepted

and why it might be a matter of justice to protect the vulnerable group consisting of those in severe pain. Particular stories taken from the UCC minister study might be useful in developing sermons. At General Synod XXI, the UCC adopted a resolution entitled “Reclaiming the Role of Pastor as Teacher” (Bogart 1998), which includes the idea that ministers should teach about current social issues. The list of teachable moments does not include the sick call, but sermons about the social issue of pain would appear to be compatible with this document.

### **Potential Use of the UCC Policy Development and Implementation Apparatus to Get Involved in Pain Policy**

Efforts in this area might include support through the Take Action! part of its website to support the National Pain Care Policy Act 2009, encouraging UCC members to contact their legislators. The UCC could add its name to organizations supporting this act, which has passed in the House, but not in the Senate. The UCC could develop a relationship with the American Pain Foundation to connect with its Diversity Project, for example, or the Alliance of State Pain Initiatives so that UCC members might take advantage of educational efforts in their own states. Actions like these, in themselves, help to educate both clergy and laity. The UCC might also consider passing a resolution at the 2011 General Synod regarding the special vulnerability of persons in pain and the responsibility to care for these patients. Even if UCC resolutions about health care would be compatible with a pain policy effort, according to Rev. Johnson, “A new resolution would be appropriate because it would represent a broadening of the conversation about pain” (personal communication, 9 July 2009).

In summary, there are many ways in which the UCC might use the concepts in this study, the data from the ministers in this study, and data from other studies to further its efforts toward social justice through pain education and action. In fact, other religious institutions might benefit from this analysis or a study of their own clergypersons' attitudes, beliefs, and practices to see how they are furthering or impeding improvements in pain care for all patients, especially the most vulnerable.

## Epilogue

At the beginning of this dissertation, in the Preface, I included a poem entitled, “ ‘Methodology,’ or Hurting a Ten or a Zillion” This poem is included in an article I published recently entitled “Taking care of grieving through poetry: Memories of palliative care's presence or absence” (Cunningham 2009). In this article, I was processing the grief I have experienced from a number of deaths in my family by writing a letter to those whose illnesses and death my husband had captured in a poem. In the last set, I included “ ‘Methodology...’ ” and the following letter. It seems to me to be a fitting end to this dissertation of narrative inquiry and philosophical reflection.

*Dear Little Nance,*

*You were just eleven or twelve years old then, weren't you? The dermatologist's knife just scraped and cut and peeled. He said to let him know if you needed the pain shot, but then he named your screams somewhere down about a five, I guess—not enough to stop his expert process to give you the shots. When I bumped into a research article about burn pain and scraping skin off and saw that “zillion” counted as a “ten,” I knew that article was about you, about me, about us. It was about the loss of innocence, about the death of dignity, not only of us, but of my mama, who sat dutifully by. She was as tied down as I was by the doctor's authority. He grasped my chemically burned up hand hard, while Mama white-knuckled her purse. So, then, of course, when I showed the article to Howard, he knew just what to do, just how to shine a bright light on that business of fraudulent naming—the naming of his grandfather and the naming of my screams.*

*Love,*

*Big Nance*



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## **Appendices**

### **Appendix 1 – History of the Pain Movement Timeline\***

#### **1973**

The International Association for the Study of Pain (IASP) was founded under John Bonica's leadership at an interdisciplinary meeting of 300 pain researchers in Issaquah, Washington. [www.iasp-pain.org](http://www.iasp-pain.org)

#### **1977**

The American Pain Society was founded as a chapter of the International Association for the Study of Pain (IASP). [www.ampainsoc.org](http://www.ampainsoc.org)

#### **1985**

The pain movement began when a secretary in Maryland discovered after the death of her premature son Jeffrey that he had undergone major surgery without anesthesia. After months of resistance by the medical establishment, Jill Lawson "went public."

Pernick MS: A calculus of suffering: pain, professionalism and anesthesia in nineteenth-century America. Columbia University Press, New York

Scarry E: The body in pain: the making and unmaking of the world. Oxford University Press, New York.

#### **1987**

Anand KJS: Hickey PR: Pain and its effects in the human neonate and fetus. New Engl J Med 317:1321-1347

Butler NC: The ethical issues involved in the practice of surgery on unanesthetized infants. AORN J 46:1136-1144

#### **1989**

Weissman DE, Haddox JD: Opioid pseudoaddiction--an iatrogenic syndrome. Pain. 1989 ;36(3):363-6.

Butler, NC: Infants, pain and what health care professionals should want to know now: an issue of epistemology and ethics. Bioethics 3:181-199

The American Alliance of Cancer Pain Initiatives (AACPI) is formed to support the State Cancer Pain movement, a grassroots effort to bring about nationwide change in the healthcare system, regulatory arena, and societal expectations through education, advocacy and collaboration. As it later broadened its scope to include non-cancer pain, it became the Alliance of State Pain Initiatives. [www.aspi.wisc.edu](http://www.aspi.wisc.edu)

## **1990**

Lawson JR: The Politics of Newborn Pain. *Mothering* 57:41-47

American Society of Pain Management Nurses (ASPMN) was established. They agreed that the primary, immediate objective of the ASPMN would be to provide a network for nurses working in the new specialty of pain management.

