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# Worlds of Connection: A Hermeneutic Formulation of the Interdisciplinary Relational Model of Care

Susana Lauraine McCune  
*Antioch University - Seattle*

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Worlds of Connection: A Hermeneutic Formulation of the  
Interdisciplinary Relational Model of Care

A Dissertation

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Antioch University Seattle  
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of the Requirements of the Degree  
Doctor of Psychology

By  
Susana Lauraine McCune

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Worlds of Connection: A Hermeneutic Formulation of the  
Interdisciplinary Relational Model of Care

This dissertation, by Susana Lauraine McCune,  
has been approved by the committee members signed below  
who recommend that it be accepted by the faculty of the  
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of requirements for the degree of

DOCTOR OF PSYCHOLOGY

Dissertation Committee:

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Philip Cushman, Ph.D.  
Chairperson

---

Mary Wieneke, Ph.D.

---

Judith Gordon, Ph.D.

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Date

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## Abstract

### Worlds of Connection: A Hermeneutic Formulation of the Interdisciplinary Relational Model of Care

Susana Lauraine McCune

Antioch University Seattle

Seattle, WA

Despite a general agreement across health care disciplines that Advanced Care Planning (ACP) and Advanced Directives (ADs) add important elements to a patient's end-of-life care desires, and can inform their loved ones and advocates, help create ease of mind, and enhance quality of care, they continue to remain significantly underused. More than half of Americans transition to chronic and terminal illness without having completed them. The aim of this study was to increase the frequency and enhance the quality of communication about Advance Directives and Advance Care Planning within the clinical relationship. The resulting Interdisciplinary Relational Model of Care (IRMOC) can help clinicians engage in more frequent and effective communication about ADs and ACP. This ontological hermeneutic study considered scholarly and professional, practice-based health services literature, along with juridical, legislative, policy, and philosophical texts that have informed previous models of care. Tacit and explicit phenomena, conditions, and practices of communication about ADs and ACP in the patient-clinician relationship were identified. In response to the phenomena, conditions, and practices identified in this study the IRMOC was formulated and applied to communication about Advance Directives and Advance Care Planning in the patient-clinician relationship. The IRMOC was then expanded, made more nuanced,

and contextualized within the overall philosophical, theoretical, and practical frameworks that informed the model. The electronic version of this dissertation is at OhioLink ETD Center, [www.ohiolink.edu/etd](http://www.ohiolink.edu/etd)

*Keywords:* Advance care planning, advance directives, end-of-life care, relational psychoanalysis, compassion, communication, hermeneutics, Interdisciplinary Relational Model of Care.

## Dedication

To those who have gone before and for those who will follow.

## Acknowledgment

“Those who learned to know death, rather than to fear and fight it, become our teachers about life” (Kübler-Ross, 1983, p. xvii).

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## **Problem Formulation**

Issues surrounding death are as old as life itself. In contrast to historical experiences of mortality, a modern-day death presents an evolving array of emotion-laden ethical concerns and dilemmas. Never before in human history has humanity been comprised of so many older people (e.g., Bloom, Canning, & Fink, 2010). The aging of large populations, in combination with rapidly advancing medical technologies has forced, and will continue to force, an unparalleled number of people to make unprecedented decisions about life and death in an age of simultaneously abundant technology, economic disparity, and strained resources (McCune, 2011).

Although death is as old as life itself, dying is different today. Technological developments in medicine that began to be developed during the 1960s and 1970s in industrially advanced societies, as Sabatino (2010) has noted, “thrust medicine into a new world where for the first time, it often became difficult to distinguish saving life from prolonging suffering and death” (p. 213). During the past 50 years, in the U.S. progress in medical care and use of life-sustaining treatment facilitated by technology has blurred the lines between medical care that extends quality of life and causes long-term suffering before death (e.g., Chapple, 2010; Colby, 2006).

As a result of technological developments in medical care, members of the general public and clinicians regularly face demanding case-conceptualization and plan-of-care decisions concerning when advanced technological treatments (such as cardiopulmonary resuscitation, mechanical ventilation, and supplying artificial nutrition and hydration) should be initiated or withheld, and if initiated, when treatments are no longer beneficial for the patient and should be stopped (Jecker, 2014). Concerns about

overtreatment and under-treatment, along with anxieties about initiating and withdrawing treatment, can engender ethical dilemmas that can cause moral distress for patients, their advocates, and clinicians (e.g., Austin, 2012; Benner, Janson-Bjerklie, Ferkeitch, & Becker, 1994; Pauly, Varcoe, & Storch, 2012). This study is an attempt to respond to some of these challenges by developing a theoretical model for the patient-clinician relationship. This model is intended to aid clinicians in facilitating communication with patients, their loved ones, and surrogate decision-makers, in order to help families and clinicians plan in advance for treatment options patients desire to receive or forego.

In an effort to ease anxieties and moral distress from difficult decisions about which care to use and when to initiate or stop advanced medical treatment, documents referred to as Advance Directives (ADs) and a process of communicating about and documenting desired care known as advance care planning (ACP) have been developed, and use of ADs and ACP has been advocated by private and public organizations (e.g., Briggs, 2014), medical ethicists (e.g., Jecker, 2014), and clinicians (e.g., Davis, 2014, Farber & Farber, 2014). ACP is a general term that refers to “a process that involves preparing for future medical decisions in the hypothetical event that individuals are no longer able to speak for themselves when those decisions need to be made” (Levi & Green, 2010, p. 4). Levi and Green explained that ACP includes communication among patients, their loved ones and advocates, and clinicians, about patients’ values, beliefs, desires, and quality of life, along with care goals. The process of ACP often culminates in the creation of advance directives (ADs).

Advance directives (ADs) is a general term that refers to documents that “formally convey an individual’s wishes about medical decisions to be made in the event

that he or she loses decision-making capacity” (Levi & Green, 2010, p. 4). These documents include the living will and the Durable Power of Attorney for Health Care (DPOA-HC). Similar to the Power of Attorney that authorizes another person to handle financial and business matters, the DPOA-HC authorizes a person to handle health care matters on another’s behalf. In the event that the person completing the document, also known as the “principal,” should become physically or mentally incapacitated and unable to speak for himself or herself about their own desires for care, the person designated in the DPOA-HC can speak or advocate on the principal’s (patient’s) behalf.

ADs are legal documents that meet requirements of federal and state laws, statutes, and regulations about delivery and receipt of end-of-life (EOL) care and EOL choices. Different states use different words to identify individuals named in the DPOA-HC. Consequently in the literature an individual named in a DPOA-HC can be referred to as a health care advocate, agent, surrogate and surrogate decision-maker, and proxy.

Another document comprising ADs is the Physician Orders for Life Sustaining Treatment (POLST). The POLST was developed to help patients near the end of their life express their desired medical care. This document is widely used by hospices and long-term care facilities. The form is intended to help physicians and other health care providers document a patient’s wishes regarding cardiopulmonary resuscitation (CPR) and other life-sustaining treatments. These orders should be completed for any person who wants to either avoid or receive life-sustaining treatments; lives in a long-term care facility or requires long-term care services; or is at risk of dying within the next year (McCune & Rogne, 2014).

Several authors, including Halpern and Emanuel (2012), White and Arnold (2011), and Black (2014), have noted that ADs can be effective tools for guiding communication about ACP between clinicians and professional caregivers (e.g., nurses, physicians, social workers, psychologists, and spiritual caregivers), patients and their loved ones, and advocates, about which medical interventions a patient wishes to pursue or avoid. In so doing, ADs can focus conversations by eliciting key factors including values, beliefs, and goals of care that can guide the advance care planning process. These include psychological, social, cultural, spiritual, and financial domains, in addition to medical concerns (Black, 2014).

Numerous scholars and clinicians (e.g., Halpern & Emanuel, 2012; Wenger, Shugarman, & Wilkinson, 2008) have noted that ADs hold much promise for ensuring self-determination and quality of life near the end of life. Yet, as Kass-Bartelmes and Hughes (2004) and Sabatino (2010) have observed, despite years of enthusiastic advocacy by major health care organizations, ADs have not been as widely used as hoped (see also Rogne & McCune, 2014).

Consequently, many patients transition into physical and mental incapacity and enter end-of-life (EOL) care without a health care advocate and without having ADs in place (e.g., Barnato et al. 2007; Castillo et al., 2011; Detering, Hancock, Reade, & Silvester 2010). Without ADs and an advocate patients can receive unwanted aggressive medical care (Jecker, 2014). Such care may be burdensome and costly and may prolong suffering in a degraded quality of life. Furthermore, clinicians and the patient's loved ones are then faced with difficult decisions, made on behalf of another without guidance about which medical care to initiate and withdraw and the timing of providing or

withholding these interventions. Additionally, ADs are not always honored even when available (Hickman, Hammes, Moss, & Tolle, 2005).

One important exception relevant to ADs, ACP, and EOL care is that the principle of patient autonomy does not prevail in situations that Schermer has identified as, “cases of emergency where immediate action must be taken to secure the patient’s life” (2003, p. 33). In an emergency, the patient might be precluded from consenting because of unconsciousness or incapacity, and delay in life-saving treatment would result in harm so grave as to outweigh any potential harm of a proposed treatment (e.g., Chapple, 2010; Lynn, 2004, 2005; Post, Blustein, Gordon, & Dubler, 1996). Under these critical conditions, some courts agree that emergency medical technicians (EMTs) and physicians may dispense with informed consent, “so long as they conform to practices customary in such emergencies” (Post et al., 1996, p. 353). It is important therefore to note that these “exceptions” frequently engender initiation of life-sustaining treatment, for which a patient may have stated and documented their wishes to have or to forego, in ADs that were the result of their effort to complete ACP.

### **The Longevity Revolution: Unrelenting Technology and Unstoppable Aging**

People are living longer. The global population is undergoing what E. Goodman (2012a, 2012b) called the “longevity revolution.” She used this term to *designate the phenomenon of the growing aging demographic of individuals who* are, as Beresford (1993) has observed, over 65 years of age—and especially over 85 years (see also Butler, 2008). Elders are naturally prone to more degenerative illness occurring over an expanded period of their lifespan. Consequently, a growing aging population in combination with rapidly advancing medical technology means that complex EOL care

considerations are faced by an increasing number of individuals, and over an extended duration of their lives. These conditions have emerged in the United States during the last 50 years and they will become more frequent and more widespread going forward (e.g., Lynn, 2004). Therefore, it is even more important for members of the general public to document their desires for medical care in advance of when the treatment is needed, while they are competent and capable of doing so.

Research has indicated that planning for medical care in advance can help in managing the emotional conflict engendered in these decisions about care near the end of life. ACP can help patients ensure self-determination and quality of life near the end of life. ACP can do so by making sure that individuals receive the care they desire, thereby bringing peace of mind, comfort, and certainty to patients, their loved ones, and clinicians (e.g., Austin, 2012; Brazil, Kassalainen, Ploeg, & Marshall, 2010; Epstein & Delgado, 2010; Jecker, 2014; Pauly et al., 2012).

In addition to other benefits, using ADs to facilitate communication about ACP can protect patients' loved ones, their advocates, and clinicians from "the burdens of surrogate decision making" (e.g., Halpern & Emanuel, 2012, p. 226). As Halpern and Emanuel observed, documenting care preferences can "assuage guilt, doubt, or lingering uncertainty" over care decisions made on behalf of another" (p. 267). Yet research shows that ADs and ACP remain underused.

### **Living Will and the Beginnings of Legal Codification**

The precursor to ACP was ADs, and the precursor to ADs was the living will. In 1967, Illinois attorney Luis Kutner proposed the first living will. He presented his proposed document in a law journal (Kutner, 1969). Kutner's document was modeled

after the estate will in order to document an individual's medical treatment preferences in case should they lose their capacity to advocate on their own behalf.

Because the document was in the form of a will but conveyed instructions relevant to the person's life while they were still alive, it came to be known as the "living will." Since the first living will (Kutner, 1969), the concept of documenting one's desired medical care preferences in advance has broadened, primarily through legislative efforts and court decisions.

It took multiple efforts to formalize the use of living wills by law. These efforts began near the time Kutner (1969) introduced the living will. Bills proposed to sanction the living will were brought before the Florida state legislature in 1968 and again in 1973 but defeated both times. Such a bill was finally passed in 1976 (only after first failing in 1974) in California. Thus, California became the first state in the US to authorize the living will for documenting individual treatment preferences for medical care. Within a year legislation governing living wills was considered in forty-three states, however only seven states passed these bills. At the same time, in 1976, the New Jersey Supreme Court, In The Matter of Karen Quinlan, handed down a decision that sanctioned ADs at the state level. During the next sixteen years legislation on documenting treatment preferences, now known as ADs, progressed. By 1992 all states and Washington, D.C. had legalized various forms of ADs.

Progressing in parallel with these legislative moves and court decisions, additional documents for documenting treatment preferences were introduced. The DPOA-HC emerged during the 1980s, and the POLST appeared in 1991. Also during this period physicians' notes in patients' charts about discussions the physician and patient

have had about patient preferences for EOL care became recognized as a valid component of ADs.

These legislative developments produced standards for what ADs exemplify. ADs came to be understood as instructions for treatment that can be very specific or very general. Instructions can consist of wishes about pain relief, antibiotics, artificial nutrition and hydration, use of CPR, and mechanical ventilation. More general instructions provide directives that all life-prolonging care is delivered, or that such care is refused, withheld, or withdrawn. Since Kutner's (1969) first living will along with legislative efforts and court decisions, medical technology continued to advance at a rapid pace and the costs of medical care increased accordingly. These advances, along with highly publicized legal cases prompted further evolution and vigorous discourse about ADs and ACP among legal scholars, legislators, ethicists, and clinicians.

### **The Federal Government Steps In: Federal-Level Legislation to Encourage Completion of ADs**

The conversation about ADs turned once the issue began to be considered at the level of federal legislation. One of the most significant events to influence the evolution of ADs, as noted by Alexander (1991), occurred with the passing by the US Congress of The Omnibus Budget Reconciliation Act of 1990 (Pub. L. No. 101 508 Stat. 1388, 1990). This act contained the Patient Self-Determination Act (PSDA), which required Medicare providers to “take an active role in informing patients about their right to participate in direct health care decisions” and required providers to “encourage and honor health care directives” (p. 770). The PSDA required hospitals and nursing homes to ask patients, upon admission, if they had ADs.

This legislative act served as an “information and education mandate” to Medicare and Medicaid Laws (Sabatino, 2010, p. 217; see also Kapp, 2014), requiring hospitals to inform patients about the opportunity to provide advance directives. The act, however, did not require completion of, communication about, or reimbursement of clinicians for communicating with patients and their loved ones about ADs. The approach to documenting treatment preferences in legal documents and forms was perpetuated by legislation such as the PSDA.

### **Emergence of Physician Orders for Life-Sustaining Treatment (POLST)**

The reliance on legal documents and forms for documenting medical treatment preferences was further cemented upon the emergence of the Physician Orders for Life-Sustaining Treatment (POLST) paradigm in Oregon in 1991. The POLST paradigm was designed in an attempt to improve end-of-life care in the United States. The POLST was intended to do so by helping patients facing chronic or serious illness to document which types of life-sustaining treatment they would or would not want to receive. The form is printed on brightly colored card stock and is usually placed in a strategic place in the patient’s home, typically posted on the refrigerator. A copy is also placed in the patient’s chart. This form has become widely used across states and currently sits at the foundation of at least 15 POLST and POLST-like paradigms that exist now, along with others in the pipeline (Kapp 2014; Sabatino & Karp, 2011).

### **Challenges and Limits of the Legal Approach to ACP**

The living will set in motion an approach for modeling health care documents after legal documents. The PSDA legislation, and the DPOA-HC, and POLST documents further established an approach to documenting desired care by completing legal forms.

Legal scholars have, in retrospect, referred to this as the legal approach or the forms approach (e.g., Sabatino, 2010) to planning in advance for EOL care, a paradigm we have lived with for decades in the United States. Today all 50 states have their own statutes and laws that speak to ADs, with the documents or forms and requirements varying by state. Differences in laws and forms from state to state can create complications if an individual moves or travels out of the state in which their documents and forms are completed and filed.

Some experts have criticized the form-focused legal approach of documenting desired medical care in advance on several grounds. A multitude of laws, policies, and forms can make completing and implementing advance directive documents difficult, as some states prescribe specific language, require certain diagnoses, restrict care choices, or require witnesses and notarization, all of which can make it difficult to complete compliant documents. Furthermore, ensuring that all requirements are met for each document can result in conflicting documents, making matters confusing for the surrogate and care providers (Sabatino, 2010). Many of the forms have been written above a 12th grade reading level, making them difficult to understand for many people. There has been much confusion among the general public, and among clinicians about which forms to use, when to use them, and how to complete and properly document or file the forms. In addition to the formal challenges in completing the documents, the fact that non-medically trained individuals must imagine hypothetical future circumstances and treatments in order to produce the documents, provides an added layer of difficulty (e.g., Ditto, Hawkins, & Pizarro, 2005; Fagerlin & Schneider, 2004; Teno & Lynn, 1994; Teno et al., 1997).

Critics of the legal forms approach have advocated for reconceptualization of ADs. In one reconceptualization individuals do not try to hypothetically predict their desires for treatment, and instead name a proxy in a DPOA-HC to act on their behalf. In the other conceptualization the focus is on an ongoing process of communication about EOL care that has come to be known as ACP.

During the 40 years that have passed since the first living will (Kutner, 1969), scholars, researchers, and practitioners have recognized that a focus on a one-time process of completing forms is not enough. It has now become clear that taken together, the legal, medical, and cultural problems of planning in advance for end-of-life care previously existed, in no small part, because the forms emphasize delineating reception or denial of care, obscuring the need for ongoing communication about ACP. The need for ongoing communication, however, is now being recognized and championed. As Rogne and McCune (2014), drawing on the work of others, have concluded: “conversations about EOL planning have shifted from product to process” (p. 4; see also Hammes, 2003; Wenger et al., 2008). We have moved from viewing planning in advance for medical care from a forms approach to a communications approach. This shift is reflected in the move from conceptualizing planning in advance for medical care as simply a one-time completion of ADs to engaging in an ongoing process of communication about ACP.

Today, the focus is no longer on completing legal forms. Instead, the focus is on using ADs as a tool to help facilitate ongoing conversations as a comprehensive approach that is now known as advance care planning (ACP). Now the momentum is toward “educating ourselves and our communities about dying and death and to provide

knowledge that can help us prepare ourselves, our families, and our society for a better way to die” (Rogne & McCune, 2014, p. 4).

But how can we accomplish these goals? Through the decades since the first living will of the late 1960s researchers have endeavored to understand the effects of completing, or not completing, ADs, examined congruence of care delivered with ADs, investigated accuracy of surrogates’ decision making, and endeavored to better understand barriers to, and advance strategies for, improving communication about ADs and ACP. Next I will present a review of literature that examined communication about ADs and ACP in the patient-clinician relationship.

### **Literature Review**

**Advance care planning: Where are we?** Today, a majority of Americans still enter end-of-life care without having completed ADs or ACP. More than half of Americans transition to chronic and terminal illness without having completed ADs (Wenger et al., 2008). Research shows that a number of closely related factors underlie the underuse of ACP, ADs, and naming of health care advocates. These factors fall into five categories: (1) questions about ADs and ACP are difficult; (2) there is a lack of awareness of how ACP can best be used; (3) clinicians avoid conducting discussions about ACP; (4) administering advanced medical care is standard practice; and, (5) clinicians lack adequate training in communication skills.

First, research reveals that people have difficulty both asking and answering important questions about end-of-life care planning for themselves and for their loved ones (e.g., Levi & Green, 2010). Some authors have emphasized this is due in part to the difficulty of imagining a hypothetical future including disease symptoms and

conjecturing which treatments one would desire to receive or decline (e.g., Ditto, 2009; Sudore, & Fried, 2010).

Second, among members of the general public and, even more alarming, among clinicians there is a lack of awareness of how the advance care planning process can best be conceived, documented, and used (e.g., Fagerlin & Schneider, 2004; Levi & Green, 2010; Sabatino, 2010). Ahluwalia, Levin, Lorenz, and Gordon (2013) pointed out that providing practical guidance for conducting discussions about ACP, which as the authors note, can be “difficult and time-intensive discussions” might increase use of ACP. However, they continue, “little guidance regarding the structure and process of an ACP discussion exists” (p. 200).

Third, clinicians frequently avoid end-of-life discussions, even though research has documented that patients and their loved ones are more satisfied when they have an opportunity to have conversations about end-of-life care, ADs, and ACPs with their health care providers (e.g., Volandes, Mitchell, Gillick, Chang, & Paasche-Orlow, 2009).

Fourth, as Chapple and Pettus (2014) pointed out there is a prominent ideology of rescue in the U.S. health care system. That is, led by the ideology of rescue, providers apply advanced medical care during advanced stages of disease as well as in emergency situations as an unconscious reflex. This rescue trajectory is compelling for clinicians, patients, and their loved ones (see also Chapple, 2010). Our current medical culture and health care system appear driven by heroic use of all available medical care to rescue all patients, and prevent, or at least delay, deaths in all situations and at all costs. As a result, “death seems distant from everyday life, bolstered by the “‘mythology’ of CPR” (Chapple, 2010, p. 3; see also Timmermans, 1999). Accompanying this rescue paradigm

is the pervasive view that a patient's death is the clinician's defeat (e.g., Beckstrand, Callister, & Kirchhoff, 2006), leaving little room for asserting the necessity of ACP.

Fifth, as Detering et al. (2010) and Kessler, Lexer, and Kendal (2009) have observed, clinicians are frequently not trained to facilitate communication with patients and their loved ones about ADs, ACP, EOL care, and death. This lack of training is due, in part, to reliance on previous models used by clinicians to conceptualize the patient-clinician relationship based on paternalism and autonomy (see for example Schermer, 2003; D. G. Smith & Newton, 1984). Paternalism is a model for the patient-clinician based on a paternalistic ethic founded on the Hippocratic Oath. In this model the clinician is held in a position of authority and engages in practices of withholding information from the patient (see Cooper & Buckner, 2013; Phillips, 1987), such as terminal diagnoses, in order to prevent distress and preserve hope. This came to be identified as the paternalistic conceptualization of the patient-clinician relationship.

Autonomy is an ethical concept that aims to ensure the patient is making an informed, un-coerced decision. Clinicians have held this respect for patient autonomy as an important aspect of conceptualizing the patient-clinician relationship. Research has shown that paternalistic and autonomous conceptualizations of the patient-clinician can inhibit communication about ADs and ACP.

Taken together these factors are interwoven with Western society's predisposition to avoid death and discussions about death and medical care before death. They produce and perpetuate conditions that lead the general public, patients, and clinicians to circumvent the existence of mortality. As a result of these factors, a majority of Americans face life-threatening illness without having completed ADs. When ACP does

take place, its historically legalistic structure has circumscribed communication throughout the process in particular ways, presenting a challenge to the efficacy of the process. The dynamics of communicating about ACP are complex. Delineating the questions and answers remains difficult. Researchers have undertaken efforts to better understand the complex dynamics that influence clinicians' communication about ADs and ACP. Next, I will discuss the framework for this review of these efforts.

### **Literature Review Framework**

Methods used for this literature review were a combination of a “focused literature review,” as defined by Feak and Swales (2009), and a mixed-method ethnographic review (Harden, 2010). Feak and Swales referred to a focused literature review as a specific type of literature review that is “limited” to (p. 3) or focused on a specific aspect, or aspects, of previous research. This review will focus on publications that use the broadest and most interdisciplinary conceptualizations of communicating about ADs and ACP in the patient-clinician relationship. This means, as much as possible, limiting search results that focus on specific disciplines (nursing or medicine) and sub-specialties (e.g., oncologists, anesthesiologists, nephrologists, ICU nurses, or cardiac care nurses). Studies selected for this review also focused on patient-clinician communication that, as much as possible, cuts across diagnostic categories rather than focusing on specific medical conditions (e.g., renal failure), prognosis (e.g., six months or less to live), or care setting (e.g., at home or hospital). Rather studies were selected that presented the broadest participant samples focused on patient-clinician communication about ADs and ACP.

According to Creswell (2009), mixed methods approaches “employ aspects of both quantitative and qualitative procedures” (p. xxiv). Harden (2010) advocates for integrating quantitative and qualitative findings via mixed-methods systematic reviews of the literature to enhance the utility and impact of reviews. Harden notes this approach is especially helpful for issues related to health and evidence-informed policy and practice. Harden also advocates for meta-ethnography as a framework for reviewing literature. Harden distinguishes meta-ethnography as a method that focuses on “interpretation rather than aggregation” (p. 4). Meta-ethnography involves two stages. The reviewer first identifies concepts of individual studies and then formulates “a new interpretation” that “integrated those concepts across studies into a line of argument” (p. 4). Accordingly, in this ontological hermeneutic study the mixed-methods ethnographic approach was also used to select studies for this review. As a result of these methods this literature review included the most recent exemplary quantitative and qualitative studies that examined patient-clinician communication about ACP. These recent studies comprised those that were published in 2013 and were available as of this writing.

### **Database and Search Methods**

Knowledge is being produced at an unprecedented rate. Circumscribing the thousands of results that included the terms “advance directives” and “communication” has proven to be one of the biggest challenges in conducting a review. Next I will present the search methods used, in response to these challenges, to identify publications for this literature review.

**PubMed.** A search of the PubMed Database for the term “advance care planning” applying the filter for “Clinical trial” yielded 7,977 results. These results are presented by

year in Appendix A. The first publication was in 1972, three years after the first living will was introduced (Kutner, 1969). The number of publications discussing ACP released each year since 1991 has exceeded 200. Growth in the number of annual publications has demonstrated that discussion in the scholarly, clinical, legislative, policy, and public spheres about ADs and ACP, which began shortly after introduction of the first living will in 1969, has continued to be robust. Publications discussing ACP between 2011 and 2013 exceeded 400 annually. The largest number of results, 485 publications, was published in 2013. Assuredly, conversations about “death panels” sparked by political debate about health care reform related to the Patient Protection and Affordable Care Act of 2010 have fueled recent discourse. But even so, it seems that the momentum for communicating about ACP remains strong.

**Google scholar.** A search using the Google Scholar search engine for the term “advance care planning” with the time frame delineated as “Any time,” yielded 10,300 results. The search terms were then limited further. A search using the Google Scholar web search engine for the terms “advance care planning” and “communicating” using the filters “anywhere in the article” and return articles “anytime” yielded 2,110 results. The search was limited still further. A search using the Google Scholar web search engine for the terms “advance care planning” and “communicating” using the filters “anywhere in the article” and “Return articles dated 2013” returned 231 results. A preliminary review of these abstracts was conducted. Several items were duplicates and were excluded. Results were excluded if they were papers, book chapters, or books that did not present the results of quantitative or qualitative studies. Additionally, opinion columns, editorials, or personal narratives were excluded. The remaining results, 42 publications, were

reviewed in their entirety. Publications selected for this review include: landmark historical studies and research touchstones, decisive legal publications, publications discussing federal-level legislation related to ADs and ACP, and current empirical studies.

In this section I have provided an overview of the methods used to select publications included in this literature review. In the next section I will provide an overview of research questions, landmark studies, and research touchstones.

### **Overview of Landmark Studies and Research Touchstones**

**Main focuses and guiding questions.** The literature about ACP communication is notable for the breadth and diversity of methods and study participants. Researchers have employed both quantitative and qualitative methods to examine experiences of formulating, documenting, and communicating about, ADs and ACP. Researchers have used individual, face-to-face interviews, structured and semi-structured interviews, focus groups, paper and pencil evaluations, and self-reports. Researchers have employed pre-tests and post-tests, both individually and together. Study participants included clinicians, patients, and those named as advocates in DPOA-HCs.

A large group of studies investigated the efficacy of advance directives, a controversial but fundamental question. Several studies focused on the presence or absence of ADs in patients' and decedents' charts and investigated congruence and adherence, and effectiveness of ADs. In other words, researchers sought to determine whether, if present in patients' charts, the ADs were followed.

Researchers have looked at congruence, adherence, and effectiveness of ADs from two standpoints. First, a group of studies evaluated congruence between care

preferences documented in ADs compared with care delivered by clinicians. Second, another group of studies examined accuracy of care advocated for by surrogate decision makers compared with care preferences documented in ADs. Some researchers conducted retrospective reviews of patients' and decedents' charts and retrospective interviews with advocates named in patients' DPOA-HC. Importantly, studies have also examined communicating about ADs and ACP from the perspectives of caregiving disciplines, such as nurses, physicians, and social workers.

Historically, most studies were developed based on conceptual frameworks that focus on clinicians, delimited by specialty (nurses, physicians), sub-specialty (oncology, cardiology); patient population delimited by diagnosis (cancer, heart failure, liver failure), prognosis (chronically ill, terminally ill); or care setting (e.g., long-term care facility, dialysis center). Studies sought for this review were those that provided the broadest patient and clinician applicability. This review will include landmark historical and exemplary studies that discussed communicating about ADs and ACP in the patient-clinician relationship during the period since the first living will was developed, in 1969, through 2013. These studies were chosen because they exemplify research at the time they were published.

### **Historical Studies About ADs and ACP**

Scholars have conducted studies to examine ways to increase the frequency and improve the quality of communication between clinicians, patients, and their loved ones and advocates, about ADs and ACP. Sachs, Stocking, and Miles (1992) conducted one of the first randomized controlled trials examining strategies for increasing discussions between older patients and primary care physicians. The researchers examined the

effectiveness of an educational intervention for patients and clinicians to determine if it would increase the presence in the patient chart of a living will, DPOA-HC, or physician's notes documenting a discussion with the patient about ADs. Participants were patients who did not have ADs in their chart at the start of the study. The results were disappointing. At the conclusion of the study only 15% of participants receiving the educational intervention had ADs or notes about having discussed ADs in their chart, while 10% of those in the control group had ADs in their chart. In post-intervention interviews participants identified procrastination as a significant barrier. This study illuminated the complexity of communicating about ACP and affirmed that information access is not the only, and perhaps not even the primary, barrier to ACP.

In 1993, E. J. Emanuel, Weinberg, Gonin, Hummel, and Emanuel conducted one of the first studies after implementation of the PSDA to determine if there was an association between the PSDA and use of formal and informal ADs, and to evaluate discussions between patients, proxies, and physicians. The researchers asked patients about formal and informal ACP and their discussions about ACP with their proxies and physicians. They conducted a time-sequence study at two medical school-affiliated teaching hospitals. The PSDA was associated with a significant increase in patients who had ACP arrangements and had engaged in general discussions about EOL with their proxies, but had not discussed specific treatment preferences. However, the PSDA did not appear to have been associated with an increase in completing formal ADs or in more discussions between patients and physicians about ADs or EOL issues.

## **The SUPPORT Study**

A landmark study that influenced ADs was publication of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment, known as the SUPPORT study (Teno et al., 1997). Even today, 17 years after initial publication, it is difficult to find a discussion about ADs and ACP that does not reference the SUPPORT study.

In the SUPPORT study Teno et al. (1997) and her colleagues set out to examine whether during the years since the passing of the PSDA the use of ADs had increased, and if increased use of ADs would lead to a reduction in hospital resource utilization. In other words, would the government's attempt to increase use of ADs save money? It was thought that doing so would conserve resources. The assumption was that resources would be saved because the ADs would outline the kind of care patients would and would not want. This would then reduce delivery of unwanted care, thereby saving resources that might have been used otherwise.

The researchers conducted a replication analysis of previous published studies using data from a prospective cohort study along with a block-randomized trial. The researchers measured hospital use to determine if the use of ADs influenced, or even reduced, hospital use. Hospital use was measured by the Therapeutic Intensity Scoring System, which included documenting length of hospital stay, which was then converted into 1994 US dollars. This was the first widely recognized study that offered an intervention. The intervention consisted of a nurse to facilitate communication among patients, surrogates, and physicians about preferences for and outcomes of treatments. The nurse also documented advance directives. A total of 9,105 seriously ill patients were

enrolled as participants. Participants included 4,301 patients in the 2 years before the PSDA (1989-91) and 4,804 in the 2 years after the PSDA was implemented (1992-94). The study also included 2,652 patients who did not receive the intervention and served as controls.

Teno and her colleagues (1997) found even when ADs were completed: (a) they were often not placed in patients' charts; (b) physicians may not have been aware of the existence of ADs; and (c) if physicians were aware ADs had been completed they had rarely discussed them with patients or their families. The researchers also found that surrogates named by a patient to make health care decisions on their behalf often did not know or did not accurately understand the patient's preferences. The researchers concluded that often ADs contained little clinical information, and the information was not realistically implementable in clinical settings.

The SUPPORT study documented that patients receiving the nurse intervention were more likely to have their pre-existing ADs documented. They also found that documentation of existing ADs upon admission had increased with the PSDA. However, despite these increases, they found no corresponding change in hospital resource use for patients who died during the hospital admission for which they were enrolled for the study. These findings dealt a blow to the movement advocating for ADs.

More than 17 years after the SUPPORT study was published, questions of resource and cost savings related to the use of ADs remain, and researchers are still conducting studies to determine if ADs save money (e.g., Nicholas, Langa, Iwashyna, & Weir, 2011). However, others have pointed out that asking if ADs save money may be the wrong question. Halpern and Emanuel (2012) asked, "Are cost savings a reasonable

measure of the success of ADs?” (p. 266). They advocated that promoting ADs may be warranted, “even if they did not lower costs if they promoted improved quality of life, facilitated care consistent with patient’s values, or resulted in other patient-centered outcomes. Documenting cost reduction is not necessary to justify the use of ADs” (p. 267). All the while, legal scholars, ethicists, policy makers, and legislators, and clinicians, have continued to advocate for ADs and hoped to increase frequency and improve quality of communication about ADs and ACP.

Succeeding the SUPPORT Study, researchers have continued to design studies aimed at providing better understanding of the complexities of communicating about ADs and ACP. Although the SUPPORT Study findings can be viewed as quite damning for the impetus for ADs, inadvertently, these findings underscored the need for improved communication about ACP among all parties involved. In the next section exemplary studies that examined communication between patients and clinicians conducted since the PSDA will be presented.

#### **Exemplary studies considering communicating about ADs and ACP.**

*Clinician interventions.* It had been assumed if physicians engage in communicating with patients about ADs and ACP that this would increase the rate of completion of ADs. Yet it has also been documented that physicians avoid these discussions. What has remained unclear is how physicians can be encouraged to engage in communication about ADs and ACP.

There is a large body of literature advocating for communication skills training to help professional caregivers feel more comfortable and competent conducting EOL conversations. While formalized communication modules have been developed during

the past decade, none have been widely adopted into curricula. In a pilot study of a communication skills training program designed for resident training curriculum L. Smith, O'Sullivan, Lo, and Chen (2013) conducted electronic pre- and post-intervention surveys. Residents self-selected for this program and 88 participants completed the study. In addition to information about the communication skills training intervention, information about participant perceptions of their self-efficacy in communicating and participant demographic data were collected. Fisher's exact test, the *t* test, along with Standardized Cronbach's alpha and McNemar test and paired *t* tests, were used to analyze data. The researchers found the communication intervention was feasible to implement, and had a small but demonstrable effect on participants' comfort and perceptions of self-efficacy for EOL communication. Participant self-selection may have influenced results, as participants who chose to engage in communication skills training to discuss EOL may have been more willing to learn about ACP communication practices than non-participants. Future research might include the intervention as part of a required curriculum and include direct observation and feedback studies to more directly measure behavioral change.

Other studies have looked at communication in context of the underuse of ACP despite legal sanctioning of ADs. Samara, Larkin, Chan, and Lopez, (2013) conducted a mixed-methods study using pre-post-test measures, and a focus group to examine barriers to clinician communication about ACP and the efficacy of a training program for clinicians on communicating about ACP. Participants receiving the intervention—nurses and other medical professionals working in oncology departments—completed questionnaires prior to and after attending the training module. Additionally, a

convenience sample of 25 nurses participated in the focus group. A convenience sample comprises participants that are close to hand, readily available at a given place and time, as contrasted with participants that are randomly selected. These samples are not representative of the total population and consequently generalizations cannot be made from such a sample to the population.

The researchers reported disappointing results. There were no significant differences between pre-and post- test results. This was attributed, in part, to staff turnover and newly graduating nurses who had not received ACP education in their formal curriculum nor participated in the training intervention. Focus group data revealed perceived barriers to ACP included lack of confidence and competence to conduct ACP discussion and documentation. Additionally, participants reported that while on duty they lacked time to implement the ACP training received. The study suggested that medical professionals, despite receiving training in ACP, nevertheless suffered from a lack of confidence and competence that was not addressed by the intervention. Another barrier to communication was the extent of responsibility involved in ACP, which included legal problems, problems with documentation, and patient readiness and attitudes towards ACP. Additionally, lack of adequate and suitable space in which conduct ACP discussions, and privacy issues further hindered clinicians' facilitation of ACP.