## **1992**

The Agency for Health Care Policy and Research (AHCPR) publishes Clinical Practice Guidelines (long and short forms) for Management of Cancer Pain and Acute Pain Management and A Patient's Guide for Cancer Pain and Post-operative Pain.

The Mayday Fund was established in 1992 to further Shirley Steinman Katzenbach's commitment to social and medical causes. The name Mayday is the international word signaling a cry for help, taken from the French "m'aidez" or "help me." The Mayday Pain Project is an international educational resource providing easily accessible, user-friendly and professionally authoritative information about pain care issues in an environment free of advertising and outside influence. [www.painandhealth.org](http://www.painandhealth.org)

## **1993**

Anand KJS, McGrath PJ (eds): *Pain in neonates*, Elsevier, Amsterdam. This was the first book published about infant pain. At the time it was considered too controversial because it included chapters on politics and ethics, as well as scientific study.

## **1994**

The Oregon Death with Dignity Act, a citizens' initiative, was first passed by Oregon voters in November 1994. Immediate implementation of the Act was delayed by a legal injunction. The Ninth Circuit Court of Appeals lifted the injunction on October 27, 1997.

## **1995**

*Pain Forum*, the journal of the American Pain Society devoted pp. 163-199 to the issue of physician assisted suicide, beginning with an article by Kathleen Foley. In the same issue, Dax Cowart wrote a commentary, in which he reiterated his view that some pain is worse than death.

Fordyce WE (ed): Back pain in the workplace: management of disability in non-specific conditions. IASP Press, Seattle. He said that if the doctor can't see what's wrong, and the patient doesn't get better by him or herself, well then, it's a psychological problem.

Ferrell BR, Dean GE, Grant M, Coluzzi P: An institutional commitment to pain management. *J Clin Oncol* 13:2158-65.

The City of Hope Pain/Palliative Care Resource Center was established to serve as a clearinghouse of information about pain assessment and pain management.

## **1996**

The Pain and Policy Studies Group was formed (PPSG) at the University of Wisconsin to address both U.S. and international regulatory barriers to pain management through research and evaluation of public policy.  
[www.painpolicy.wisc.edu/](http://www.painpolicy.wisc.edu/)

Anand KJS, Craig KD: New perspectives on the definition of pain. *Pain* 67:3-6

## **1997**

**The** American Pain Foundation (APF) was founded to improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management. [www.painfoundation.org](http://www.painfoundation.org)

A website called [www.painandthelaw.org](http://www.painandthelaw.org) was developed in with funding from the Mayday Fund by American Society for Law, Medicine and Ethics and St. Louis University School of Law to help protect those most vulnerable in pain.

The National Fibromyalgia Association was founded by sufferers Lynne Matallana and Karen Lee Richards, with their first biking event designed to bring national and worldwide attention to the chronic illness called Fibromyalgia. [www.fmaware.org](http://www.fmaware.org)

## **1998**

The Federation of State Medical Boards published its first "Model Guidelines for the Use of Controlled Substances for the Treatment of Pain." [www.fsmb.org](http://www.fsmb.org)

## 1999

*Pain Forum* devoted almost the entire Summer issue to a discussion of the need for the International Association for the Study of Pain (IASP) to change the definition of pain to include those who cannot talk.

Katz M, Ferrell BR: Nursing texts fall short in teaching end-of-life care: even basics of pain control are poorly covered. *J Assoc Nurses AIDS Care* 10:102-3 This article describes efforts to get the textbook publishers, nursing licensing boards, and nursing schools to coordinate improvements in education about pain.

American Pain Society. 1999. *Guideline for the management of acute and chronic pain in sickle cell disease*. Glenview IL: American Pain Society. This guideline is the first comprehensive evidence-based guideline to address treatment of the pain of sickle-cell disease.

First edition of the EPEC Curriculum published in October. Six regional conferences present the Curriculum to a select group of 500 physician-educators for implementation and feedback. The purpose is to prepare physicians to provide palliative care.

McCaffery M, Pasero C: *Pain: Clinical Manual*, 2nd ed. Mosby, St. Louis. Every page is photocopy ready. As the most comprehensive, practical pain book published, by 2004, the most purchased book on pain from the amazon.com website.

## 2000

Congress passed and the president signed into law a provision declaring the decade beginning January 1, 2001, as the Decade of Pain Control and Research.  
[www.ampainsoc.org/decadeofpain](http://www.ampainsoc.org/decadeofpain)

The Pain & Policy Studies Group published the first of several analyses of state and federal laws and regulations in terms of whether they helped or hurt efforts to achieve good pain management.

City of Hope develops “**Cancer Pain Education for Patients and the Public**,” supported by a grant from the National Cancer Institute, NIH. Lay persons *can* understand this! <http://www.cityofhope.org/prc/>

## 2001

JCAHO developed pain management guidelines to mandate the regular assessment of pain, to establish policies and procedures to support the appropriate use of pain medications, and to require education of healthcare providers, patients and families.  
[http://www.jointcommission.org/AboutUs/joint\\_commission\\_history.htm](http://www.jointcommission.org/AboutUs/joint_commission_history.htm)

ELNEC Curriculum and course development occurred during the period February 2000 - January 2001 under the guidance of City of Hope National Medical Center investigators Betty Ferrell, PhD, RN, FAAN and Marcia Grant, DNSc, RN, FAAN. The purpose was to prepare qualified nurse educators to provide end-of-life education for nursing students and practicing nurses.