Granek, Krzyzanowska, Tozer, & Mazzotta (2013) conducted the first qualitative exploration I could locate that directly explored clinicians' communication strategies and perceived barriers to effective communication about EOL. They used a purposive sample to target three groups of oncologists. Participant criteria included having had a patient die

in their care. The researchers analyzed the data using the grounded theory method (Glaser & Strauss, 1967/2009).

Six themes related to communication strategies emerged: (1) physician responsibility and obligation; (2) open and honest communication about EOL defined as providing relevant information about prognosis, not necessarily all information at their disposal; (3) ongoing, early conversations, which were limited by how much information patients and their families could absorb; (4) communicating about treatment goals, including shifting focus from treatment to palliative care (that is, from cure to comfort) and modifying treatment expectations; (5) balancing hope and reality, including making patients aware of their prognosis; and, (6) taking cues from patients, which is an indicator of the appropriate level of physician disclosure.

According to the study, barriers to communication were multifold. Results indicated personal difficulty in providing oncological care, delivering painful information, and discomfort with death and dying. Participants experienced difficulty balancing the seemingly contradictory, treatment and palliative-focused care. Other physicians and colleagues who were resistant to engage in EOL conversations caused barriers. Participants expressed they felt a general lack of experience with the end of life. Patient and family factors including opposition to doctors and not being ready to discuss EOL care inhibited communication. Participants noted a lack of protocols and guidelines for discussing EOL issues. Their findings corroborated results of earlier studies, and contributed to the literature by providing qualitative data about the thought processes and perceived barriers of clinicians as they engaged in communication with patients about ACP.

## **Patient Interventions**

Rhondali et al. (2013) conducted a randomized controlled trial with patients as participants to examine the impact of physicians' communication style, employing an autonomy approach as compared to a beneficence approach when discussing do not resuscitate (DNR) and cardiopulmonary resuscitation (CPR) preferences with patients. An autonomy approach refers to the rights-based models of care that are prevalent in the U.S. in which the patient is understood to have the right to autonomy. Autonomy is an ethical concept that aims to ensure the patient is making an informed, un-coerced decision. Clinicians have held this respect for patient autonomy as an important aspect in conceptualizing the patient-clinician relationship.

A beneficence approach refers to an approach in which the clinician is obligated by the ethic of beneficence in the Hippocratic Oath. Beneficence is an ethic that informs models clinicians use to conceptualize the patient-clinician relationship that values taking actions for the benefit of others. These actions are taken by the clinician to prevent or remove harm to the patient.

Research has demonstrated that caregiving professionals frequently fail to discuss DNR/CPR preferences with patients. Furthermore, physician's communication strategies are informed by their conceptualization of the clinical relationship (i.e., autonomy or beneficence models), yet in DNR/CPR discussions these factors have not previously been examined in randomized controlled trials. In a move to fill this gap in the literature Rhondali et al. (2013) randomly assigned patients to groups that viewed two possible video sequences of a patient deciding about DNR. One video ended with a recommendation that exemplified the beneficence model. The other video ended with a

question that exemplified the autonomy model. Patients were then asked to recommend a DNR choice for the patient in the video. Patient characteristics collected and analyzed included demographics, DNR/CPR preference, and whether patients had, themselves, discussed their DNR/CPR preference with their doctor. The researchers found that both autonomy and beneficence approaches are appropriate when discussing DNR preference. Prior to the study, 51% of participants had not made a decision about their own DNR/CPR status and only 4% had DNR/CPR status documented in their chart. Regardless of the video they watched, of patients who did not have a DNR order in place prior to watching the video sequence, 62% chose a DNR for the video patient, and all of the patients who had a DNR order in place prior to watching the video sequence also chose a DNR for the video patient. Age and race were independent predictors of DNR preference. Patients who were older, married, and of white ethnicity were more likely to choose DNR status. One limitation to this study was that patients were shown a standardized video, while in practice physician training, confidence, and communication skills and style vary. Also, diagnosis and prognosis, patient's age and family circumstances (e.g., does the patient have young children), and the extent and status of the patient's support network might be confounding factors that influence discussions and decisions about DNR.

**ADs, ACP, and social justice.** During 2013 several researchers conducted studies that investigated the use, and exclusion of usage, of ADs and ACPs based on social justice issues. Social justice issues that influenced ADs and ACP, included vulnerability (e.g., older people, frail people, individuals with diminished mental capacity, individuals with low literacy, homeless adults, and immigrants).

***Older people and diminished mental capacity.*** According to World Health Organization (2012) estimates, worldwide there were 35.6 million people with dementia in 2012. This number is expected to double during the next 20 years.

It has been estimated that a quarter of older people experience limited decision-making capacity (DMC) for more than a month before death, with two-thirds of older people experiencing varying degrees of DMC during the last week of life. Reduced DMC can affect older individuals' abilities to communicate about ACP and EOL care decisions. To investigate the impact of DMC on ADs, ACP, and EOL care, Kaspers, Onwuteaka-Philipsen, Deeg, and Pasman (2013) examined the impact of limited decision-making capacity (DMC) on ACP via retrospective data collected from decedents' relatives and proxies. The researchers studied a representative sample of documents from the Longitudinal Aging Study Amsterdam (LASA) (Huisman et al., 2001) and a purposive sample of the advance directive cohort study (ADC). Cohort members died between 2006-2009. The researchers collected data about the last three months of decedents' lives by using written questionnaires sent to proxies and surviving family members. Chi-square tests and analyses compared surviving participants related to patients who experienced limited DMC a week or longer with participants related to patients who experienced DMC for a week or less prior to death. The researchers also examined groups according to those who had named a proxy compared with the group without a proxy AD. The researchers found that physicians were aware of the ADs for those with limited DMC that had an AD, at levels of 83%-87% across groups. Further, they found that for patients with full and limited DMC, care received prior to death was in accordance with patients' preferences (71% across groups). Looking, however only at

those with limited DMC for more than a week, only 60% received care according to their preferences. While this study benefited from data collected from two separate cohorts, the data included all deaths, including sudden deaths, which may not have allowed for an EOL decision-process phase. It has been demonstrated that proxies are often not accurately aware of the patient's care desires, and recall bias due to retrospective reporting by decedents' loved ones and proxies may have influenced the results. Another limitation of this study was that it was not possible to assess whether care was received according to preferences for those decedents who had not named a proxy. This limitation makes it difficult to contextually situate the results. Finally, participants' retrospective reports about overall satisfaction of care may be skewed due to the difficulty people have revisiting difficult life events, such as surviving the death of a loved one and shouldering the responsibility of making EOL care decisions on behalf of another. Even so, the results of this study point out the importance of formulating and documenting ADs, including naming a proxy before limited DMC occurs.

Gathering retrospective data has been the traditional method for examining the impact of dementia on ACP. However, C. Goodman, Amador, Elmore, Machen, and Mathie (2013) conducted the first study available at this writing that examined the impact of dementia on ACP by collecting data from the patients themselves—patients diagnosed with dementia. In this explorative qualitative study, guided conversations were used with a purposive sample comprised of 18 individuals with dementia who lived in six care facilities. Data were analyzed for themes. The data demonstrate that if guided sensitively and given the opportunity, people with dementia can articulate their care preferences and perspectives on living and dying in care facilities. The data also revealed the need for

ongoing exploration with these individuals about the impact of key relationships with loved ones and professional caregivers, and the ways in which care decisions continue to inform their decision making about future care, including EOL care. The researchers were not part of the participants' daily life, which can be an important factor for individuals living with dementia. Participants' cognitions, emotions, memory, and recall may have been affected by engagement with unfamiliar persons during the interviews.

Despite these limitations this study is important because until now, there has been little evidence for communicating about ACP elicited directly from individuals living with dementia. This study brings hope about the abilities of patients with dementia to engage in ACP in more meaningful ways and over a greater duration of their lives than had previously been understood. These results might encourage family members, proxies, and professional caregivers to engage with patients as they guide care. By doing so, overall delivery of care might be more in line with patients' preferences. However, caution is needed as it remains unclear as to at what point a single conversation about ACP with a person with limited DMC and/or dementia may have unintended consequences about future care decisions. Additionally, as Castillo et al. (2011) and Alexander (1991) pointed out, if a patient with DMC makes a change in their ACP or ADs, it might be difficult to ascertain if this change was intended, and such changes may be irreversible. However, in the alternative, we currently risk delivering care that is not in alignment with patient preferences because until now, for the most part, no one has taken the time and the care to ask.

***Other disenfranchised patients.*** Many studies show that disenfranchised patients continue to be underserved in their medical care. Due to these gaps in care, vulnerable

individuals' needs for hospice and palliative care, and support for communicating about ACP have continued to go unmet.

A study by Waite et al. (2013) revealed that differences in literacy rates is a significant factor in accessing palliative and hospice care during EOL. Research has also shown that literacy influences completion of ADs and engaging in ACP. The researchers sought to understand the effect that the relationship between literacy and race would have on communicating about ACP with older adults. They conducted face-to-face, structured, interviews with 784 adults aged 55 to 74. They assessed for literacy rates and socio-demographic factors using Chi-square and Wilcoxon rank sums to evaluate the associations between factors.

Waite et al. (2013) did not report who conducted the interviews. Diversity differences between participants and interviewers could have influenced participant responses, thus limiting reliability and validity. Even so, this study helped shed light on the important issues of literacy and minority access to health care services and support for the disenfranchised regarding communicating about and documenting ADs and ACPs. The researchers found that race was a significant factor and that African Americans were approximately half as likely as participants of other races to have an AD in place.

In consort with these findings, Crawley et al. (2000) noted that according to the National Hospice and Palliative Care Organization, "African Americans represent 8% of patients who participate in hospice care" (p. 2518). Crawley et al. speculated about the cultural, ethical, legal, economic, and historical influences that inform end-of-life care choices by African Americans and identified "the legacy of slavery, abuses in medical experimentation, economic injustices, racial-profiling practices and the disproportionate

numbers of incarcerations” as factors that may have possibly “lead to a general loss of credibility of many institutions, including the health care system” (p. 2518), which may contribute to lower use of ACP and ADs within this community.

Ko and Nelson-Becker (2013) conducted a qualitative pilot study that explored ACP concerns among older homeless adults. Participants were 21 English-speaking individuals who self-selected. Data were collected in face-to-face interviews using a semi-structured questionnaire. Interviews were recorded on audiotape then transcribed. Participants were also interviewed with a structured questionnaire that assessed social support. A grounded theory approach was used to identify emergent themes among responses. Five main themes emerged including (1) EOL is an uncomfortable topic; (2) God plays a role in EOL care; (3) physicians are preferred as decision makers; (4) EOL care is not a priority; and, (5) people who are homeless want to be approached with sensitivity. The researchers speculated about reasons that may underlie these themes. The researchers hypothesized that perceived discrimination in health care systems and fears of being treated unfairly may lead to homeless patients having life-sustaining treatments withheld or withdrawn for discriminatory and economic reasons. These fears may have contributed to an aversion of planning for EOL care. Due to the uncertainty of daily life and meeting basic needs, EOL care and ACP seemed distant and not a primary task, especially when patients lack a stable social support network of people to serve as surrogate decision-makers. Additionally, in the absence of a stable network of possible surrogate decision-makers, physicians were seen as the best person to make EOL care decisions, yet laws prohibit patients from naming professional caregivers as health care advocates in their DPOA-HCs. This study illuminated several aspects of discrimination

faced by this disenfranchised population. Most participants were ambulatory and health status has been shown to impact ACP decision-making. Future studies could recruit homeless populations from multiple settings and include individuals with a variety of health statuses.

Research has also shown that ACP among minorities presents particular challenges. Ethnic minorities in the U.S. are estimated to make up about 25% of the U.S. population. In an effort to better understand dynamics influencing planning for EOL and ACP within Asian cultures, Ko, Roh, and Higgins (2013) examined EOL care planning among older Korean immigrants. Participants were selected by a convenience sample at two Korean senior centers. In this cross-sectional design, 195 older (age 65 years or older) Korean immigrants were interviewed in face-to-face interviews. The researchers used structured questionnaires that measured, among other areas, acculturation, perceived burden, and religiosity, and collected ACP and EOL care history. Only 12 participants reported having discussions with family members and having formulated specific EOL care plans, and 8 participants had communicated plans with a physician. In the study, more traditional cultural preferences and greater religious practices resulted in less likelihood of EOL discussions. Perceived burden on family members was a predictor of increased likelihood for engaging in EOL communication. Results revealed that 21.9% of participants indicated they had generally discussed their EOL treatment preferences with others. These results support the results of other studies that have established the need to explore cultural and religious concerns about death and dying, and the need to sensitively address the benefits of ACP. Future research could include broader sampling and

eligibility criteria. Longitudinal studies would be helpful for understanding how these factors change over time.

**Considering dyads: New directions in communication about ACP.**

*The patient and advocate dyad.* Another dimension of communication examined was that among patients and their advocates. Early on, researchers found that without an AD, clinicians and patients' families and surrogates are inaccurate in predicting patients' treatment preferences (e.g., Volandes et al., 2009; Teno et al., 1997). To answer the question "Do surrogates accurately advocate for care as documented in ADs?," Ditto, et al. (2001) conducted the first randomized controlled trial to examine the effectiveness of multiple interventions to improve accuracy of surrogates' decisions. Participants were outpatients who had completed ADs and their designated surrogate decision makers. Surrogates were asked to predict patients' preferences for life-sustaining treatments in illness scenarios in experimental conditions with several interventions including exposure to scenario-based and values-based directives, and guided conversation with the patient. The controls received no intervention. Results of this study extended the conclusions of the SUPPORT study. This study demonstrated that the mere presence of ADs did not improve surrogate decisions. Furthermore, none of the interventions significantly increased accuracy of surrogates' predictions.

*The patient and clinician dyad.* Earlier studies investigated whether interventions with patients (e.g., mailing educational materials) or with clinicians (e.g., computer reminders, education modules) increased discussions about ADs and ACP and increased frequency of ADs and ACP documentation in patient charts. While many studies investigated communication about ADs and ACPs from either the patients', proxies' or

clinicians' perspectives, other research has focused on the quality of communication between physicians and patients from the perspective of both parties in the dyad. This move, considering the dyad, showed a shift in researchers' awareness that recognized of the importance of mutual reciprocal influence in the patient-clinician relationship.

In an early study, Tulskey, Fischer, Rose, and Arnold (1998) sought to understand how physicians communicated with patients about ADs in an effort to improve how physicians conduct these discussions. They audiotaped physician-patient discussions in five outpatient primary care clinics located in three U.S. cities. Participants were 56 internists-patient dyads. Patients were diagnosed with a serious illness and were at least 65 years of age. Transcripts of dyadic discussions were coded by two raters. The researchers found that when physicians introduced discussions about ADs, they did not listen much to patients. Instead physicians spoke two thirds of the time. In so doing they did not address patients' values, beliefs, and feelings. This approach to communicating about ACP did not meet standards proposed in the literature, and these discussions were not ultimately useful in helping patients complete ADs and ACP.

In 2004, Heiman, Bates, Fairchild, Shaykevich, and Lehman sought to extend the research that followed the 1991 introduction of the PSDA and the SUPPORT Study (Teno et al, 1997). This study is important because the interventions were for both physicians and patients. These researchers conducted a randomized controlled trial at five academic medical centers examining the effectiveness of three interventions that addressed both clinicians and patients in the clinical dyad. The interventions included reminders for physicians and patient mailings that included health care proxy forms along with literature about ADs. The researchers found that patients who received mailers and

were also in the group with physicians that received a reminder yielded a small but significant increase in completion of ADs. Physician reminders alone had no effect. These results confirm previously demonstrated understanding that communicating about ACP is complex, and it will likely take multidimensional interventions to improve the quality and increase the frequency of ACP discussions. Instead of addressing ADs and ACP as one-dimensional, solutions should include many dimensions including patient and clinician education.

Recently, Ahluwalia et al. (2013) examined the frequency and extent to which physicians engaged communication about ACP during outpatient visits with heart failure (HF) patients. In this qualitative study, data consisted of audio-recorded and transcribed responses during outpatient post-discharge follow-up visits with a primary care internist or cardiologist. Participants were patients, 65 years of age or older, who were hospitalized for heart failure at two Veterans Affairs Medical Centers and their physicians. Demographics were collected for both physicians and patients. Patient chart reviews were conducted. Additionally, via self-report, characteristics of the providers' practice were collected. The researchers conducted a qualitative content analysis of 71 transcripts of physician-patient discussions about treatment planning and care choices. The researchers developed a codebook for physicians guided by three elements of ACP communication: (1) explaining the nature and course of heart failure; (2) eliciting patient preferences for care; and, (3) encouraging documentation of patient preferences including specific treatment goals of care such as life-prolonging or palliative care.

Ahluwalia et al. (2013) concluded, "important elements of ACP communication occur infrequently if at all" (p. 203) and endorsed a heuristic framework, such as the

codebook used in this study, for helping physicians communicate with patients about ACP. The participant sample was small and was limited to U.S. veterans age 65 and over, which may not generalize to other populations. Another limitation of the study is that the researchers did not determine if ACP conversations had taken place prior to the study. The researchers failed to identify or examine the reasons physicians' did not acknowledge with patients the potential of death that can accompany heart failure. This study indicates future research is needed to delve more deeply into the reasons physicians fail to discuss and gain understanding of the specifics of their patients' ACP, and explore reasons clinicians fail discuss to the possibility of death that accompanies their diagnosis which, in this case, is heart failure.

The failure by physicians to acknowledge death when discussing ADs, ACP, and EOL care also emerged in a qualitative study that considered both the clinician and the patient by Anderson, Kools, and Lyndon (2013). These researchers examined communication between physician-patient dyads about serious illness during hospital admission encounters. The researchers employed a grounded theory approach and dimensional analysis of audio-recorded admission encounters to examine the presence, or absence, of acknowledging the possibility of the patient dying. Encounters were completely open-ended and relied on the physician's standard practices. Audio recordings of 39 patients' admission encounters with 23 physicians were transcribed and analyzed.

The researchers observed intricate and dynamic interactions occurring between physicians and patients. These interactions involved cognitive and emotional aspects of communicating about serious illness. Furthermore, in conversations between physicians

and patients about serious illness, the researchers observed a continuum of acknowledging the possibility of death. This finding is complex and relevant because, as Anderson et al. (2013) observed, there appeared to be collusion between the physician and patient regarding acknowledging, or not acknowledging, the possibility of death. This collusion could have been embodied in verbal and nonverbal cueing that transpired within the patient-physician dyad. The cueing finding is also important because data from other studies revealed that verbally acknowledging the possibility of dying was a key to more effectively communicating about life-threatening illness and EOL care. Based on the literature, decisions about health care, ADs, and ACP, are frequently discussed without acknowledging dying or death, but how effective have these communications been?