The American Cancer Society published its first book on pain control for cancer pain patients, *A Guide to Pain Control: Powerful Methods to Overcome Cancer Pain*. (2nd Ed. in 2004)

## 2002

The American Chronic Pain Association and the Partners for Understanding Pain provide materials for the first Pain Awareness Month. [www.theacpa.org](http://www.theacpa.org)

## 2003

In 2003 the American Pain Foundation helped over 1 million people with pain, their families, and caregivers through a variety of free service, including “The Pain Care Bill of Rights.” [www.painfoundation.org](http://www.painfoundation.org)

The National Pain Care Policy Act was first introduced in the House of Representatives as H.R. 1863.

## 2004

Global Day Against Pain  
"THE RELIEF OF PAIN SHOULD BE A HUMAN RIGHT"  
Crowne Plaza, Geneva, Switzerland, October 11th, 2004  
[www.painreliefhumanright.com](http://www.painreliefhumanright.com)

In August to much fanfare the DEA and a consortium of pain groups present:  
*Prescription Pain Medications: Frequently Asked Questions and Answers for Health Care Professionals, and Law Enforcement Personnel*

In October, the DEA withdraws its support, saying that it was not involved in the original writing. Go to this site for the whole story:  
<http://www.medsch.wisc.edu/painpolicy/DEA/index.htm>

Partners Against Pain is one of the many groups continuing to provide updated information for laypersons and professionals.  
[www.partnersagainstpain.com/painadvocacycommunity](http://www.partnersagainstpain.com/painadvocacycommunity)

## 2006

National Center for Health Statistics. 2006. *Health, United States, 2006: With Chartbook on Trends in the Health of Americans*. Hyattsville MD: U.S. Government Printing Office. Included special 20-page feature on pain.

## **2007**

The Federation of State Medical Boards publishes a book for physicians that will make up for the *Frequently Asked Questions*. Fishman, Scott M. 2007. *Responsible opioid prescribing: a physician's guide*. Washington, DC: Waterford Life Sciences.

The Pain Care Policy Act was reintroduced in the House of Representatives.

The International Association for the Study of Pain designates 2008 as the Global Year Against Pain in Women.

## **2008**

The International Association for the Study of Pain designates 2009 as the Global Year Cancer Pain.

## **2009**

The House Passed the National Pain Care Policy Act of 2009, H.R. 756. The senate version, S. 660 is still under consideration.

\*This timeline is adapted from the following presentation: Cunningham, Nance. "The Status of Compassion: A History of the Pain Movement Part II," Palliative Care: Merging Compassion and Technology, Oklahoma City OK, 11/04.

## Appendix 2 – Pain Care Bill of Rights



201 N. Charles Street, Suite 710  
Baltimore, MD 21201  
Phone (888) 615-7246  
Fax (410) 385-1832  
[www.painfoundation.org](http://www.painfoundation.org)

### Pain Care Bill of Rights

As a person with pain, you have the right to:

- Have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, social workers and other healthcare professionals.
- Have your pain thoroughly assessed and promptly treated.
- Participate actively in decisions about how to manage your pain.
- Be informed and know your options: talk with your healthcare provider about your pain - possible cause(s), treatment options, and the benefits, risks and costs of each choice.
- Have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- Be referred to a pain specialist if your pain persists.
- Get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

*Although not always required by law, these are the rights  
you should expect for your pain care.*



## **Helpful Hints on Your Road to Pain Relief**

Managing your pain is an important step to reclaim your life. The earlier you seek treatment, the better.

Here are some other helpful tips:

- Only you know the extent of your pain and how it affects your quality of life. Don't be afraid to speak up!
- Remember, there are a variety of drug and non-drug therapies (e.g., physical therapy, yoga, meditation) available to effectively control pain; these are typically used in combination.
- Knowledge is power. Many people living with pain and even some healthcare providers believe that opioid medications are addictive. The truth is that when properly prescribed by a healthcare professional and taken as directed, these medications give relief - not a "high."
- Tell your provider what over-the-counter medications, vitamins and supplements you take, at what dose and how often. Also let him or her know about other personal health habits (e.g., smoking tobacco, alcohol use), which can interfere with some pain treatments and increase pain levels.
- Keep a pain journal to record the frequency and intensity of your pain. Use descriptive words, such as sharp, crushing, throbbing, shooting or tender. Also, take note of how well your treatment plan is working and what makes your pain worse or better.
- Write down questions you have before each appointment. Bring a relative or friend with you for support and to help take notes and remember what was said.
- Research available support groups and educational programs.

American Pain Foundation  
201 N. Charles Street, Suite 710  
Baltimore, MD 21201-4111

Toll-free information line: 888-615-7246  
[www.painfoundation.org](http://www.painfoundation.org)

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### **Appendix 3 – Background and Biases of the Researcher**

#### Researcher's personal pain history

*Vulnerability education* would be the best name for it. I was raised in a family where accepting, taking care of, and befriending babies, old people, the strange, and the outcast were the rule. One of the powerful memories that came up during my first unit of chaplaincy training was of my mother when she was a kindergarten teacher. She told about hearing a child screaming in the bathroom of her classroom. When she entered, the child, stool, and floor were covered with diarrhea, and the child was afraid of what would happen next. So, my mother knelt down and held this little one and spoke softly to him until he stopped crying. Then she chattered cheerfully while she cleaned up the kindergartner, herself and the room. Other memories include the times my mother encouraged her five children to take turns buying groceries for the elderly lady next door, even though it was scary to go into that woman's house to get the list. When my great uncle was very sick with lung cancer, we went to see him anyway and stood by his bed while he coughed and coughed. For years, my father would pick up a fellow Elk at the nursing home and take him out to dinner on Friday nights. In his retirement, my dad delivered meals-on-wheels and took on the role of pen-pal to many men in prison. This family background and continuing context helped me to visit NICU's for my professional work on pain and to volunteer in a children's hospital without fear or revulsion. It helped me to remain near during chaplaincy training whether a patient was spitting, cursing, or whatever.

*Power education* would be the best name for the second part of my early training from my parents and church. One of my grandmothers obtained her B.A. in 1922; as a result, my own mother learned out to act outside the box. So did my dad. Some of my earliest memories involve listening to my father insist that the principal or school superintendent where he taught elementary math might have power over some of his actions, but not his ideas about how to teach. Although bigotry about what people in our town called “Mexicans” and “Japs” was officially accepted, my dad refused to allow it to happen in his classroom. Since “Mexicans” and lower-class whites were not allowed to be in the regular Camp Fire Girls groups, my mother started her own group of just these folks. My mother was on the board of the House of Neighborly Service, a Spanish-speaking social service agency and Presbyterian church for those not served by the big, all-white Presbyterian church in town. Though there were no African American families in the town where I grew up, my parents invited a man of African descent from Haiti to live with them while he worked and went to college.

As a student, I spent a lot of time watching what I considered power plays by teachers. I was willing to work with them only enough to get A’s, no more. Because of my background, I was comfortable becoming a philosophy minor in undergraduate school and major in graduate school—the more we questioned the teachers, famous philosophers, other experts, and the government, the better! Of course, as a college student between 1967 and 1974 for my first two degrees, I experienced the extreme of vulnerability and power education. For so long, we felt powerless to stop the ripping of men away from college, to stop the draft, to stop the killing in Vietnam, to stop the

lies by the government and military, who seemed to give so little ground. It was clear in this situation that less powerful persons could be held down by more powerful persons or by powerful structures.

When I completed a two-month internship for my applied philosophy master's degree in a Catholic hospital, I experienced my first contrast of powerful institutional healthcare structure and vulnerable patients, families, and sometimes employees. I didn't know the half of it until I first talked on the phone some years later with Jill Lawson, the mother from Washington DC, who found out that her premature infant son underwent heart surgery with paralyzing drugs, but no anesthesia before his death. Another mother with whom I collaborated, whose child survived the many painful surgeries in the neonatal intensive care unit, was Helen Harrison (1986). Both served as models to me of lay persons who could learn to read the medical literature and take on the medical establishment. They studied and wrote and gave speeches; and they invited me to use my philosophical skills to join them on behalf all infants who suffered unnecessary pain.

Over the last 20 years, I have written, spoken, and taught extensively on the issues of palliative care and healthcare ethics. My earliest publication was called "The NICU culture versus the hospice culture: Can they mix?" published in *Neonatal Network* in 1986. That article in its original form was my project for hospice training in Jacksonville, Florida in 1982. The hospice movement, itself, was a project to protect dying persons; but early on, most physicians and nurses viewed the service with disdain or alarm because it seemed to them to represent a loss of professional control. In 1987, I published in *AORN Journal* "The ethical issues involved in the practice of

surgery on unanesthetized infants,” one of the first articles published nationally on the issue of ethics and pain. What I learned in that circumstance was that, for many operating room nurses, their solidarity with the surgeons they worked for was stronger than their fidelity to the American Nurses Association Code of Ethics. Or, rather, their insistence that the doctors they worked for would never hurt an infant patient unnecessarily affected their interpretation of both medical research and the ANA Code. As I attended more and more conferences on pain, I began to see that the interpretation of research on infant physiology and behavior was affected by who had the most power. Although I was forced out of a job in 1988 because I refused to stop writing about the “controversial issue” of infant pain, and although I was escorted out of a medical meeting on pain by the police later that year because of what I had written, I was able to make some contributions because of my alliances the small number of powerful people (at that time) wanting to make change. For example, I wrote with Costantino Benedetti the chapter “Ethical standards in pain management and research” for the International Association for the Study of Pain *Core Curriculum for Professional Education in Pain, 2<sup>nd</sup> ed.* , published in 1995. At that time, the three subsections under the section “Clinical Care” I created were “Professional power and responsibility,” “Vulnerable groups,” and “Quality assurance.” The most recent version of that document (2005) still includes that structure and most of the same references. I published in 1999 for the American Pain Society’s *Pain Forum* “Primary requirements for an ethical definition of pain,” as a part of almost an entire issue focusing on the need for the International Association for the Study of Pain (IASP) to change its definition of pain to include those patients who cannot talk. This was the

culmination of discussions two pediatric intensivists invited me to have with them in 1994. In 1998, I read a version of the 1999 publication at an international pain meeting, with the result that the physician who wrote the definition and his colleague stood up and screamed at me. I was part of what had become an internal conflict within the society, but I was the one who was low enough on the totem pole to be shouted at. What made them the most furious was that I had described pain as a social problem, comparing it to the problems of race and poverty; all three are social constructions in that the problems are treated as if they reside within the most vulnerable, when they should be treated as relations among groups holding different amounts of power.