#### **Models and guidance for clinicians for communicating about ADs and ACP.**

Several publications presented guidance for clinicians, offering models for the patient-clinician relationship. One such example was proposed by L. L. Emanuel, Danis, Pearlman, and Singer (1995). The authors proposed a set of five steps along with recommending skills to help clinicians facilitate the process of ACP. These steps begin with introducing the topic and engaging in what is referred to frequently in the medical literature as “information giving,” in which the clinician delivers medical information such as diagnosis, prognosis, and treatment outcomes, to the patient and the patient’s family. Next, the clinician is advised to facilitate discussion. Then, ADs are to be completed and recorded. The clinician then reviews and updates the ADs. Finally, the ADs are to be applied to actual circumstances when needed.

The point at which the clinician must deliver bad news—such as a terminal diagnosis, a prognosis that includes short time to live, or imminent death—is a point at which ADs and ACP come to the foreground and warrant discussion. Based on a survey of oncologists conducted at an oncology-focused symposium in 1998, Baile et al. (2000) proposed the SPIKES protocol, a six-step protocol for delivering bad news. This protocol was directed toward physicians faced with delivering bad news, such as a cancer diagnosis, to patients and their loved ones. The protocol advised:

S—setting up the time to talk, which included advice about selecting the time, location, and setting for the discussion. P—assessing the *patient's* perception, I—receiving an *invitation* from the patient to deliver news (that is, asking the patient if they would like the information), K—delivering the *knowledge* and facts of diagnosis and prognosis, E—*empathetically* responding to the patients *emotional* reactions, and S—*Summarizing* the discussion and formulating a *strategy* for the future.

Another exemplary model that has been widely discussed as applicable to ACP is the Transtheoretical Model-Stages of Change (e.g., Bridle et al., 2005; Prochaska & Velicer, 1997; Westley & Briggs, 2004). This model is based on a stage theory of behavioral change. The model aims to facilitate behavioral changes. In this conceptualization, an individual progresses through a series of stages including precontemplation, contemplation, preparation, action, and maintenance. This model is applied to ACP as an attempt to understand and explain why individuals do or do not complete ADs and ACP, what underlies the timing in which an individual would complete their ADs and ACP, and how they would go about constructing their advance care plan.

In 2008, Back et al. extended the research conducted in earlier studies, exemplified in the work of Tulsky (2005) and Tulsky et al. (1998). These earlier studies examined physicians' communication with patients near the end of the patient's life. Back et al. (2008) offered clinicians guidance and identified a distinct set of core communication skills needed for conducting these discussions with patients. This publication discussed much of the previous work on the topic and provided additional historical and cultural context such as briefly reviewing some history about the development and evolution of ADs and ACP and touching on bioethics involved in delivering difficult diagnoses and prognoses, and treatment planning.

Sudore and Fried (2010) challenged the traditional objective of ACP, which they contextualize as pre-specifying treatment preferences. They say this is inappropriate and impossible to accomplish. They draw on earlier research that demonstrated in general people have a difficult time imagining a hypothetical future in which their capacity is diminished (e.g., Ditto, 2009; Ditto et al., 2005). Sudore and Fried contended that people have an even more difficult time imagining care they would want in such a situation. This is due in no small part to the fact that most people do not understand the implications and outcomes of complex, advanced, modern medical treatments. They offered specific steps to help patients and surrogates navigate in-the-moment decision-making regarding medical care. They recommended choosing an appropriate surrogate, and importantly, establishing leeway for the surrogate decision maker, clarifying the patient's values. They also encouraged clinicians to assess the patient's readiness, or lack of readiness, to engage in ACP. They offered theoretical concepts, but did not offer much in the way of guidance or models for the patient-clinician relationship.

In this section I have reviewed publications that offered guidance and conceptual models for clinician-patient communication about ADS and ACP.

Next I will present exemplary reviews of the literature.

**Recent reviews.** A representative sample of recently published reviews was selected for inclusion in this review. These reviews were selected because they provided a germane overview of the current state of discourse about ADs and ACP.

In 2013 Séchaud, Goulet, Morin, and Mazzocato conducted an integrative review of the literature that aimed to describe the evolution of, and identify concepts, trends, models and experiments that support the paradigm shift from, conceptualizing planning for EOL medical care from ADs to ACP. The researchers' focus was on the impact of this shift to ACP on institutionalized older people. The researchers reviewed 23 articles published between 1999 and 2012. They concluded that quality of life as delineated by the patient is the best guide to ACP. Another conclusion was that the biomedical approach was overused and this approach did not adequately address the quality of life concerns of patients and their families. This review further established the results of many other studies that examined communicating about ACP from the perspectives of professional caregivers and confirmed the results of previous studies that have examined communicating about ACP from the perspectives of patients, their loved ones, and those designated as surrogate decision makers in DPOA-HCs. This review further established the need for a relational approach to communicating about ACP in order to meet patient needs and desires for medical care through EOL until death. This review also demonstrated the need for psychologists to become active participants in communicating about ADs and ACP.

Bensing, Rimondini, and Visser (2013) conducted an overview of papers submitted for a special issue of a publication that examined patients' experiences of medical consultations. Researchers used both quantitative and qualitative methods. The review identified two primary trends that emerged according to research method used. The data from quantitative studies identified participant experiences of medical consultations as information giving sessions. Data from qualitative studies showed participants placed an importance on warmth, personal attention, and empathy. The reviewers concluded that if patients are not limited by pre-structured questionnaires, but are allowed to express themselves via open-ended responses, participants stressed importance of "fostering the relationship" (p. 288).

In the previous section I have briefly identified reviews of contemporary literature that capture present-day research examining patient-clinician communication about ADs and ACP. Legal scholars, clinicians, and bioethicists (e.g., L. L. Emanuel et al., 1995; Halpern & Emanuel, 2012) have weighed the force that ethical principles and legal authority have wielded on ADs and ACP. Next I will present a recent study that discussed ethicolegal issues, that is the underlying ethical issues, which inform legal aspects of clinicians' approaches to communicating about ACP.

**Ethicolegal issues in healthcare.** Cooper and Buckner (2013) described ethicolegal issues as those issues that involve ethical and legal considerations when settling on a course of action regarding meeting basic human needs and health care decision-making including completing ADs. The models clinicians use to conceptualize the patient-clinician relationship influence communication about ACP. Historically these models have been based on ethics of paternalism. Cooper and Buckner defined

paternalism as “the practice of health care personnel making decisions for a patient without consideration of the patient’s wishes” (p. 3). They noted this has been a primary concern for elderly patients. They investigated the perspectives of elders as they received health care and affirmed that for elders, paternalism by caregivers has continued to be problematic. They speculated that clinicians’ paternalistic responses to patients have continued to underlie a trend exemplified in this study, in which only 37 percent of elders chose a doctor with whom to discuss ADs. Participants consisted of a convenience sample of 9 Caucasian individuals between the ages of 67 and 95 years who were patients in a for-profit hospital. Data were obtained via interviews using an investigator-designed tool, the Perspectives Regarding Elder Care Issues (SPRECI) questionnaire, comprised of eight open-ended questions about general nursing care, basic needs, understanding, decision-making, and ADs. Themes that emerged from the results included a desire for care to be holistic, more collaboration between patients and their families, and a reduction in paternalism. Historic research (e.g., Phillips, 1987; K. V. Smith, 2005) has documented that paternalism was the most central concern of elders about their caregivers. This study revealed that paternalism by caregivers is still occurring. Limitations to this study included a small sample size and using an investigator-designed tool, the Perspectives Regarding Elder Care Issues (SPRECI) questionnaire. While the researchers took care to have this tool reviewed for content validity it was not yet a standardized and normed instrument. Even so, the implications for care, reducing paternalism and centering care in the relationship between the patient and caregiver, are significant and worthy of future research.

**Literature review conclusions.** The literature on ADs and ACP has grown. Yet, in the Advance Directives and Advance Care Planning Report to Congress (Wenger et al., 2008) the authors noted that fewer than half of severely or terminally ill patients had ADs in their medical record and “among individuals with chronic illnesses, only one in three completed an advance directive” (p. 13). Additionally, the authors observed studies have suggested, “two thirds of physicians whose patients had advance directives were unaware of the existence of those documents” (Wenger et al., 2008, p. 13).

Researchers have used quantitative and qualitative methods to examine the complex aspects of communication between clinicians and patients and patient advocates about ADs and ACP. Studies have primarily been designed to focus on either the clinician, by specialty, or on specific patient populations, or patient advocates. Small sample populations and self-selection of participants has been a limitation of research. Specific attributes of sample populations have limited generalizability of results. Despite limitations, researchers have concluded that complex interpersonal interactions occur between clinicians and patients and that cognitive and emotional aspects of communicating about serious illness are salient for both patients and clinicians.

Some studies have indicated the presence of collusion between patient and clinician, and of a continuum of acknowledging, or omitting from consideration, the possibility of death in patient-clinician communication. Research also revealed clinicians’ avoidance of communicating about ACP, and even more important, a failure by clinicians to acknowledge the possibility of death. Yet, these findings have remained largely unidentified and unarticulated. At the same time, other studies have revealed that verbally

acknowledging the possibility of dying was a key to communicating about life-threatening illness and EOL care.

Notwithstanding the research, questions remain. How can members of the American public feel more comfortable discussing and documenting their medical care choices? How can clinicians feel more comfortable discussing ADs and ACP with patients and their proxies and loved ones? How does communication between patients, their loved ones, and professional caregivers, and advocates, about ACP transition from superficial, incomplete, and inaccurate, to a shared, accurate, discussion that includes acknowledgement of dying as a possible, even inevitable, outcome? These are but a few of the unanswered questions concerning communicating about ADs and ACP.

### **Statement of the Problem**

Due to the widespread use of life-sustaining medical interventions, clinicians, and patients and their loved ones and advocates routinely face daunting decisions about what medical treatments to use and when to use them. ADs and ACP can reduce unwanted overtreatment and ensure that patients get the care they desire (Jecker, 2014) when honored. Therefore, the underuse of ADs and ACP has real consequences for patients, their loved ones, and the clinicians who provide care. Yet, due to lack of understanding, anxiety, confusion, and uncertainty, members of the general public fail to engage in communication about ADs and ACP and fail to name a health care advocate (Detering et al., 2010; Levi & Green, 2010; Sabatino, 2010; Teno & Lynn, 1994; White & Arnold, 2011).

This confusion and anxiety is further exacerbated because previous models for conceptualizing the patient-clinician relationship have been based on philosophical and

ethical principles of paternalism, autonomy, and beneficence.-These models have engendered a clinical distance that has presented obstacles to relationality in the patient-clinician relationship.

No less important, clinicians often do not receive necessary training to develop their therapeutic communication and reflective practice skills. Consequently, clinicians often fail to facilitate communication with patients and their loved ones about ADs and ACP that can (a) help patients name an advocate, and (b) formulate advance directives based on the patient's values, beliefs, and goals of care before medical care and the advocate are needed (e.g., Detering et al., 2010; Volandes et al., 2009).

Moreover, the universal human fear of death (Becker, 1973, p. xvii; see also Hughes, 2003), in combination with the pervasive clinicians' perspective that a patient's death is tantamount to the clinicians' defeat has reinforced the general avoidance of discussing and planning in advance for medical care during the end of life and through death. When taken together, these conditions have inhibited clinicians' communication with patients and their loved ones about ADs and ACP. Therefore there is a need for a new model for the clinician-patient relationship and a new conceptualization of the clinician's role in facilitating communication about ADs and ACP.

### **Description of the Study**

By engaging in hermeneutic processes of interpretation I aspired to identify explicit phenomena and conditions, and discover implicit phenomena and conditions, that have interacted to inform current practices of communication about ADs and ACP in the patient-clinician relationship. I endeavored to make meaning of and contextualize the

ways in which these phenomena and conditions have interacted to inform current practices.

I focused my attention on scholarly and professional, practice-based health services literature. I also considered judicial and policy texts, and philosophical texts that have informed previous models of care.

I deeply engaged with these artifacts through iterative processes of critical reflection, interpretation, and synthesis. I used the recursive back and forth processes of the hermeneutic circle or hermeneutic spiral, (discussed in the Methodology Chapter), in which the whole is understood through reference to the parts, and the parts are understood through references to the whole.

As a result of these processes and in response to phenomena and conditions discovered during this study, I formulated a model of care. I then expanded the overall philosophical, theoretical, and practical frameworks that inform the model.

### **Areas of Inquiry**

1. What are some of the reasons why clinicians fail to facilitate communication with patients and their loved ones about ADs, ACP, and EOL care?
2. How might the above reasons for limited communication about ADs, ACP, and EOL care be addressed?
3. How might the frequency of communication about ADs, ACP, EOL care, and death among clinicians, patients, and their loved ones be increased?
4. How might we rethink theoretical conceptualizations of patient-clinician relationships? How can this reconceptualization be combined with clinical skills to help clinicians better and more frequently facilitate communication about ADs,

ACP, and EOL care?

5. How might training for clinicians (e.g., nurses, physicians, chaplains, social workers, and psychologists) to facilitate communication about ADs, ACP, and EOL care be improved?

### **Theoretical Framework**

In this chapter I present the theoretical framework that guides the approach to this study. First, I briefly present background on hermeneutics. Second, I present ontological hermeneutics as the overarching theoretical framework. Then I discuss application of hermeneutics to psychotherapy and medicine and in so doing lay the groundwork for my rationale for applying ontological hermeneutics to elicit understandings and improve practices, theoretical conceptualizations, and training for professional caregivers as they communicate with patients and their loved ones about ACP.

**Hermeneutics: Interpreting human experience.** “Humans beings are self-interpreting” (Taylor, 1985, p. 45).

Hermeneutics is concerned with the theory, art, practice, and process of interpretation. Many philosophers, researchers, scholars, and clinicians have written about the contributions of hermeneutics toward attaining deeper understanding of human experience, yielding a substantial body of literature. Ontology is the branch of philosophy concerned with the nature of being, questions about coming into being and the existence of entities. Ontological hermeneutics, then, is concerned with exploring, interpreting, understanding, and discovering meaning of the human experience of being. In this project I use an ontological hermeneutical theoretical framework. In this chapter I draw, albeit regrettably briefly, on the writings of a few authors who advocate for

applying ontological hermeneutics to research and clinical practices. In doing so, I draw on the landmark work of Richardson, Fowers, and Guignon (1999) who affirmed that ontological hermeneutics is a reflective practice that aims “to clarify the being of the entities that interpret and understand, namely ourselves” (p. 200).

Guignon (2002) noted hermeneutics is often “called the theory of interpretation” (p. 84). Stigliano described hermeneutics as “the practice of reflective interpretation” (1989, p. 47). Bernstein (1983) observed that hermeneutics helps to clarify and deepen our understanding of human existence. It is generally accepted in the literature that hermeneutics is grounded in the understanding that humans are “self-interpreting” (Taylor, 1985, p. 45). Ergo, understandings about the meanings of human experiences are arrived at through human apprehension, the process of making intelligible—interpretation.

Palmer (1969) traced the roots of the word “hermeneutics” to the Greek language and the word “hermeios,” which referred to the Delphic oracle who interpreted the messages from the gods for the humans. The word is also associated with verb “hermeneuin” and the noun “hermeneia,” and is associated with the messenger-god Hermes. Of Hermes, Palmer observed:

Hermes is associated with the function of transmuting what is beyond human understanding into a form that human intelligence can grasp. The various forms of the word suggest the process of bringing a thing or situation from unintelligibility to understanding. The Greeks credited Hermes with the discovery of language and writing—the tools which human understanding employs to grasp meaning and convey it to others. (p. 13)

Hermeneutics was introduced, along with semiotics, into Western philosophy via Aristotle’s work *On Interpretation*, and was a component in Plato’s dialogues. Plato

contrasted interpretive ways of knowing, hermeneutics, with sophia, knowledge via establishing truth value.

Traditionally, hermeneutic theory was applied to sacred texts, to gain deeper understanding of Biblical texts. As such, hermeneutics has roots in midrash and the rabbinic tradition of talmudic interpretation, or talmudical hermeneutics, (Cushman, 2011; Thiselton, 2009). Later hermeneutics was applied to study of the Bible, in Biblical hermeneutics (Jasper, 2004). Through late antiquity and into the medieval period, hermeneutics continued to be applied to exegesis of the Torah and later to the New Testament.

**Modern hermeneutics.** In the preface to his book, Mueller-Vollmer (1988) identified the beginning of modern hermeneutics in the early nineteenth century and noted, “With Schleiermacher, modern hermeneutics begins (p. xi).” Mueller-Vollmer chronicled the development of the Continental scholarly tradition of hermeneutics into the twentieth century with Dilthey, Heidegger, and Gadamer, all of whom, Mueller-Vollmer (1988) stated, “succeeded in transforming hermeneutics from the study and collection of specialized rules of interpretation for the use of theologians or jurists to that of a genuine philosophical discipline and general theory of the social and human sciences” (p. ix). Hermeneutists approach most anything—a situation, or an artifact such as a work of art or a judicial code—as a kind of text to be interpreted. Hermeneutics also calls attention to context. In so doing, hermeneutics attends to social, cultural, historical, and political aspects of what is being interpreted.

Mueller-Vollmer (1988) identified two distinct phases in the development of the modern German hermeneutic tradition: the “philological” that is represented by names

such as Schleiermacher, Ast, Droysen, Humboldt, and Boeckh and the “philosophical” phase or school of thought, which includes Dilthey, Husserl, Heidegger, and Gadamer (p. x-xi). The hermeneutic tradition has continued to evolve with the work of contemporary Anglo-American philosophers (e.g., Davidson, McDowell, Rorty, and Taylor), and within Continental discourse (e.g., Habermas, Apel, Ricoeur, and Derrida).

Mueller-Vollmer (1988) observed that in our current era, “hermeneutics denotes a concern that is shared by members of such diverse fields of knowledge as philosophy, sociology, history, theology, psychology, jurisprudence, literary criticism, and the humanities at large” (p. ix). Philosophers and scholars have applied the hermeneutic theory of interpretation to an array of subjects, including psychology (e.g., Cushman, 1995; Richardson et al., 1999; Sugarman & Martin, 2010) and anthropology (e.g., Coombe, 1991; Ulin, 2001).

Today, hermeneutics is understood as a multifaceted discipline. Major hermeneutic traditions include textual, critical, philosophical, phenomenological, and ontological hermeneutics. The hermeneutic theory of interpretation is applied to written, verbal, and nonverbal communication as well as to other artifacts, artistic and aesthetic creations (e.g., films, art, literature), and practices (e.g., nursing, medicine, psychotherapy, law). Hermeneutics has been used to interpret psychological, social, cultural, and religious phenomena. Hermeneutics has also been used to attain deeper understanding of the nature of the self (Cushman, 1995), personal existence (Guignon, 2002, 2004; Martin & Sugarman, 2001; Richardson & Fowers, 2010), and relationships (Sugarman & Martin, 2010). Hermeneutics is applied in order to uncover meaning. Examples Leder (1990) offered include “a literary work to uncover its meaning and

poetic structure; a judicial code, to determine the application of law; a set of scientific data, to find explanatory regularities” (p. 10).

Sugarman and Martin (2010) note that today, hermeneutics is concerned “particularly with the interpretation of what it is to be human and how human understanding is possible” (p. 164). Guignon (2002) writes: “Hermeneutic philosophers attempt to identify “traits that determine optimal human functioning” and a conception of “what it is to *be* a human”(pp. 94-95). Hermeneutics thus offers a means for interpreting, understanding, and finding meaning in the very fact of being. Indeed living is an interpretive endeavor. I interpret the numbers on the clock to determine what time it is. I interpret the sun in the sky or the clouds to signify the weather. Leder (1990) summarized: “Only via ceaseless acts of interpretation do my encounters with the world become coherent and meaningful events” (p. 10). The act of interpreting reveals meanings and truths of living. So we see hermeneutics is a process, not a method, but an attempt to understand, make meaning, and interpret the human experience.

**Hermeneutics and psychotherapy.** Martin and Sugarman (2001), Sugarman and Martin (2010), and others (e.g., Cushman, 1995; Messer, Sass, & Woolfolk, 1988; Richardson et al., 1999) have encouraged applying hermeneutics to psychotherapy because such an approach allows for deep reflection on therapeutic practices. As Martin and Sugarman (2001) observed, Cushman (1995) argued for applying hermeneutics to psychotherapy in order to “help both therapists and clients oppose the status quo by assisting them to think historically, culturally and critically” (2001, p. 199). Reflecting on the means of therapeutic practice should be a constitutive part of living as a whole while

also interpreting the historical, cultural, social, political, and economic aspects of life (Cushman, 1995; Guignon, 2002).

**Hermeneutics and medicine.** Since communicating about ADs and ACP involves discussions about medical care it is helpful to consider the ways in which hermeneutics has been applied to medicine. In many ways, hermeneutics and medicine are a natural pair. Leder (1990) noted, “medicine is a hermeneutical enterprise par excellence. Most simply, the health care practitioner interprets the patient’s signs and symptoms, to ferret out their meaning, the underlying disease” (p. 10). According to Leder, the clinician interprets the “‘experiential text’ as lived out by the patient; the ‘narrative text’ constituted during history-taking; the ‘physical text’ of the patient’s body as objectively examined; the ‘instrumental text’ constructed by diagnostic technologies” (p. 9). In addition to interpreting a patient as a text, in this approach, the patient is understood within their context of being.

Philosophers, ethicists, nurses, and physicians are among the authors that have discussed applying hermeneutics in philosophy of medicine, medical scholarship, and medical practice. Hermeneutics has been used to find meaning in (e.g., Leder, 1990; Marcum, 2012), and gain deeper understanding of (e.g., Daniel, 1986), the patient-physician relationship. Hermeneutics has also been used in order to examine the patient’s experience and meaning (Daniel, 1986; Rosenberg, 1995), to understand the patient’s experience of living with serious chronic illness (e.g., Benner et al., 1994; Öhman, Söderberg, & Lundman, 2003), to examine nursing science and nursing practices (e.g., Benner, 1994), and to examine methodologies in nursing research (e.g., Annells,

1996; Draucker, 1999), as well as to assist in formulation of medical ethics and bioethics (e.g., Svenaeus, 2003; Thomasma, 1994).

### **Importance of the Study**

More than half of Americans transition to chronic and terminal illness without having completed ADs and ACP. Previous models for conceptualizing the patient-clinician relationship have failed to support clinicians in communicating with patients, their loved ones, and health care advocates about ADs and ACP.

In response to these phenomena and conditions the primary finding of this study, the IRMOC, offers a new conceptualization of the patient-clinician relationship in which communication about ADs and ACP takes place. This study then contextualizes and expands on this model. In this way, this study can: (a) lead to an increase in the frequency, and enhance the quality, of communication about ADs and ACP within the clinical relationship; (b) reduce the number of patients who transition into physical and mental incapacity and enter EOL care without having named a health care advocate and without having ADs in place; and, (c) help more patients receive their desired level of care, no more and no less, as they near the end of their life and through their death.

### **Definitions**

In some cases definitions provided here appeared in my previous work (e.g., McCune, 2007, 2011, 2012, 2013, 2014; Rogne & McCune, 2014). They have been rewritten here, but the general ideas are contained in my previous work.

- advance care planning (ACP) is a process of considering, documenting, and discussing one's preferences for medical care should one be unable to speak, and advocate for one's self.

- advance directives (ADs) are documents including Durable Power of Attorney for Health Care (DPOA-HC) and Physicians Orders for Life-Sustaining Treatment (POLST) that tell professional caregivers which treatments one wishes to receive or forgo if one is dying, unconscious, or otherwise unable to speak and advocate for oneself. These documents are usually added to a patient's medical chart.
- allow natural death (AND) orders. This is another advance directive document that is an alternative to the do not resuscitate (DNR) designation. The patient documents for caregivers that they wish to forgo CPR and prefer a natural death.
- a priori is from the Latin translated as from the one before. It refers to an observation or experience or trait that is deemed to be valid independent of the observer or observation.
- artifacts are things created by humans, such as objects, texts, or works of art, that are understood to reflect characteristics of human life, including social, cultural, historical, and political aspects of the situation that is being interpreted.
- autonomy is a bioethical concept that aims to ensure the patient is making an informed, un-coerced decision. Clinicians have held this respect for patient autonomy as an important aspect of conceptualizing the patient-clinician relationship.
- beneficence is an ethic that values taking actions for the benefit of others. These actions are taken on behalf of another to prevent or remove them from

harm. In a beneficence model of care, such actions are taken by the clinician to prevent or remove harm to the patient.

- Bioethics is a term used interchangeably with “medical ethics,” a branch of ethics that emerged in response to, and considers, ethical dilemmas that arise from technological advances in biology and medicine. Bioethicists consider ethical questions of medical policy, politics, law, philosophy, and questions of values that arise from providing medical care.
- cardiopulmonary resuscitation (CPR) CPR is an emergency procedure applied when a person is in cardiac arrest. CPR comprises chest compressions and artificial respiration.
- cotransference Orange (1995, 2006) introduced the term *cotransference* to describe influences of the clinician’s history and personality that help them to empathetically understand the patient’s experience.
- countertransference is a psychoanalytic concept first identified by Sigmund Freud (1905/1955). This is the practitioner’s, often unconscious, reactions and feelings toward the care recipient and their transference. Countertransference emanates from both professional training and personal experience. While historically seen as problematic, today countertransference is generally understood to be useful therapeutically (see also transference).
- dialogue is recognized as a central process of hermeneutics. Gadamer (1960/2006) developed this concept, which has roots in the Platonic-Aristotelian tradition, and later in the work of Hegel and Heidegger. Gadamer encouraged the use of dialogue as a process that encompasses the discursive,

dialogic, and conversational character of exchange, engagement, and encounter with difference. In such an encounter one embodies openness to the understandings of the other. In this way, making meaning, interpreting, and understanding can occur through a shift in perspective, what Gadamer called “a fusion of horizons” (see also Cushman, 1995, in press; Richardson et al., 1999; Stern, 1991, 2010).

- do not resuscitate (DNR) order is a legal order usually documented in the patient’s chart that informs caregivers the patient does not wish to undergo CPR.
- Durable Power of Attorney for Health Care (DPOA-HC) is a legal document that authorizes a person to handle health care matters on another’s behalf. In the event that the person completing the document, also known as the “principal,” should become physically or mentally incapacitated and unable to speak for herself or himself about their desires for care, the person designated in the DPOA-HC can speak or advocate on the principal’s (patient’s) behalf.
- epistemology is the philosophical study of knowledge and understanding and inquiry into how they are acquired. Questions considered include what do we know, and how do we know what we know? Historically, epistemology has also included distinguishing opinions, beliefs, and justifications from true, rational, knowledge.
- ethics is a branch of philosophy concerned with identifying, recommending, and defending morals and values and how they inform right and wrong conduct, the best way for humans to live and act in specific situations. Ethics

comprises philosophical ethics, moral philosophy, moral theory, and ethical theory.

- fore-structures of understanding are a priori structures, also known as prejudgments or prejudices, such as values, beliefs, practices, and social, cultural, historical, and political influences, of which the interpreter may not be aware, but are nevertheless always present. Being aware of them helps one better interpret social phenomenon by understanding one's limitations and realizing the contributions of historical traditions of one's thinking. They are required for, and allow one, to interpret external phenomena (see also prejudices).
- fusion of horizons is obtained through the discursive, dialectic and dialogical engagement. The fusion occurs when one is willing to be open to challenge one's own views. To do so requires remaining open to the views of others and allowing the views of others to challenge, and change previously held views. When an agreement is reached between these views, new understanding emerges.
- Hermeneutics is the process of attempting to understand, make meaning, and interpret. Hermeneutists recognize there is interdependence between the interpreter and the interpreted. Therefore, hermeneuticists advocate bringing oneself into question in conjunction with all other questioning.
- hermeneutic circle (also recognized as the hermeneutic spiral) is the idea that the processes of interpretation and apprehending understanding are accomplished through cycles of a to-and-fro process in which the whole is

understood through reference to the parts, and the parts are understood only through reference to the whole.

- horizon is the concept in hermeneutics that the interpreter is located in a particular situation, a hermeneutical situation. As such the interpreter's understandings circumscribe the horizon. Their perspective is determined by the horizon that encompasses the hermeneutic situation in which the interpreter finds herself or himself. Therefore the interpreter's understandings, meanings, and interpretations depend on, and are limited by, the horizon, by the interpreter's perspective.
- intersubjectivity is a conceptualization that builds on the concept of subjectivity and allows for the recognition and integration of both the patient's and the clinician's unique and mutually reciprocal intersubjective experiences (see also subjectivity).
- ontology is the branch of philosophy concerned with existence, with being in the world and with questions about the coming into being and the existence of entities. ontological hermeneutics is an open-ended practice of reflective interpretation that attempts to understand and make meaning of the phenomena of human existence.
- paternalism is a model for the patient-clinician model founded on a "paternalistic" ethic based on the Hippocratic Oath. In this model the clinician is held in a position of authority and engages in practices of withholding information from the patient, such as terminal diagnoses, in order to prevent

distress and preserve hope. This has come to be identified as the paternalistic conceptualization of the patient-clinician relationship.

- prejudices are a priori structures of self-reference and self-constitution. These include values, beliefs, and practices, social, cultural, historical, and political influences of which the interpreter may not be aware, but are always present. They are required, and allow, for interpretation of external phenomena (see also fore-meanings).
- reflective practice is the self-reflective act of contemplating the clinical encounter with the intent to evaluate and continually improve the clinician's proficiency. Reflection has the intent to assess and search for meaning, and to understand how the clinician has been affected by, and has responded to, the patient and how the patient and clinician have influenced, affected, each other. In the process, clinicians ask themselves questions along the lines of: How have I been affected by this encounter with this patient? How has my personal past and professional training influenced my clinical receptivity and my responsiveness to this patient? (see McCune, 2014).
- relationality refers to a central focus on the relationship between patient and clinician and the recognition that both persons in the clinical relationship mutually influence each other (see also relational theory and intersubjectivity).
- relational theory is a body of psychological theory that recognizes the importance of the patient-clinician relationship and acknowledges the importance of reciprocal mutual influence in the clinical relationship. Relational psychological theory is founded on mutual respect for the

subjective realities of both participants in the relationship and the understanding that contexts of relatedness, mutual influence, and interaction between people are crucial.

- researcher's stance is formulated within, and is dependent on, the horizon that circumscribes the hermeneutic situation—the situatedness, and the location—of the researcher. This stance comprises the pre-judgments and fore-meanings the researcher, the interpreter, holds. This stance is to be interrogated and changed when appropriate.
- therapeutic communication skills are effective ways of listening and responding in clinical relationships. They include appropriate levels of emotional involvement, positive regard for others, recognizing non-verbal communication skills, and acknowledging feelings of both parties.
- transference is a psychoanalytic concept first identified by Sigmund (1905/1955). The term refers to the often unconscious phenomenon in which patients transfer feelings toward persons who were important early in the patient's life to the therapist (see also countertransference).
- Physician Orders for Life-Sustaining Treatment (POLST) is a form completed by patients facing chronic or serious illness and signed by their medical provider to document which types of life-sustaining treatment the patient does or does not want to receive. The form is printed on brightly colored paper or card stock and is placed in a strategic place in the patient's home, usually posted on the refrigerator. A copy is also placed in the patient's chart.

## **Methodology**

“The reality is the interpretations which we make. This is why the distinctions we use are not merely theoretical categories, but an ontology—a determination of what things there are in the world” (Stigliano, 1989, p. 62). In this chapter I present ontological hermeneutics as the overarching philosophy for this study. First, I consider aspects of ontological hermeneutical study that abjure using a prescribed set of routine methods or procedures. Then, I identify specific dynamics of hermeneutics that apply to this study including the dialogic nature of hermeneutics, and the fusion of horizons. Finally, I take up the hermeneutic circle and hermeneutic spiral.

### **Ontological Hermeneutics as Practice, Process, Approach, and Engagement: Not a Method**

It is important to note that some researchers have used hermeneutic approaches that included step-by-step methods or procedures. Such has been the case in qualitative research. In qualitative approaches, researchers have used phenomenological hermeneutics that employed methodological procedures for interpreting interview transcripts (e.g., Lindseth & Norberg, 2004). Some clinicians have also advocated using interpretive procedures, such as applying the fourfold approach to biblical exegesis, as procedures for interpreting the patient as a text (e.g., Daniel, 1986).

But these phenomenological and textual branches of hermeneutics are not the branches of hermeneutics used in this study. The methodology used for this project is ontological hermeneutics. In contrast to other hermeneutic traditions, ontological hermeneutists makes a point of not prescribing an a priori, step-by-step method.

**A quest for certain knowledge and the truth.** “Devising rules for interpreting humans is impossible . . . The whole fascination with method is a by-product of the very scientism being called into question” (Richardson et al., 1999, p. 200).

Epistemology is the branch of philosophy concerned with the study of knowledge and understanding and how they are acquired. The epistemological underpinnings and philosophical assumptions that underlie research methodologies are frequently overlooked. However, this is a problem. The epistemological underpinnings of research designs are shaped by inherent but unidentified assumptions that result in present, yet frequently unrecognized, methodological flaws that can lead to inaccurate conclusions (e.g., Bernstein, 1983; Bishop, 2007; Polkinghorne, 2006).

Since Plato’s time, Western philosophical thought has been occupied with what Dewey (1929) succinctly called “the quest for certainty.” The quest for certainty of knowledge and truth has been central to many disciplines including mathematics, religion, and the natural sciences. The quest has been undertaken by applying the scientific method, comprising quantitative methodologies in which knowledge and truth are objectively identified and verified through measurement, reasoning, and rationality. Of this tradition, Stone observed: “Reason has always been central to knowing” and importantly, Stone also observed that reason “became an end in itself” (2008, p. 265).

This tradition follows from the writings of Descartes, Hume, Locke, and Kant. According to Stone, in this tradition, “*the answer to the quest*” (2008, p. 264) has been sought through the scientific method, rationalism, empiricism, idealism, and positivism.

The social and human sciences, which emerged during the 19th century and continued to evolve throughout the 20<sup>th</sup> century, have also assumed the existence of a

certain truth and knowledge certainty, and have employed the scientific method in the quest for them. However, during the past century several philosophers in the continental and Anglo-American traditions advocated for giving up the quest. They believed that the rational, scientific method could not account for, or aid in, understanding the complexity of human experience.

In contrast to applying an a priori method to find the one truth, ontological hermeneutists recognize there is no one truth, and there is no one method for discovering a single truth. Ontological hermeneuticists work within a paradigm that contends that meaning, deepening understanding, and revealing truths cannot be accomplished by method. As Stigliano wrote: “Hermeneutics is not a ‘methodology’ in the sense that experimental research is” (1989, p. 47). Contrary to studies conducted within rationalist, behaviorist, and empiricist traditions, ontological hermeneutics does not employ—and in fact eschews—a strict set of step-by-step methods.

Hermeneutics, and ontological hermeneutics, is used in this study because, as Spence (1988) observed: “a simple positivism is no longer sufficient” (p. 64). Spence reminds us here that a world view based on definite assurance, on the quest for certain knowledge and one objective truth, such as comprises the world view of rationalist, empiricist, and scientific approaches to research, is not only an impossibility, but continuing to work within this world view conceals more accurate, if not so neatly categorized realities. In furthering this perspective, which disavows the scientific, rationalist project, Spence draws on the writing of Manicas and Secord (1983) who observed: “It is by now commonplace that there is no such thing as a non-interpreted ‘given’ that can serve as the foundation of knowledge” (p. 410).

So, although contrary to the approach to most dissertations and theses, no prescribed step-by-step method was employed in this study. If there were a method for this study, it would comprise the aspects of interpretation that ontological hermeneutics emphasizes: Dialogue, horizon and fusion of horizons, and the hermeneutic circle. These are processes of engagement. They do not constitute step-by-step methods. In the next section I will discuss the processes of ontological hermeneutics. The first of these will be hermeneutic dialogue.

**Hermeneutic dialogue.** Christopher, Richardson, and Christopher (2000) described hermeneutic dialogues as “the living process of dialogue,” a process of “attempting to understand or make sense of the meanings, interpretations, and commitments of others, especially when they differ from our own.” (p. 18). They portrayed dialogic understanding as “a kind of interplay between *openness* and *application*” (p. 18).

Drawing on the writing of Gadamer (1960/2006) Christopher et al. (2000) observed that the beginning phase of openness “rests on the assumption that we do not have any corner on the truth and that others might have important things to say to us” (p. 18). And, referring to Warnke, Christopher et al. noted: “Genuine openness to any meaning or claim actually involves granting it provisional authority (1987, p. 167ff) to challenge our beliefs and prejudices.” Stigliano (1989) noted that in a hermeneutical study, it is dialogue that “invites conflicting interpretations,” and “posing and rejection of relevant counter-interpretations; the offering and analysis of contrasting and/or conflicting interpretations is the method, the ‘doing’ of sound hermeneutical work”

(p. 53). It is also understood among hermeneutic thinkers, as Christopher et al. (2000) affirmed, that any effort at this “will always be partial and incomplete” (p. 18).