Through the years, I have been an enthusiastic participant in this public education effort. For example, in 2003, I organized and moderated a panel on disparities in pain care due to race or ethnicity for an audience that was primarily social workers. In another example, when the American Cancer Society (2004) published a book on pain for cancer patients and their families, I worked with Oklahoma state pain initiative, Pain Relief Oklahoma, to help distribute copies of the book donated by ACS to every public library in the state. When I was a hospice chaplain, I spoke to groups such as nursing home employees and church Sunday school class members about pain management issues. I specifically taught my sister what to say to hospital nurses in order to help procure faster, better pain management for my mother.

Through both refereed and invited presentations, I have spoken to nearly 60 education, medical, nursing, philosophy, and religious groups. Examples include:

“Infant Pain Control Practices: What Has Gone Wrong?” Department of Neonatology, Columbia Hospital for Women Medical Center, Washington D.C. (1987); “The Neonatal Researcher’s Primary Ethical Challenge” National Institute of Health planning workshop, Detroit MI (1994); “Can Medical Answers Rescue Us from Ethical Questions?” Oklahoma Hospice Association Post-Conference on Pain, Enid OK, (1995); “Job, Job’s Friends, and Guided Imagery: Whose Comfort, Whose Abandonment?” Society for Health and Human Values, Baltimore MD (1997); “Why Pastoral Counselors Should Advocate for Patients in Pain” Pastoral Services CPE Program, Emory Hospitals, Atlanta GA (2000); “What We Owe to Those Who Won’t Remember: Pain Treatment Practices on Patients Under Conscious Sedation,” for the Society for Philosophy in the Contemporary World in Chicago (2002); and “Explanatory Power of Embodiment and the Fear of Degeneration” at the American Educational Studies Association (2006). Most recently, I presented “The FAQ Pain Education Document, Pain Activist Counterpublics, and the Drug Enforcement Agency: A Story of Conflict over Educational Authority about Pain and Pain Control,” for the Rocky Mountain Educational Research Association (2008) and “Power, the Meaning of Subjectivity, and Public Education about Fibromyalgia,” at the Society of Philosophy and History of Education (2008). In each of these, I tried to push the envelope with regard to the issue of pain as a relational event. As I attended each educational event, I was a learner, too. For example, it was at one of the pain conferences that I first learned about a researcher who determined that the nursing textbook publishers, the nursing licensing boards, and the nursing university professors all knew that pain education needed to be changed, but each felt stymied

because no one entity could change unless the others did. So, she created a process so that they could all work together for change.

For these talks I have given, as well as the papers I have published, my research has included the philosophy of education literature, medical and nursing literature, pain listserves, conferences, interviews, and watching interactions between staff and patients in hospitals, as well as interactions between different parts of the staff. It was only after I had been in the field for twelve or fifteen years that I realized that my education had begun much earlier in my personal life. This education included events like the following: During the summer between my first and second grade years, the whole family moved from our little town where there was not hospital to Denver for the summer just so that my mother could get bladder surgery. I remember that she almost didn't come out of her dark bedroom for weeks. Later I learned that the neither the pain control nor the amnesia drugs the doctors used during the surgery worked; she remembered every excruciating part of the surgery. I felt helpless when I found this out. When I was about twelve, my hand was debrided with a scalpel with no pain control, in spite of my obvious need for it. When I was about fourteen, I had to sit in the waiting room of our general doctor while he tried to straighten out a young relative's arm that had stiffened into an L after six weeks in a cast. I could do nothing about this child's crying out. When I visited my mother in the hospital just after her hysterectomy surgery, I cringed and felt helpless as the nurse insisted that my mother cough. I will never forget her lips, white and trembling in agony, yet determination to comply. No doubt, all of these were educational events that I had successfully blocked out for many years. They were consequences of professional, institutional and societal



beliefs and demonstrations of authority and power. So, it probably wasn't that I got into the field of ethical issues of pain control just because it was interesting. One part of me, at least, understood the vulnerability and power issues involved from a very personal perspective. Consequently, I spent a lot of time and effort learning more about the clinical possibilities for assessing and treating pain; about the actual professional practices, attitudes and reasoning processes; about the beliefs and behaviors of patients and family members; and about the historical and cultural events, and world views that have influenced all these things. This learning was especially concrete during the weekly staff meetings at the hospice where I worked because the nurses discussed specific pain issues related to patients, family members, physicians and pharmacies.

#### Researcher's core values, as described in the pilot study

In the fall semester of 2007, I completed the pilot project for the current study, to determine how particular ministers experience visiting their church members in the hospital when these members are in moderate to acute pain. Although I was attending to my memories as a *researcher* and *chaplain* during these interviews and the analysis, I was *not* attending to my memories of being a *patient* or *witness of family members*. However, during the current study, I have been more aware of the latter memories. Below are the core values I recognized during the first round of study.

1. I believe in the usefulness of both quantitative and qualitative data, though I may have initial skepticism about most studies, and initial acceptance of data

in the form of autobiographies or short stories. For example, I am likely to look closely at the assumptions guiding the choice of variables and definitions in scientific studies about pain. However, I did not question that there might be much truth in May Sarton's *As We are Now: A Novel*. This core values means that I am willing to look at lots of data as part of my literature search.