**Hermeneutic horizon and fusion of horizons.** The hermeneutic horizon refers to hermeneuticists’ recognition that the interpreter is located in a particular situation—situated within a particular horizon. In this conceptualization one’s perspective circumscribes the horizon in which one finds oneself.

As Christopher et al. (2000) relate, highlighting the work of Gadamer, a fusion of horizons occurs “when we can adopt such a stance of respectful openness to the Other; when we grant others the provisional authority to challenge our own most deeply held values and assumptions” (p. 18). Fusion of horizons is attained through the discursive, dialectic, and dialogical engagement processes that hermeneutics recognizes. The fusion occurs when one is willing to be open to challenge one’s own views. To do so, one remains open to the views of others, and allows the views of others to challenge and change previously held views. When an agreement is reached between views, new understanding emerges; this is the fusion of horizons.

But how is interpretation accomplished? How is a fusion of horizons cultivated? The hermeneutic circle or spiral will prepare the way.

**The hermeneutic circle/hermeneutic spiral.** Hermeneuticists recognize the ever-present phenomena of human interpretation and encourage an ongoing practice whereby one can seek to attain ever-deepening understanding. Toward these ends, hermeneuticists emphasize the idea that interpretation and understanding are accomplished through cycles of a to-and-fro process in which the whole is understood through reference to the parts, and the parts are understood only through reference to the

whole. This to-and-fro process of interpretation and attaining understanding is known as the “hermeneutic circle” (see also Dreyfus, 1991; Hamacher, 1990; Risser, 1997).

Cushman characterizes this as a “tacking back and forth between the part and the whole” (1995, p. 4).

Thiselton (2009) described the hermeneutic circle as analogous to putting together a jigsaw puzzle. We look at each piece, but only “as the larger picture emerges can we be sure about where the piece belongs and what it signifies” (p. 13). Thiselton also presented the term Grant Osborne has used, “the hermeneutic spiral,” which is the title of Osborne’s (1991) book on hermeneutics. Osborne used the term because, according to Thiselton, it “denotes an *upward and constructive* process of moving from earlier pre-understanding to fuller understanding, and then returning back to check and to review the need for correction or change in this preliminary understanding” [emphasis in original] (p. 14). And, “this dialogue between pre-understanding and understanding merges into a further process” (p. 14). This process yields understanding of the whole picture. Thiselton concluded, “We cannot arrive at a picture of the whole without scrutinizing the parts or pieces, but we cannot tell what the individual pieces mean until we have some sense of the wider picture as a whole (p. 14).

**Conclusion.** Conducting a study through a process—not with a method—required a willingness to live with uncertainty. Much like the processes of living and dying. The hermeneutic process is mysterious and will continue to unfold. In concluding this chapter I draw on the work of Caputo (1987).

Finally, we come up against the mystery itself, the unencompassable [sic] depth in both things and our non(selves). And then we are brought up short. That it seems to me is where hermeneutics leads us: not to a conclusion which gives comfort but to a thunderstorm, not to a closure but to a dis-closure, an openness toward what

cannot be encompassed, where we lose our breath and are stopped in our tracks, at least momentarily, for it always belongs to our condition to remain on the way. (Caputo, 1987, p. 214)

And the way never ends. Richardson et al. (1999) referred to this as a “circularity that is built into life itself” (1999, p. 204). They also pointed out that this circularity is “built into all inquiry” (p. 207). As a consequence of this circular nature of existence and inquiry, especially in the human sciences, researchers “can never achieve final closure in their investigations” (p. 207). Hermeneuticists value the process of engaging in the ongoing, never-ending, processes of discovery. Hermeneutists recognize that processes of discovery are endless. Discovery is a spiral: Never-ending, ever moving, ever deepening, and ever growing. More understandings can always be discovered. More insights can always be gleaned. More meaning revealed. In respect to this understanding, I acknowledge that the results presented herein are understood to be only a snapshot of one moment on the way that never ends. I eagerly anticipate the next, newly revealed understanding, even though it may contradict all that has come before. And, as psychotherapists know, even when change is good, it is still disruptive. We shall see what discoveries await. In this chapter I have presented the methodological framework for this study. In the next chapter I will present the findings of this study.

## Findings

“What one has at the end of a hermeneutical study is a body of distinctions which make a given practice or network of practices possible” (Stigliano, 1989, p. 66).

In this ontological hermeneutic study I sought to discover distinctions that have made possible current practices of communication about ADs and ACP in the patient-clinician relationship. I endeavored to make meaning of and contextualize the ways in which these distinctions—phenomena and conditions, gaps and limitations—have interacted to inform current practices.

I focused my attention on scholarly and professional, practice-based health services literature. I also considered juridical, legislative, policy, and philosophical texts that have informed previous models of care.

I interpreted these artifacts by deeply engaging with them through iterative processes of critical reflection, interpretation, and synthesis. I used the recursive back and forth processes of the hermeneutic circle or hermeneutic spiral, the to-and-fro process in which the whole is understood through reference to the parts, and the parts are understood through references to the whole.

As a result of these processes, I identified a body of distinctions—explicit phenomena and contextual conditions that emerged as core themes, which echoed through the literature. I also discovered tacit phenomena and conditions that, while having remained largely unacknowledged until now have nevertheless influenced practices of patient-clinician communication about ADs and ACP. I recognized that current models of care needed to be refined to be more useful than previous models.

Given the evidence, I developed a conceptual explanation of the phenomena and conditions and offered a response. I formulated a new model for the patient-clinician relationship, the IRMOC, within which practices of communicating about ADs and ACP could be enhanced. I then considered the IRMOC (McCune, 2014) to expand and make more nuanced the overall philosophical, theoretical, and practical frameworks that informed my formulation of this model. Next I present the distinctions—the phenomena, conditions, and themes that emerged as a result of this study.

### **Phenomena, Conditions, and Practices**

“A hermeneutical analysis would be successful not if its results corresponded to an independent reality, since there isn’t any such item . . . but whether it opens the world to being redesigned (if only in principle)” (Stigliano, 1989, p. 62).

This study revealed a number of closely related phenomena, conditions, and practices that underlie the underuse of ACP, ADs, and naming of health care advocates. These factors fall into eight categories: (1) difficulty in handling questions about ADs and ACP; (2) lack of awareness of how ACP can best be used; (3) clinicians’ avoidance of discussions about ACP; (4) inadequate communications training for clinicians; (5) the standard practice of administering advanced medical care; (6) the failure of previous models of care to support communication about EOL care, ADs, ACP, dying, and death; (7) the nearly-universal anxiety and fear of death inhibiting patient-clinician communication; (8) American cultural fears about of dying and death.

First, research reveals that people have difficulty both asking and answering important questions about end-of-life care planning for themselves and for their loved ones (e.g., Levi & Green, 2010). Some authors have emphasized this is due in part to the

difficulty of imagining a hypothetical future including disease symptoms and conjecturing which treatments one would desire to receive or decline (e.g., Ditto, 2009; Sudore & Fried, 2010).

Second, among members of the general public and, even more alarming, among clinicians there is a lack of awareness of how the advance care planning process can best be conceived, documented, and used (e.g., Fagerlin & Schneider, 2004; Levi & Green, 2010; Sabatino, 2010). Ahluwalia et al. (2013) pointed out that providing practical guidance for conducting discussions about ACP, which as the authors note, can be “difficult and time-intensive discussions” might increase use of ACP. However, they continue, “little guidance regarding the structure and process of an ACP discussion exists” (p. 200).

Third, clinicians frequently avoid end-of-life discussions, even though research has documented that patients and their loved ones are more satisfied when they have an opportunity to have conversations about end-of-life care, ADs, and ACPs with their health care providers (e.g., Volandes et al. 2009).

Fourth, as Detering et al. (2010) and Kessler et al. (2009) have observed, clinicians are frequently not trained to facilitate communication with patients and their loved ones about ADs, ACP, EOL care, and death. This lack of training is due, in part, to reliance on previous models used by clinicians to conceptualize the patient-clinician relationship based on beneficence, paternalism, autonomy, rights, and objectivity, (see for example Schermer, 2003; D. G. Smith & Newton, 1984).

Fifth, as Chapple and Pettus (2014) pointed out there is a prominent ideology of rescue in the U.S. health care system. That is, providers apply advanced medical care

during advanced stages of disease as well as in emergency situations as an unconscious reflex. This rescue trajectory is compelling for clinicians, patients, and their loved ones (see also Chapple, 2010). Our current medical culture and health care system appear driven by heroic use of all available medical care to rescue all patients, and prevent, or at least delay, deaths in all situations and at all costs. As a result, “death seems distant from everyday life, bolstered by the “‘mythology’ of CPR” (Chapple, 2010, p. 3; see also Timmermans, 1999). Accompanying this rescue paradigm is the pervasive view that a patient’s death is the clinician’s defeat (e.g., Beckstrand et al., 2006), leaving little room for asserting the necessity of ACP.

Sixth, previous models of care have devalued the relational aspect of care and compassionate human engagement between clinician and patient in favor of proceduralized technical care. These conceptualizations have emphasized a natural sciences model that valorizes procedures and technology as models of caring for human beings.

Seventh, humans possess an innate knowledge of the inexorability of death. The struggle with this innate knowledge is in dissonance with the human biological drive toward staying alive. These conflicting dynamics can create paralyzing terror evoked by thinking about, discussing, facing, reckoning with, and planning for, death.

Eighth, modern-day American culture reflects, transmits, and reinforces unconscious and conscious ideas and fears about dying and death. Taken together, the previous eight factors are interwoven with Western society’s predisposition to avoid discussions about death and medical care before death.

These phenomena and conditions reflect, produce, and perpetuate practices that lead the general public, patients, and clinicians to circumvent the existence of mortality and avoid communicating about ADs and ACP. When ACP does take place, its historically legalistic structure has circumscribed communication throughout the process in particular ways that have presented a challenge to the efficacy of the process. The overarching problem is that denying the inevitability of death forecloses opportunities for communicating about death, ADs, and ACP that can inform and lead to better-quality living through the last phase of life and lead to better dying. In response to these distinctions—phenomena and conditions, gaps and limitations—I formulated the IRMOC.

### **Primary Finding**

“The role of a relational model is to interpret what is transpiring in a relationship” (D. G. Smith & Newton, 1984, p. 48).

Previous models of care have resulted in what Glass (1996) classified as “a narrow focus on the biology of disease that ignores psychosocial factors and inhibits forming the kind of personal relationship with the patient that enhances effective diagnosis and treatment” (p. 147). These models have largely failed to incorporate hermeneutic interpretation, intersubjective and relational understanding.

Advocates—including physicians, nurses, and medical ethicists—have called for a model of care that stresses the importance of relationship and compassion. In response, as result of this study, I formulated the IRMOC, applied this model to communicating about ADs, ACP, and EOL care in the patient-clinician relationship, and expanded on the formulated model. The IRMOC acknowledges:

- The provider of care and the recipient of care affect each other. Through their relational engagement, and as a consequence of this engagement, change occurs within both people.
- Patients and clinicians both bear formulated and unformulated (Stern, 2010) experiences and feelings about facing, questioning, reckoning, and planning for death, which in turn inform their approaches to communicating about EOL care, ADs, and ACP.
- Compassion can enhance the clinical relationship in which clinicians facilitate communication about ADs and ACP.
- Counter- and cotransference can inform, enhance, and inhibit communication about ADs and ACP.
- Reflective practice can help clinicians understand and address counter-and cotransference.
- Communication occurs in verbal and non-verbal modalities in all relationships, including the patient-clinician relationship.
- Therapeutic communication skills can help clinicians facilitate communication about ADs and ACP.

Below is the IRMOC.<sup>1</sup>

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The following is adapted and expanded from a previously published book chapter titled “Worlds of Connection: Applying an Interdisciplinary Relational Model of Care to Advance Care Planning” in *Advance Care Planning: Communicating About Matters of Life and Death* (pp. 139-154). Editors: Leah Rogne, PhD, and Susana Lauraine McCune, MA, CT. New York: Springer Publishing Company. Copyright 2014. Reproduced with the permission of Springer Publishing Company, LLC (see Appendix B). ISBN: 9780826110213

## **Worlds of Connection: Applying an Interdisciplinary Relational Model of Care to Communicating About End of Life**

### **Death Is Not the Enemy**

“Eventually, all living things die” (A. Kellehear, personal communication, August 1, 2011).

In a segment on the cost of dying, the American television program *60 Minutes* reported: “All research conducted in this area has concluded that every human will ultimately die” (Kroft, 2009). Death is a human universal. Death is inclusive. Death is multicultural and multiracial. Death is not ageist or sexist. Death is the great equalizer. Death impacts everyone who is living, and does so during all phases of the lifespan. Why then is modern American society so resistant to discussing death and the truths of aging and medical care that bring us to death? Our current medical culture and health care system appear driven to use all available medical care to prevent, or at least postpone, all deaths in all situations and at all costs.

In America today, advanced medical technologies can extend life almost indefinitely. Sulmasy (2002) commented that “Today’s health professions seem to have become superb at addressing the physical finitude of the human body. Previously lethal diseases have either become curable or have been transformed into the chronic” (p. 24). Sulmasy notes here that while medicine has advanced to the point of being able to cure many lethal diseases, one effect of such advances is the current high prevalence of chronic diseases. This means that while more people are living longer, experiences of disease and frailty that lead to physical and mental incapacity over an extended duration of the lifespan are now common patient experiences that require long-term planning.

Even though advanced medical technology has been able to cure deadly diseases and postpone death, the prominence of chronic diseases and new choices about which technologies to use and when to use them requires longer-term attention. This requires all of us, including clinicians, to give more attention to the prospect of extended medical care over a longer period of life. This in turn requires that clinicians be able to address the needs of whole human persons, and not just give attention to producing physiological effects on parts of the finite body that are most visibly affected by disease. However, contemporary medicine, as Sulmasy stated, “still stands justly accused of having failed to address itself to the needs of whole human persons and of preferring to limit its attention to the finitude of human bodies” (p. 24).

Holistic treatment of patients can help counteract the body-bound, or strictly physiological, understanding of the patient that technology has encouraged. Sulmasy (2002) observed that “genuinely holistic health care must address the totality of the patient’s relational existence” (p. 24). Total care of the patient must also account for the ways in which the patient exists in relation not only to his or her disease, but also to the myriad factors—not solely the physical, but also the psycho-social dynamics that structure the patient’s life. Sulmasy goes on to say that “the fundamental task of medicine, nursing, and the other health care professions is to minister to the suffering occasioned by the necessary physical finitude of human persons, in their living and in their dying” (p. 24). Toward this end, Sulmasy advocates a more comprehensive model of care that takes account of patients in the “fullest possible understanding of their wholeness—as persons grappling with their ultimate finitude” (p. 24).

A person's quest for psychological and existential meaning in the face of their finitude continues across the lifespan (Reker & Chamberlain, 2000). The challenge for clinicians then is to recognize that companionship—accompanying—a patient as he or she conceptualizes and develops an advance care plan—a plan for dying and death—is as important as companionship a patient in developing a plan of care for curing disease—a plan for living.

Toward these ends, this study presents the Interdisciplinary Relational Model of Care<sup>©</sup> (IRMOC) as a theoretical framework that aspires to support clinicians' ability to engage with patients and their loved ones about advance care planning (ACP) for end-of-life (EOL) care and, in so doing, improve the quality and increase the frequency of communication about ACP. The IRMOC brings together theoretical concepts and clinical skills that have until now been regarded and employed disparately. When applied together, these concepts and skills can help clinicians feel more comfortable and confident conducting, and thus better facilitating, more frequent communications about ACP.

Presenting the IRMOC, I begin with a discussion of the historical impact that the presuppositions of objectivity, paternalism, and autonomy have had on patient-clinician models of care in which ACP takes place. Next, I consider the ways in which these presuppositions inhere in and perpetuate dynamics that relational psychology understands as counter- and cotransference (Orange, 1995, 2006). Then, I present emergent understanding from contemporary relational psychological theory that emphasizes compassion as a fundamental element in the patient-clinician relationship (Orange, 2006). This is followed by an overview of reflective practice and therapeutic communication

skills that can help clinicians facilitate communication about ACP. I conclude with a summary and a case study demonstrating the need for the IRMOC and ACP.

### **Beyond Objectivity, Paternalism, and Autonomy**

“The ‘objectification myth,’ which requires psychological distance in professional relationships is detrimental to the patient and impairs clinical empathy” (D. G. Smith & Newton, 1984, p. 57).

The birth of modern science began with the scientific and philosophical revolution of the seventeenth century, catalyzed by the work of philosopher Renee Descartes. Bordo (1987) observed that Descartes’ “seventeenth-century rationalist project” has brought forward the “objectivist, mechanist presuppositions of modern science” (p. 1). Objectivity holds that each person exists independently of each other, and that people are able to be, view things, and interact with others independent of—detached from—their emotions, thoughts, and biases. Bordo notes that since the seventeenth century, “The Cartesian epistemological ideals of clarity, detachment, and objectivity” have remained “largely unquestioned” (p. 4). As such, the presuppositions of clarity, detachment, and objectivity have become the underlying assumptions that have shaped the modern era. These ideals have also informed theoretical conceptualizations of the patient-clinician relationship, and influenced formulation of models of care. These models of care have been predominately based on what Bordo labeled “absolute epistemic objectivity” (1987, p. 2). That is, previous models of care have been based on the assumption that certain knowledge and independent truth exist and this knowledge and truth can only be accessed through objectivity.

The philosophy of objectivity is not the only or the best approach to caring for human beings. History demonstrates how over time, along with objectivity, the moral principles of paternalism and autonomy have also informed conceptual frameworks for models of care and paradigms for the patient-clinician relationship (Roter, 2000; Schermer, 2003; D. G. Smith & Newton, 1984). At the beginning of the 20<sup>th</sup> century, the patient-clinician model included a “paternalistic” ethic and physician privilege, which were based on the Hippocratic Oath. According to the paternalistic ethic, in this paradigm the professional care provider was held as an objective “authority” that delivered information, and power relations (E. J. Emanuel & Emanuel, 1992; Roter, 2000) inherent in the clinical relationship were not acknowledged.

Developing in parallel with, and in response to, paternalism, models for the patient-clinician relationship evolved that emphasized the role of patient autonomy. The principle of autonomy underscores the patient’s right to make her or his own decisions about care (Schermer, 2003; D. G. Smith & Newton, 1984).

Models of care based on patient autonomy also emphasize the clinician’s nondirectiveness and value-neutrality (Wachbroit & Wasserman, 1995). The clinician’s value-neutrality is based on the underlying assumption that the clinician can be “objective” and in so doing, the clinician’s objectivity facilitates upholding a clinical distance to ensure that the clinician does not interfere with the patient’s autonomy.

These three paradigms have thus at times intertwined and reinforced each other. In the objectivist, paternalist, and autonomous models, the clinician’s and the patient’s lived experiences are partitioned off from each other. The “autonomous patient” remains independent of the “objective clinician,” and thus, the illusion of separateness is

perpetuated. In this view an assumption of the existence of an external reality that is observable from a state of objectivity is not only understood as possible, it is valorized.

### **The Myth of Clinical Distance**

“Our training has not prepared us to see, grasp, experience the patients’ reality. Instead, a clinical distance between our patients and us is encouraged, to provide a professional, ‘objective’ standard for the encounter” (D. G. Smith & Newton, 1984, p. 50).

D. G. Smith and Newton (1984) elaborated on the limits of objectivity and clinical distance, asserting, “Attempting to adhere to the professional requirement of objective distance in the clinical relationship may be more harmful than frankly acknowledging the realm of the intersubjective between physician and patient” (p. 53). At worst, the philosophy of clinical distance inhibits patient-clinician relationships and effective treatment. Roter (2000) observed that the presuppositions of objectivity and clinical distance have been “fundamental in directing medical inquiry away from the person of the patient to the biochemical and pathophysiology of the patient” (p. 6). This reductionist focus, according to Glass (1996), “ignores psychosocial factors and inhibits forming the kind of personal relationship with the patient that enhances effective diagnosis and treatment” (p. 147). Objectivity and clinical distance are thus revealed to reduce the relationship between clinician and patient to an observer and an object that is observed.

So inherent is this way of seeing that Western thinkers are mostly unable to separate themselves from it. As a consequence, clinicians have failed to acknowledge any limits of a natural sciences model that assumes objectivity and a separation—a clinical

distance—between object and subject, between patient and clinician. By caring for humans using a model that is based on objectivity and clinical distance, clinicians have excluded from care the value of lived human experiences and relationships.

However, D. G. Smith and Newton (1984), an internist and a philosopher, recognized that “the old ‘objective’ medical tradition, which aims to separate me from my patient, is invoked as a mechanism—a very ineffective mechanism—to prevent such entanglement of our lives” (p. 53). D. G. Smith and Newton concluded: “The myth of clinical distance between the patient and the physician is, after all, only a myth” (p. 53). It becomes clear then that the notion of a clinician who is isolated, maintaining clinical distance from the patient, and who is sustaining the myth of objectivity, emerges as just that—a myth.

Orange observed that in the clinician-patient relationship, relationality can “help free us from our enslavement to a natural-science model” and point us toward a theory for conceptualizing the clinical relationship that offers clinicians “an alternative to tempting reductionisms” (Orange, 2011, p. 15). When the patient-clinician relationship is seen in light of these emergent theoretical understandings, the illusions of applying a natural sciences model that is based on objectivist, reductionist approaches to human beings, and the ideas of clinical distance and scientific objectivity, fall away.

In contrast to objectivity, subjectivity describes the presence of one’s personal thoughts and emotions, and one’s unique personal reality. D. G. Smith and Newton (1984) captured the subtle, yet important, aspect of subjectivity in the clinical relationship: “To understand the patient, the physician must *see* the patient, which

requires personal contact with the sphere of the subjective, a difficult skill to learn or teach” (p. 57).

Intersubjectivity extends subjectivity by recognizing the interactive features of human relatedness. The paradigm of intersubjectivity acknowledges that relational interactions between people take place within an intersubjective sphere that is comprised of each person’s subjectivity.

A new model for the patient-clinician relationship, the IRMOC aims to account for the importance of intersubjectivity. The IRMOC conceptualization stresses the importance of understanding the unique intersubjective experiences of the patient and the clinician and the mutual influence they have on each other. This paradigm also values and calls attention to the meaning of relationship. In this way, instead of emphasizing paternalism, objectivity, autonomy, and clinical distance, this new model recognizes the mutually reciprocal intersubjective spheres of engagement—the worlds of connection—between the patient and the clinician, and in so doing encourages mutual trust, the awareness of suffering, and compassion.

### **A Shift to Relationality: Applying the Interdisciplinary Model of Care (IRMOC)**

Relationship is one member of humanity sharing their humanity with another member of humanity. As a result of this study I call for a parallax—a shift of perspective—in the theoretical paradigm for the patient-clinician relationship. In this new concept, the clinician is no longer the distant and objective authority in charge of making a patient well, and delivering information unidirectionally, as in the paternalistic model. Neither is the clinician the authority who listens unidirectionally, leaving the patient to make his or her “autonomous” choices in a vacuum, as in the autonomy model. Rather, in

the IRMOC, the clinician is encouraged to shift his or her self-conceptualization—to begin to see his or her self as a professional who compassionately companions—or accompanies—the patient and does so with awareness of the ways in which the clinician is affected by the patient, and the patient is affected by the clinician. Such a shift can underscore the importance of relationality that is conditioned by—but certainly not limited to—medical professionals’ concern with improving the body’s condition. In so doing, the IRMOC suggests that a focus on relational psychological theories that incorporate counter- and cotransference, compassion, and therapeutic communication skills might help establish the intersubjective relationship as the basis of advance care planning situations.

The IRMOC is a model for conceptualizing the patient-clinician relationship that is based in relational psychological theory (e.g., Aron & Harris, 2005, 2011; Mitchell & Aron, 1999). Relational psychological theory is grounded in “respect for the personal realities of both participants” (Stolorow, Atwood, & Brandchaft, 2004, p. xii) and the understanding that contexts of relatedness and interaction between people are crucial.

This body of theory recognizes the importance of the patient-clinician relationship and acknowledges the importance of “reciprocal mutual influence” (Beebe & Lachmann, 1988, p. 37; see also Stolorow, 2004). Drawing on relational theory, the IRMOC allows for the recognition and integration of both the patient’s and the clinician’s unique and mutually reciprocal intersubjective experiences. In so doing, the IRMOC aims to undo the illusion of separateness and instead, re-centers the focus on the relationship between patient and clinician.

In addition to a focus on relationship, the IRMOC encourages compassion and conversation in the spirit of discovery as a means of reaching mutual understanding about the patient's desired medical care, which is then documented through the process of ACP. The IRMOC also calls for reflective practice to help clinicians' transference and countertransference. The aim of the IRMOC is not to require all care providers to become psychologists, but to recognize that clinicians can provide better care for the whole person with the aid of some understanding of vital psychological concepts.

Some might see the highly specific goals of care in psychotherapy as not always fitting the needs of clinicians facilitating communication about ACP in medical settings—settings in which at times a flurry of activity is occurring and quick life-and-death decisions may need to be made. However, psychological concepts are valuable in ACP. Psychological services are useful for individuals who wish to make thoughtful plans about their own future care (Haley, Larson, Kasl-Godley, Neimeyer, and Kwilosz, 2003). Additionally, Haley et al. argue that psychology is not usually recognized as a part of the current paradigm for medical care. The omission of psychology in medical care and advance care planning situations may result in a gap in finding solutions that meet the psychological needs of patients.

### **Unspoken Clinical Realities: Transference, Countertransference, and Cotransference**

“Everyone is much more simply human than otherwise” (Sullivan, 1953, p. 32).

*Transference* and *countertransference* are psychoanalytic concepts first identified by Sigmund Freud (1905/1955). *Transference* refers to the phenomenon in which patients

transfer feelings toward persons who were important early in the patient's life to the clinician. The American Psychological Association *Dictionary of Psychology* defines *countertransference* as the clinician's "unconscious reactions to the patient and to the patient's transference" (VandenBos, 2007, p. 239). Psychoanalytic theories, along with definitions of transference and countertransference, have evolved during the past century since Freud coined the terms. Today, relational psychological theory acknowledges that, as Stolorow, Brandchaft, Atwood, & Lachmann (2000) observed, "transference and countertransference together form an intersubjective system of reciprocal mutual influence" (p. 42). This mutual influence can manifest as the clinician's countertransference. In relational psychological theory countertransference is not seen as taboo in the patient-clinician relationship, but is seen instead as an instrument that is necessary to the relationship, as a means to inform the clinician's understanding.

Countertransference can arise for clinicians due to the non-reciprocal professional duty to care that is intrinsic to caring professions. Silver (1999) observed that while transference and countertransference exist in all human relationships, transference and countertransference are "most notable and potentially problematic in those relationships involving the "imbalance of power" (p. 265) inherent in the "power relationship of caring professions" (p. 267). These professional relationships—relationships in which the obligations and duty of caring are one-sided—can invite misplaced emotional responses and countertransference. Non-reciprocal professional relationships include nurse-patient relationships (O'Kelly, 1998) doctor-patient relationships (Stein, 1985), and relationships between social workers and patients (Berzoff & Kita, 2010), among others.

According to Silver (1999) countertransference emanates from both professional training and personal experience. It is therefore important for clinicians to recognize that their history, including personal experiences and professional training, “filters, informs, and organizes” their perceptions and responsiveness to patients (Orange, 1995, p. 63). Orange parses further the clinician’s responses to the patient and the clinical setting and proposes that clinicians reserve the term “countertransference” for the clinician’s “reactive emotional memories that interfere with empathetic understanding” and “optimal responsiveness” to the patient (1995, p. 74). In contrast to countertransference, Orange introduced the term *cotransference* to describe influences of the clinician’s history and personality that help them to empathetically understand the patient’s experience “through our [the clinician’s] own equally subjective experience” (1995, p. 66). Orange (1995) concludes: “We must know and acknowledge our [clinicians’] cotransference, our point of view or perspective, if we are to become capable of empathy” (p. 71).

Another source of counter- and cotransference can emerge from projection bias (Loewenstein, 2005). Projection bias occurs when one attempts to predict how another will behave, yet errs in the prediction as a result of underestimating or overestimating “differences between oneself and others” (p. 99). In the case of ACP, the clinician may project his or her own projective biases into the ACP process.

One last yet important point about counter- and cotransference as conceptualized by Orange (2006) is that the clinician’s “self-expectations” are vital. Orange reminds us, as she reminds herself that, at times, “there is no way to fix the situation or ‘cure’ the patient, so I must accept my own powerlessness to help” (p. 16).

Counter- and cotransference are important in discussions about ACP because contemplating end-of-life care and facing mortality, whether one's own or that of another, can evoke existential anxiety, fear, and uncertainty in both the patient and the clinician. Attempting to maintain assumptions of objectivity, paternalism, and autonomy can camouflage the clinician's self-expectations, projection biases, feelings of powerlessness, and unconscious death anxieties. If these hidden assumptions remain unidentified and unacknowledged, they can lead the clinician to, perhaps unwittingly, project his or her own values into the patient's ACP process. The clinician may also defend against his or her own anxieties and fears about death. As a result, rather than helping the patient develop and document their advance care plans, the clinician may unknowingly influence the patient's ACP formulation or avoid discussions about ACP, planning for EOL care, and death altogether.

Consequently, the IRMOC challenges clinicians to endeavor to recognize the ways in which their self-expectations and personal views accompany, or are perhaps hidden by, assumptions from medical training and previous experiences. Relatedly, the IRMOC asks clinicians to reflect on the ways in which countertransference and projection bias can inadvertently influence the ability to facilitate communication about ACP with patients and their loved ones.

### **Reflective Practice: Discovering Countertransference and Cotransference**

Counter- and cotransference involve personal matters, which can have public implications. These dynamics may at times either hinder or help a clinician's ability to facilitate communication about ACP. Only when counter- and cotransference are identified and understood can professionals ensure that they have made every effort to

provide the best professional care assisting patients in developing their advance care plans. Therefore, clinicians must be able to identify the ways in which their personal experiences and professional training are impacting their clinical practice. At the same time, clinicians must both respect these experiences and advocate for the patient's advance care plans. To do this—specifically, to identify and address counter- and cotransference—requires reflective practice.

Reflective practice is the act of reflecting on the clinical encounter with the intent to evaluate and continually improve the clinician's proficiency. Reflection has the intent to assess and search for meaning, and to understand how the clinician has been affected by, and has responded to, the patient (Freshwater & John, 2009; Ruth-Sahd, 2003). In the process, clinicians ask themselves questions along the lines of: How have I been affected by this encounter with this patient? How has my personal past and professional training influenced my clinical receptivity and my responsiveness to this patient? How have these affected my ability to engage in communication about ACP? In prompting these questions the IRMOC promotes moments of quiet introspection and encourages compassion for both the patient and for the clinician.

### **Compassion in the Clinical Relationship**

“We will have to struggle with ourselves and suffer with our patients. Compassion means suffering with” (Orange, 2011, p. 188).

Orange (2006) advocates for clinicians to restore compassion to a central role in the patient-clinician relationship (p. 7). She goes on to observe that in everyday English, “compassion” often connotes “pity or sympathy” and thus compassion could also imply the act of “being-nice-to-patients” (p. 14). However, the IMROC's conceptualization of

compassion goes beyond this everyday understanding. In keeping with Orange's interpretation, the IRMOC draws on the etymology of the word. The Latin origin of *compassion*, as Orange reminds clinicians, is *suffering with*.

Orange (2006) noted that, complementarily, the Latin origin of the word *patient* is *patior: to suffer, or undergo*. Thus, "A patient is one who suffers, who bears what feels unbearable" (p. 15). In relationship to the patient, who is bearing what feels unbearable, the clinician's compassion is thus "a suffering-with, a being together" (p. 15). The author concludes that compassion is "a way of being-with" and is "both process and attitude" (p. 15). Orange advises, if "we are not too intent on naming pathologies and defenses or being right, but instead relentlessly seek to understand and accompany the sufferer, an implicitly interpretive system emerges" (p. 15). By seeking to understand and accompany—to *suffer with*—the patient (*the sufferer*), the clinician can help mitigate remaining echoes of paternalism and objectivity, and attenuate clinicians' tendency to "name pathologies," focus exclusively on physiology, and maintain the illusion of clinical distance. In this way, compassion can guide clinicians as they facilitate communication about ACP and EOL care.

In addition to facilitating better communication between patient and clinician, compassion is a more ethical way of being and, for clinicians, a more ethical way of acknowledging the importance of the clinician's relationality with his or her patients. Orange (2006) reminded clinicians that accompanying the sufferer is, "a way of being-with, not a formula" (p. 15). According to Orange, when the clinician treats a person as "endlessly worth understanding and his or her suffering as worth

feeling-together, this attitude of compassion implicitly affirms the human worth of the patient” (p. 15).

### **Compassionate Communication**

In the forward to his book, Knapp (2007) notes that therapeutic communication skills are “universal principles among health and human service providers” (p. xi). They are effective ways of listening and responding in clinical relationships (Hammond, Hepworth, & Smith, 2002). These skills have been posited for inclusion in training curricula for nurses (Kluge & Glick, 2006) doctors (Back, Arnold, & Tulsy, 2009) social workers, and other helping professionals (Wolvin & Coakley, 1985). From a psychotherapeutic view Orange (2011) has advocated a “readiness to listen and learn from the voice of the other [the patient]—as a clinical philosophy” (p. 15). However, there has been historically a lack of clinical training in these skills.

Many clinicians provide exquisitely compassionate care and sensitively engage in communication with patients. Yet the literature demonstrates that this is not the experience of many patients or their loved ones (Tulsy, 2004). At the same time, therapeutic communication skills have been widely identified as crucial to building clinician confidence in that such skills can enhance ACP by augmenting clinicians’ interpersonal competence and increasing patient trust (Rodriguez et al., 2011; Skirbekk, Middelthon, Hjortdahl, & Finset, 2011). Improved therapeutic communication skills have also been shown to reduce professional health care providers’ anxiety (Back et al., 2009; Fried, Bradley, O’Leary, & Byers, 2005). Moreover, Levinson (1994) and Roter (2000) propose that clinicians improve their communication skills as a way to reduce malpractice suits.

Schaffer and Norlander (2009) offer eight principles that underlie therapeutic communication in the health care setting. Together, these principles provide a supportive framework for clinicians to draw upon when communicating with patients and their advocates and loved ones. These principles can help clinicians skillfully facilitate communication about ACP. Schaffer and Norlander's principles have been adapted here, in conjunction with other authors' recommendations, to the particular imperatives of ACP:

- Ensure privacy and adequate time for ACP discussions.
- Assess patients' and their loved ones' and advocates' understanding of disease processes, treatment options, and effects of treatment. Respond by providing accurate information about diagnosis, prognosis, and effects of treatment simply and honestly while avoiding euphemisms and medical jargon. Give broad, realistic (not overly optimistic) time frames for possible effects of diseases and treatments in order to help the patient and their advocates take full advantage of "relevant and accurate information about the medical details of various clinical conditions and treatments" (Ditto et al., 2005, p. 494) as they formulate and complete advance directives.
- Encourage expression of feelings and elicit patients' values, beliefs, and care goals as guides for formulating ACP (Doukas & McCollough, 1991).
- Be empathetic and embody both a process and attitude of compassion (Orange, 2006).
- Arrange for follow-up. This final point is particularly noteworthy in ACP situations.

Follow up in ACP is crucial because ACP is not a one-time event. Advance care plans should be revisited whenever patient's care needs, desires, and circumstances change.

An important additional component to the principles offered by Schaffer and Norlander, is found in the SPIKES Protocol (Baile et al., 2000), which encourages clinicians to ask open-ended questions to reach increased understanding. Clinicians often mistakenly believe that asking open-ended questions and cultivating deeper understanding requires more time than is available. However, Stewart, Brown, and Weston (1989) found that this is not the case if clinicians follow basic communication principles including paying attention to the patient's emotional schema, listening actively rather than controlling the discussion, and communicating empathetically.

It is also important for clinicians to recognize non-verbal communication cues—what Stolorow et al. (2002) have identified as “unconscious nonverbal affective communication” (p. 85), such as a glance away, a change of focus or facial expression, a shift in posture such as leaning forward, or a subtle turn away. It is vital for clinicians to explore with the patient what these non-verbal signals might mean—that is, engaging with the patient in dialogue with the aim of discovering the meaning of the unspoken. No less in importance, Orange advocates for “close and compassionate listening” (2006, p. 15). An attitude of compassion conveys to the patient, “You are worth hearing and understanding” (p. 16). These skills, individually and collectively, can help clinicians participate relationally and engage compassionately in dialogue with patients to help formulate their ACP. In so doing the clinician can engender and convey, as Orange advocates, both a process and an attitude of compassion.

### **Hope, Death, and Communication: Reflections That Inform the IRMOC**

“I see our intimate involvement with, and commitment to, our patients as requiring that we be partners with them in their struggles with often agonizing existential choices and predicaments” (Hoffman, 1993, p. 19).