However, I may give more credence to narratives than is appropriate. A corollary of this value is that lay persons can and have a right to read the medical literature.

2. Although I am aware of the complexities of healthcare, academic, and governmental organizations, I believe that positive changes can be made. The Pain and Policy Studies Group out of the University of Wisconsin is just one example of a groups I have watched over the years make a significant difference in state laws impacting the quality of pain care in each state. This is helpful in that I feel research can be valuable. However, it may be difficult for me to accept others' acceptance of the status quo.
3. The most helpful ethical theory is "difference ethics," as exemplified in *The Social Medicine Reader*, edited by Gail E. Henderson, Nancy M. P. King, Ronald P. Strauss, and Sue E. Estroff (1997). No analysis of a healthcare situation is complete until the power and political relationships have been made clear. This perspective can be helpful in that I can listen carefully for reflections of fear, vulnerability, authority, flexibility, etc. This view can prevent me from hearing the perspective of some players, especially the extent to which the most powerful may also feel trapped.

4. I am suspicious of the easy use of models. Sometimes researchers use models just because they are handy, because the model is much used, or because its categories are clear. I believe this is lazy. This perspective is helpful when it comes to my consideration of new theories, or when I am trying to develop one of my own. However, this perspective prevents me from hearing nuggets that persons using the theory may discover.

## **Appendix 4 – IRB Documents**

Description of Study Protocol

Informed Consent Form

Data Collection Instrument

Amendment Approval Letters

## University of Oklahoma – Norman Campus Institutional Review Board Description of Study Protocol

Submission of a copy of a grant application does not replace completion of this form. Please respond to each item. Incomplete submission forms will be returned to you.

- 1) Click below to describe the research design of the study.

The design will be a qualitative narrative analysis in which the PI will conduct open-ended interviews. Transcripts of the interviews will be analyzed. If subjects offer copies of the resource materials they use, the PI will include these in the analysis.

- 2) In the input area below, describe the recruitment procedures. Attach a copy of any material used to recruit subjects (e.g., informed consent forms, advertisement, flyers, telephone scripts, verbal recruitment scripts, cover letters, etc.) Explain who will approach potential participants to request participation in the research study and what will be done to protect the individual's privacy in this process.

The PI will approach potential subjects through her network of contacts. Once one or two interviews have been completed, the PI may also use the qualitative technique of snowball sampling (asking participants to suggest others who may agree to participate). See Ulin, PR, Robinson, E.T., Tolley. 2005. Qualitative Methods in Public Health. San Francisco CA: Jossey-Bass. This study is part of a larger narrative research project involving analysis of medical, nursing, pastoral care, educational, cultural, and philosophical published literature.

- 3) Below, list and describe the tasks that participants will be asked to perform, including a step-by-step description for each procedure you plan to use with your subjects. Provide the approximate duration of subject participation for each procedure. If data collection instruments will be used, indicate the time necessary to complete them, the frequency of administration, and the setting in which they will be administered, such as telephone, mail, or face-to-face interview. (You must submit a copy of each study instrument, including all questionnaires, surveys, protocols for interviews, etc.)

One tape-recorded face-to-face interview per subject will be completed; participant may request that the interview not be taped and that the PI only take notes. A data collection instrument will be used. The time expected per interview is 30-90 minutes. Subjects will be given the possibility of scheduling a second interview in person if they feel they would like to

add to their previous descriptions. At the end of the interview, subjects will be offered a form to fill out if they would like the PI to send a summary of the research results.

- 4) Describe your data collection procedures. If data collection instruments will be used, indicate the time necessary to complete them, the frequency of administration, and the setting in which they will be administered, such as telephone, mail, or face-to-face interview. (You must submit a copy of each study instrument, including all questionnaires, surveys, protocols for interviews, etc.)

This is a qualitative study using the technique of open-ended interview. The researcher allows the interviewee to lead the interview. The general question is: How do you experience visiting patients in pain? The researcher makes no assumptions about how the interviewee will answer this general inquiry. The researcher will not be trying to get all interviewees to answer the same questions or cover the same topics. However, if the interviewee needs encouragement or exhibits uncertainty about what topics might be covered next, the interviewer will have a list of questions to offer. See attachment.

- 5) Click below and provide background information for the study including the objective of the proposed research, purpose, research question, hypothesis and other information deemed relevant.

Studies have been conducted to describe the experiences of patients in pain, of their families, and of healthcare providers such as physicians, nurses, and home healthcare aids. However, little attention has been paid to the experiences of clergypersons. The purpose of this study is to explore and describe how clergypersons experience seeing, hearing, and providing pastoral care to patients in moderate to severe pain. As a qualitative study, the research does not begin with a hypothesis; but the researcher may develop one or more hypotheses as the data are collected. (See Cresswell, JW. 1998. Qualitative Inquiry and Research Design. Thousand Oaks CA: Sage Publications) My interpretation of the data will reflect relevant personal and professional life experiences, as these relate to the experiencing of others in pain. Qualitative researchers are professionally responsible for acknowledging professional and personal experiences which motivate a particular project and/or comprise some of the lenses through which they will interpret the data of the project. (See Munhall, PL. 2007. Nursing Research: A Qualitative Perspective. Boston: Jones and Bartlett Publishers; Denzin, NK and YS Lincoln, eds. The Sage Handbook of Qualitative Research, 3rd ed. Thousand Oaks CA: Sage Publications.) Life experiences of witnessing others in pain will not include any identification by name or inference, except the reference to my late mother. I will not name her, but someone

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IRB #:  
(For IRB Use Only)

could look up her name. Other relevant life experiences reflect my role as professional researcher, writer and teacher in the field of pain for over 20 years.

**University of Oklahoma  
Institutional Review Board  
Informed Consent to Participate in a Research Study**

**Project Title:** Clergypersons' Experiences in Visitation to Persons in Pain  
**Principal Investigator:** Nance Cunningham  
**Department:** Educational Leadership and Policy Studies

You are being asked to volunteer for this research study. This study is being conducted at the University of Oklahoma. You were selected as a possible participant because you are an ordained clergyperson whose assigned responsibilities include or have included calling on members of your parish, congregation, or community who are sick or injured and in pain.

Please read this form and ask any questions that you may have before agreeing to take part in this study.

**Purpose of the Research Study**

The purpose of this study is:

To explore and describe how clergypersons experience seeing, hearing, and providing pastoral care to patients in moderate to severe pain. Studies have been conducted to describe the experiences of patients in pain, of their families, and of healthcare providers; however, little attention has been paid to the experiences of clergypersons.

**Number of Participants**

About 20 people will take part in this study.

**Procedures**

If you agree to be in this study, you will be asked to do the following:

1) Sign the consent form. 2) Schedule an interview with Nance Cunningham in a location convenient to you. It may be in your office or church, in a room at the OU College of Education, or another quiet and private place agreed upon by you and Nance Cunningham. 3) Participate in the interview. 4) Request a second interview if you want to say more about your experiences. (This may be by phone.) At the end of the interview, you will be offered a form to fill out if you would like the interviewer to send a summary of the research results.

**Length of Participation**

One interview is expected to take 30-90 minutes. You may request a second interview if you want to say more about your experiences.

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**This study has the following risks:**

You may describe memories of events during which you were psychologically or spiritually uncomfortable. Although it is unlikely, such descriptions may create strong feelings during the interview.

**Benefits of being in the study are**

There may or may not be any benefits to you. However, you will have an attentive, non-critical listener of your stories; there may have been no other circumstances under which you have shared these experiences. You may learn more about yourself and your resources.

**Confidentiality**

In published reports, there will be no information included that will make it possible to identify you without your permission. Research records will be stored securely and only approved researchers will have access to the records.

There are organizations that may inspect and/or copy your research records for quality assurance and data analysis. These organizations include the researcher's dissertation committee and the OU Institutional Review Board.

**Compensation**

You will not be reimbursed for you time and participation in this study. However, at the end of the interview, you will be offered a form to fill out if you would like the interviewer to send a summary of the research results.

**Voluntary Nature of the Study**

Participation in this study is voluntary. If you withdraw or decline participation, you will not be penalized or lose benefits or services unrelated to the study. If you decide to participate, you may decline to answer any question and may choose to withdraw at any time.

**Audio Recording of Study Activities**

To assist with accurate recording of participant responses, interviews may be recorded on an audio recording device. You have the right to refuse to allow such recording without penalty. Please select one of the following options.

I consent to audio recording.  Yes  No.

**Contacts and Questions**

If you have concerns or complaints about the research, the researcher(s) conducting this study can be contacted at 405-590-8230 or [nance.cunningham@ou.edu](mailto:nance.cunningham@ou.edu). Susan Laird, PhD, Department of Educational Leadership and Policy Studies, College of Education, University of Oklahoma, may be reached at Collings Hall, Room #227, 820 Van Vleet Oval, Norman OK 73019-2041. Her phone number is 405-325-4202 and her

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email address is [laird@ou.edu](mailto:laird@ou.edu). Education Dean Joan Smith may be reached at 405-325-1081. Her email address is [jksmith@ou.edu](mailto:jksmith@ou.edu). You are encouraged to contact the researcher(s) if you have any questions.

Contact the researcher(s) if you have questions or if you have experienced a research-related injury.

If you have any questions about your rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than individuals on the research team or if you cannot reach the research team, you may contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or [irb@ou.edu](mailto:irb@ou.edu).

***You will be given a copy of this information to keep for your records. If you are not given a copy of this consent form, please request one.***

### Statement of Consent

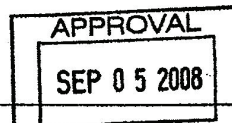
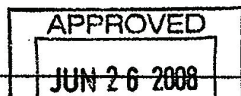
I have read the above information. I have asked questions and have received satisfactory answers. I consent to participate in the study.

---

Signature

Date

Revised 07/23/2007



Page 3 of 3

**Project Title: Clergypersons' Experiences of Visitation to Persons in Pain**

**Principal Investigator: Nance Cunningham, M.A.**

**Data Collection Instrument:**

This is a qualitative study using the technique of open-ended interview. The researcher allows the interviewee to lead the interview. The general question is: How do you experience visiting patients in pain? The researcher makes no assumptions about how the interviewee will answer this general inquiry. The researcher will not be trying to get all interviewees to answer the same questions or cover the same topics. However, if the interviewee needs encouragement or exhibits uncertainty about what topics might be covered next, the following are a list of questions that the researcher may offer.