The presence of death in life can evoke existential dilemmas and afford possibilities for completion, transformation, and transcendence (McCune, 2012). Understanding contained in the IRMOC, coupled with training in these areas: relational theory, counter- and cotransference, and therapeutic communication skills, can allow the existential dilemmas that can be evoked by advance planning for EOL care to emerge. Reflective practice can reveal and help clinicians attend to their own death anxiety and sense of personal loss—the cotransference—that can engender empathy and compassion. Moreover reflective practice can help clinicians attend to projection biases as well as to unconscious and problematic defenses—the countertransference—that can emerge when facing mortality and engaging in communication with patients about end-of-life care. In so doing the clinician can more ethically advocate for the patient’s ACP. The IRMOC can help clinicians engage in ACP with patients and their families by attaining deeper understanding of their role in the patients’ final journey.

The IRMOC is designed not be a final answer or a nostrum, but rather as a starting point for compassionate inquiry that acknowledges the worlds of connection in the patient-clinician relationship, and as a source of support for clinicians as they engage with patients in facilitating communication about, and developing advance care plans for, the journey to end of life—a journey that each of us will inevitably take and a destination at which each of us will ultimately arrive. Next I will present an exemplar demonstrating

one of the most important influences on my stance as a clinician and as a researcher in this project, my experience with my mother's end-of-life care and her advance directives.

### **Your Wish, My Command: Finding Solace in Advance Directives**

Portions of the following section have been adapted from a previously published article (McCune, 2012).

In 2003, we had celebrated my mother's 80th birthday. She had lived for over 25 years with a rare degenerative nerve disease. Her health was declining even further due to congestive heart failure. Her health care power of attorney designated me as her health care advocate, with responsibility to enact her advance directives.

My mother was in and out of the emergency room and intensive care repeatedly over the course of three months. During one of these episodes, I stood in the hospital hallway with the doctor. He said to me, "Your mother needs a feeding tube."

I dug down deep within myself and found the strength to say: "No feeding tube." He looked puzzled. I explained: "My mother has advance directives. No feeding tube."

"You're murdering your mother!" He shouted at me. His face and his words are emblazoned in my memory.

Companioning a loved one through illness is difficult. Serving as a health care advocate for the patient is also difficult. Finding oneself in both roles simultaneously—companioning a loved one who is ill, and being called to serve that loved one by advocating for his or her medical care—is a doubly difficult set of experiences. I experienced the burden of advocating for the medical care the patient, my mother, desired when these choices were not those typically condoned by the medical establishment, as embodied by the doctor at the helm of my mother's case. In both capacities, I suffered

from the clinician's failure to engage relationally through compassionate communication. The clinician failed to compassionately companion the patient, my mother, and her advocate, me, which would have helped ensure that the patient received no more, and no less, than her desired care.

Although years have passed since that day, I remain distressed by being accused of "murdering my mother." At the same time, I benefited at that moment from, and continue to find solace today in, the confidence my mother gave me to make decisions on her behalf through her advance care planning. I remain grateful for the gift of my mother's clear advance declaration of her choices for medical care and for her choices about how she wanted to die. She gave me the gift of a clearly thought-through and well-articulated position statement accompanied by clear communication about her values, EOL care goals, and choices for her death. As an advocate, I can't imagine making these difficult end-of-life care decisions on behalf of another without the gifts of certainty that my mother gave me by completing her advance directives, and communicating with me about her values, beliefs, and care goals.

I knew that advocating for my mother's choices meant she would die sooner. Yet, as the advocate my duty was to ensure her wishes were executed, rather than taking care of myself—delaying my grief about her death by postponing her death—by keeping her alive with a feeding tube she did not want. What my mother's specific EOL care choices were is secondary to the fact that she made her choices, communicated with me, her chosen advocate, about her choices, and signed papers to document her choices before they were needed. My mother was later diagnosed with dementia, yet she articulated and

documented her medical care choices while she was still able to make, articulate, and document them.

Subsequently, in my professional work providing psychological services with hospice I have sought to understand, through reflective practice, the ways in which my counter- and cotransference might influence my duty to advocate for patient's care choices. I continually seek to remind myself that regardless of the specifics of those choices, it is my duty to advocate for the patient's choices. In doing so, I have attempted to not impose coercively my personal values or beliefs, while striving to embody compassion and use therapeutic communication skills. I have attempted to recognize and understand the ways in which I have been affected by my personal past and psychological training and by my patients and their loved ones—my counter- and cotransference. These personal and professional experiences have contributed to development of the IRMOC, which I hope will offer a practical theoretical model that recognizes the influences of clinicians' personal and professional experiences, encourages reflective practice and careful listening, and inspires compassionate companionship in the clinical setting and ACP situations.

## Discussion

Say not, “I have found the truth,” but rather, “I have found a truth.” Say not, “I have found the path of the soul.” Say rather, “I have met the soul walking upon my path.” For the soul walks upon all paths. The soul walks not upon a line, neither does it grow like a reed. The soul unfolds itself, like a lotus of countless petals. (Gibran, 1972, p. 55)

In this ontological hermeneutic study I investigated scholarly and professional, practice-based health services literature. I also examined juridical, legislative, policy, and philosophical texts that have informed previous models of care. I engaged with these artifacts through iterative processes of critical reflection, interpretation, and synthesis. I used the recursive back and forth processes of the hermeneutic circle or hermeneutic spiral.

By engaging in these processes I discovered, made meaning of, and contextualized the ways in which phenomena and conditions, gaps and limitations, have interacted to inform current practices of communicating about ADs and ACP in the patient-clinician relationship. In response to the phenomena and conditions revealed during this study I formulated the IRMOC and then expanded and made more nuanced the philosophical, theoretical, and practical frameworks that informed formulation of this model.

## Limitations of the Study

### A Book Chapter

“A book must be the ax for the frozen sea within us” (Kafka, 1094, as cited in Pawel, 1984, p. 158).

Part of the results chapter for this dissertation is a book chapter in a previously published edited volume, titled *Advance Care Planning: Communicating About Matters of Life and Death* (Rogne & McCune, 2014). *Advance Care Planning* is a textbook intended for advanced undergraduate and graduate students in health care, nursing, anthropology, sociology, family science, gerontology, social work, medicine, bioethics, and psychology, as well as a text for educating professionals, such as physicians and nurses. Presenting the IRMOC in that 15-page chapter limited the breath and depth of material that could be presented about the IRMOC. That is why this study expanded the IRMOC and discussed the issues raised in more detail and with a more contextual perspective.

Due to the multidisciplinary nature of the audience for the IRMOC, students and clinicians in a variety of disciplines may not have a background in relational theory and psychotherapeutic practice, which are foundational to the IRMOC. They may also be unfamiliar with therapeutic communication skills, reflective practice, and compassion as processes that are central to the clinical relationship, all of which inform the IRMOC. Consequently, although it was intended as such, the IRMOC may not be readily adopted as a conceptualization for the patient-clinician relationship by clinicians in a multitude of disciplines.

### **Clinical Settings**

“Efforts to clarify the clinical situation should not ultimately obstruct the path which must be walked together” (D.G. Smith & Newton, 1984, p. 52).

The settings in which care is provided can influence the patient-clinician relationship and communication about ADs, ACP, EOL care, dying, and death. In medical settings frequently a frenzy of activity is occurring and treatment decisions need to be made and implemented quickly. These settings may not be conducive to in-depth communication, such as is required when communicating about the potentially anxiety-producing subjects of ADs, ACP, EOL care, dying and death. The limits of these settings may inhibit adoption of the IRMOC. Furthermore, there is a lack of protocols and guidelines in clinical settings to assist clinicians in discussing and documenting ADs, ACP, and EOL issues with patients, and their proxies, and loved ones. This may further inhibit adoption of the IRMOC.

### **Clinicians' Training**

“Our training has not prepared us to see, grasp, experience the patients' reality” (D. G. Smith & Newton, 1984, p. 50).

The dominant training curricula for professional caregivers poses challenges for adaptation of the IRMOC. Psychotherapeutic training usually includes education about self-reflection, meaning-making, and distinguishing culture, values, and beliefs, as intrinsic components of transference and countertransference. Clinicians in disciplines outside psychotherapy may not have received training in these processes, which may limit clinicians' understanding of, and ability and willingness to adopt the IRMOC.

### **Clinicians' Resistance**

“Our understanding of human nature will inevitably influence the way we understand the nature of illness, the provision of treatment and care, and the relationship between the patient and the provider” (Welie, 1994, p. 212).

Caregiving professionals can be uncomfortable with intimate relationships, especially when they include dying and death. Clinicians are frequently unwilling or unable to tolerate their personal anxiety and existential angst in the face of the uncertainty experienced by patients and their loved ones as they contemplate the need for end-of-life care and mortality. If a clinician has not faced the possibility of her or his own mortality it may be almost impossible for her or him to companion a patient and their loved ones as they engage in completing ADs and ACP and face EOL care and the possibility of dying and death. In such circumstances—when mortality enters the clinical relationship—professional adaptive defense mechanisms and personal countertransference can emerge in response to facing and fearing possibilities of dying and death, of both the self and another. Countertransference can emerge when mortality enters the clinical relationship. As a result, clinicians may resist engaging in relational-based communicating about ADs, ACP, EOL care, dying, and death.

## **Implications**

### **Hermeneutic Understanding**

The task of hermeneutics is to clarify this miracle of understanding, which is not a mysterious communion of souls, but sharing in a common meaning” (1960/2006, p. 292)

As suggested by the hermeneutic approaches reviewed in this dissertation, theories and models reflect ideas and practices of the societies from which they emerge. As such, they must be understandable within the social, political, economic, and in this case clinical, contexts at that moment in time. Similarly, a model of care is also circumscribed by, and is contingent on, clinical understanding of the contexts in which it is developed. Accordingly, the IRMOC is a response to and reflection of prevailing conditions, phenomena, and practices of care and communication about ADs and ACP in the patient-clinician relationship.

### **A Relational Model**

The person who is understanding does not know and judge as one who stands apart and unaffected but rather he thinks along with the other from the perspective of a specific bond of belonging, as if he too were affected. (Gadamer 1960/2006, p. 320)

At this moment in contemporary American society, models of care are frequently premised on the replication of a set of relations that enable and encourage clinicians to implement a prescribed, a priori, method or set of standardized techniques. The current predominant, and ever-increasing, proceduralization and industrialization of health care is driven by materialist, rationalist, and reductionist approaches that limit relational understanding of the patient-clinician relationship.

In contrast, the IRMOC does not provide a procedure or recipe, memorized scripts, or pre-determined responses for clinicians as is valued, and in some cases

required, by bureaucracies that enforce current emphasis on procedures. The IRMOC is a counter to the valorization of proceduralist, industrialist, and reductionist views of care.

### **A No Method Model**

“The truth of interpretation cannot be arrived at by means of a method” (Stigliano, 1989, p. 47).

Even as this study posits the IRMOC as the result, D. G. Smith and Newton (1984) identified “the peculiar role played by a ‘model’ in structuring human relationships” (p. 48). In line with their observation, the concept of applying a model to human relationships bears examining. They noted that “what models for relationship are acceptable will depend on the criteria of acceptability set by the larger society” and a relational model will be “understandable to the members of the society, including the parties to the relationship” (p. 48). In keeping with interpretive hermeneutic theory, D. G. Smith and Newton (1984) articulated the goal, which is, “to achieve a meaningful human-with-human caring reality—possibly without benefit of models at all” (p. 54).

Even though it is conceived as a model, the IRMOC is calling for no model, and is doing so at a time when professional caregivers’ roles are being circumscribed by increasing industrialization and proceduralization in clinical fields, which is occurring at the expense of clinical relationships. The result of this study, the IRMOC, is presented as a model, and it may be mistaken for a thing, or a procedure, rather than as advocacy for hermeneutic and relational processes to foster meaningful human-with-human engagement within the clinical relationship. Yet in view of the IRMOC, there can be no fixed models or procedures for relationship-based presence, reflection, compassion, and communication. By contrast to prevailing trends, hermeneutic understanding and

relational theory, which are central to the IRMOC, emphasize and reveal a dynamism that a proceduralized model cannot provide.

Instead the IRMOC recognizes the importance of clinicians being compassionately present within the dynamic and intersubjective nature of the clinical relationship. The IRMOC centers the focus on relationality, compassion, communication, and clinician's self-reflection, all of which are processes, attitudes, and ways of being, not things. These processes, attitudes, and ways of being cannot be manualized or proceduralized.

### **Recommendations**

“The way people enter into a conversation influences its outcome and that true change occurs only in the context of relationships” (Pipher, 2006, p. 89).

Previous models of care have failed to focus on the relational nature of the patient-clinician relationship. Consequently, the primary recommendation of this study is for improved training for clinicians. This training would offer a shift in the theoretical conceptualization for the patient-clinician relationship. It would re-center the focus on the intersubjective meeting of the clinician and patient and would encourage clinicians to engage in reflective practice to identify and address co- and countertransference. Training in therapeutic communication skills is also recommended. Lastly, but of no less importance is training that encourages clinicians to bring an attitude and process of compassion to the clinical relationship.

## **Future Research**

“We have to look deeply at things in order to see. When a swimmer enjoys the clear water of the river, he or she should also be able to be the river” (Nhat Hanh, 1987/2005, p. 71).

Today fewer than half of severely or terminally ill patients have ADs in their medical record. Additionally, when ADs are present, two-thirds of the time physicians are unaware of these documents in their patients’ charts. Future research is needed to better understand why. Further research on all of the phenomena, conditions, and practices comprising the findings of this study, would result in increased understanding and knowledge of communication about ADs and ACP, better training for clinicians, enhanced communication, refinements to the IRMOC, and improved provision of care.

Quantitative and qualitative studies can be undertaken that include members of multiple disciplines that frequently comprise the caregiving team, including physicians, nurses, social workers, psychologists, chaplains, professional assistants, and health care aids. Such work should include broader sampling, more randomization, and more relevant sampling criteria for participant selection and assignment. Prospective investigations could incorporate diverse settings and multiple locations. Longitudinal studies would be helpful for understanding how ACP changes over time.

**Legal considerations.** Legal considerations cannot be excluded from the patient-clinician relationship and communication about ADs and ACP. The legal, form-based approach to ACP often still guides, and at times is a barrier to, communicating about ADs and ACP. Despite sanctioning of ADs by the federal government, with legislation such as the PSDA, clinicians are not reimbursed for

communicating with patients and their loved ones and advocates about ADs and ACP. This lamentable systemic obstruction limits patient-clinician communication about these important subjects. Further research is needed to shed light on, and improve, juridical and legislative policies that guide ACP and ADs.

**Historical models.** Historical models clinicians have used to conceptualize the patient-clinician relationship have been based on paternalism, beneficence, autonomy, and objectivity. These models have failed to recognize the importance and impact of the relationship between clinician and patient, which research has shown is crucial for facilitating communication about ADs and ACP. Studies are needed to better understand the influences of models clinicians use to conceptualize the patient-clinician relationship, and how those models inform engagement and communication about ADs and ACP.

**IRMOC.** Intricate and dynamic interactions occur in the clinical relationship, especially when communicating about ADs and ACP. Yet much remains unknown about how professional caregivers can use the IRMOC. In the future, researchers can explore the efficacy of bringing the IRMOC, comprising relational dynamics, reflective practice, therapeutic communication skills, and compassion—as processes, not procedures—to the clinical relationship in which communicating about ADs and ACP takes place.

**IRMOC and curricula.** Future research can examine ways to develop curricula for professional caregivers' educational programs. These curricula would encourage the attitudes and processes comprising the IRMOC: Engaging in self-reflection to identify and address co- and counter transference, practicing therapeutic communication skills, and bringing compassion to the patient-clinician relationship.

**Collusion.** It is hoped that future researchers will seek to better understand why clinicians—physicians in particular—frequently fail to acknowledge the possibility of death when communicating with patients who are facing life-threatening illness. Similar efforts can be applied to patient education programs and non-professional caregivers, and members of the general public, as these are other areas that remain under-researched and poorly understood.

**Communication.** What is the best way to better understand the innumerable, complex communicative engagements between clinician and patient? Most of the research into clinician-patient communication has focused on clinicians, and particularly on physicians. Yet, we know that communication processes cannot adequately be researched or understood by focusing on only one half of a dyad. Instead, researchers, scholars, and clinicians may come to better understand communication skills, effects, processes, interpretations, and meanings through qualitative research methodologies. Such methodologies allow for focus on the interactive engagement that occurs in the relationship between clinician and patient. More research is needed to understand how clinicians and patients engage in relational communication, and to grasp how communication is understood and interpreted by both people in the relational dyad. Qualitative research, in particular, can contribute to teaching and evaluation of communication in the patient-clinician relationship. This research can inform development of more effective training programs for all clinicians as well as for non-professional care providers, including patients' loved ones and advocates.

In future studies, researchers can use quantitative and qualitative methods to better understand how communication between the patient and clinician can transition

from superficial, incomplete, and inaccurate, to a shared, accurate, relational discussion that can include acknowledgement of dying as a possible, and at times even an inevitable, outcome. Acknowledging or omitting considerations of death as a possibility on the continuum of care is key to communicating about ADs, ACP, and EOL care. Without this honesty, these all-important conversations will remain unspoken.

### **Summary and Conclusion**

“Understanding is a ‘relational’ way of being and knowing” (Orange, 1995, p. 15).

By using a hermeneutic approach I aimed to identify tacit and explicit phenomena, conditions, and practices of communication about ADs and ACP. I sought to gain deeper understanding of the patient-clinician relationship in which communication about ADs, ACP, EOL care, dying, and death can occur. In response to these discoveries, the primary finding of this study was formulation and expansion of the IRMOC. The IRMOC offers a new direction for clinical care. The IRMOC attempts to move beyond dualisms that focus on either the paternalism or objectivity of the clinician or the autonomy and rights of the patient by recognizing that care takes place in relationships. This study may help further the development and implementation of theoretical models and practice-based skills that can help clinicians provide, and help patients receive, care that allows people to live and to die according to their wishes.

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Appendix A

Results of Pubmed Database Search

For the Term “advance care planning”

Year of Publication	Number of Publications	
2014	145	partial year
2013	485	
2012	452	
2011	447	
2010	365	
2009	298	
2008	342	
2007	266	
2006	290	
2005	343	
2004	283	
2003	246	
2002	204	
2001	232	
2000	246	
1999	248	
1998	273	
1997	266	
1996	269	
1995	278	
1994	297	
1993	334	
1992	392	
1991	361	
1990	151	
1989	49	
1988	61	
1987	52	
1986	36	
1985	32	
1984	31	
1983	16	
1982	14	
1981	16	
1980	13	
1979	17	
1978	22	
1977	45	
1976	25	
1975	16	
1974	12	

1973	6
1972	1

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