How do you find out about the need to visit your church members?  
How do you feel about visiting patients in hospitals or nursing homes?  
What happens inside you when you see that a patient is in great pain?  
What kinds of things does the patient say or do? What about the family?  
What do you say or do?  
What resources are most valuable to you?  
When you are in this situation, what kind of inner conversation are you having?  
How do you feel and what do you say if a nurse or doctor arrives when you are there?  
What personal memories are evoked in this kind of situation?  
How would you respond if the person in the bed were related to you?  
Is there an experience like this that you will never forget? What happened?  
During your training as a minister, what best prepared you for moments like this?  
What you have learned from the media or continuing education that has helped you or influenced you in some way?  
How might good pain management fit into the social justice issue of access to health care?



The University of Oklahoma  
OFFICE FOR HUMAN RESEARCH PARTICIPANT PROTECTION

IRB Number: 11459  
Amendment Approval Date: June 26, 2008

June 26, 2008

Nance Cunningham  
Dept. Educational Leadership & Policy Studies  
820 Van Fleet Oval, ECH 227  
Norman, OK 73019

RE: IRB No. 11459: Clergypersons' Experiences of Visitation to Persons in Pain

Dear Ms. Cunningham:

On behalf of the Institutional Review Board (IRB), I have reviewed your protocol modification form. It is my judgement that this modification allows for the rights and welfare of the research subjects to be respected. Further, it has been determined that the study will continue to be conducted in a manner consistent with the requirements of 45 CFR 46 as amended; and that the potential benefits to subjects and others warrant the risks subjects may choose to incur.

This letter documents approval to conduct the research as described in:

- Amend Form Dated: June 08, 2008
- Protocol Dated: June 08, 2008 Revised
- Other Dated: June 08, 2008 Recruitment Script - Revised
- Survey Instrument Dated: June 08, 2008 Interview Questions - Revised
- Consent form - Subject Dated: June 08, 2008 Revised

**Amendment Summary:**

- 1) The research is no longer a class project. It is now a dissertation project.
- 2) Change in Study Personnel - Delete Dr. Janet Wilson as Faculty Sponsor. Add Dr. Susan Laird as Faculty Sponsor & Dr. Joan Smith as Co-Investigator.
- 3) Addition of Research Sites - PI may interview subjects in Kansas, Texas and Colorado.
- 4) Increase in Subject Enrollment - From a previously approved maximum of 10 participants to a new maximum of 20 participants.
- 5) Revised Recruitment Script - To reflect the change in Study Personnel and the change from a class project to a dissertation project.
- 6) Revised Informed Consent Form - To reflect changes in Study Personnel, number of participants and the change from a class project to a dissertation project.
- 7) Revised Interview Questions - Addition of two questions.
- 5) Revised Protocol - To reflect changes in procedure.

This letter covers only the approval of the above referenced modification. All other conditions, including the original expiration date, from the approval granted September 06, 2007 are still effective.

If consent form revisions are a part of this modification, you will be provided with a new stamped copy of your consent form. Please use this stamped copy for all future consent documentation. Please discontinue use of all outdated versions of this consent form.

If you have any questions about these procedures or need additional assistance, please do not hesitate to call the IRB office at (405) 325-8110 or send an email to irb@ou.edu.

Cordially,

Donald Baker, Ph.D.  
Vice Chair, Institutional Review Board





The University of Oklahoma  
OFFICE FOR HUMAN RESEARCH PARTICIPANT PROTECTION

IRB Number: 11459  
Amendment Approval Date: April 23, 2009

April 24, 2009

Nance Cunningham  
Dept. Educational Leadership & Policy Studies  
820 Van Fleet Oval, ECH 227  
Norman, OK 73019

RE: IRB No. 11459: Clergypersons' Experiences of Visitation to Persons in Pain

Dear Ms. Cunningham:

On behalf of the Institutional Review Board (IRB), I have reviewed your protocol modification form. It is my judgement that this modification allows for the rights and welfare of the research subjects to be respected. Further, it has been determined that the study will continue to be conducted in a manner consistent with the requirements of 45 CFR 46 as amended; and that the potential benefits to subjects and others warrant the risks subjects may choose to incur.

This letter documents approval to conduct the research as described in:

Amend Form Dated: April 23, 2009 Revised

Protocol Dated: April 23, 2009 Revised

**Amendment Summary:**


- 1) Addition of an interpretation of the data to reflect relevant personal and professional life experiences of the Principal Investigator as related to the experiencing of others in pain. Identifiers will not be presented except for the Principal Investigator's late mother who will be referenced but whose name will not be included in any report.
- 2) Revised protocol to reflect the changes noted above.

This letter covers only the approval of the above referenced modification. All other conditions, including the original expiration date, from the approval granted August 22, 2008 are still effective.

If consent form revisions are a part of this modification, you will be provided with a new stamped copy of your consent form. Please use this stamped copy for all future consent documentation. Please discontinue use of all outdated versions of this consent form.

If you have any questions about these procedures or need additional assistance, please do not hesitate to call the IRB office at (405) 325-8110 or send an email to [irb@ou.edu](mailto:irb@ou.edu).

Cordially,

  
Lynn Devenport, Ph.D.  
Chair, Institutional Review Board

Ltr\_Amend\_Final\_Appv\_Exp

660 Parrington Oval, Suite 316, Norman, Oklahoma 73019-3085 PHONE: (405) 325-8110 FAX:(405) 325-2373

