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# The University of Southern Mississippi

# AGE, GENDER, RACE AND CULTURE IN THE ER: A CONTENT ANALYSIS OF END-OF-LIFE ISSUES IN THE TELEVISION DRAMA

by

# Katrina Wilson Burtt

Abstract of a Dissertation Submitted to the Graduate School of The University of Southern Mississippi in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

### **ABSTRACT**

# AGE, GENDER, RACE AND CULTURE IN THE ER: A CONTENT ANALYSIS OF END-OF-LIFE ISSUES

### IN THE TELEVISION DRAMA

# by Katrina Wilson Burtt

# May 2013

Within one of the most popular television dramas on American television, hundreds of depictions of end-of-life (EOL) care and decision-making conveyed impressions of how death and dying occurred in a hospital. This content analysis of EOL incidents that appeared in every episode of the television drama *ER* indicated that viewers got powerful messages about EOL. The long-playing, popular television drama exaggerated the role of physician within the EOL scenes and minimized the roles of women, racial minorities and ethnic groups. Notably lacking from the EOL content were accurate or positive representations of racial, ethnic or cultural differences in death and dying practices. The absence of these important distinctions in EOL effectively marginalized groups that have been at risk, historically, for receiving less or substandard health care services.

The American health care system as it exists, fit the definition of an Althusserian Ideological State Apparatus. The potential, therefore, exists for this newly-identified ISA to disseminate an EOL ideology calling for limits on care to the dying, through the mass communication structure. This study, however, did not reveal any substantial indication that fictionalized content about EOL fulfills that expectation. This study revealed previously-unidentified themes that recurred in the majority of the 222

end-of-life-incidents (EOLIs), most of which were about organ donation. Each of these three areas-- new themes, population differences in approaching EOL, and organ donation-- bear additional scrutiny to develop insight into how mass media portray them in dramatic television content.

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# DEDICATION

I dedicate this work to my son, Alex, to my mother, Catherine Wilson, and to the memory of my late father, Arnold Wilson.

# **ACKNOWLEDGMENTS**

I would like to acknowledge the guidance and patience of my dissertation committee chairwoman, Dr. Kim LeDuff. I appreciate most the encouragement she and Dr. Chris Campbell gave to me, in early discussions of this work. I owe Dr. Fei Xue for his enthusiasm and prodding me to *Just write*. I thank the remaining members of my committee, Drs. Cheryl Jenkins and Jun Heo, for their expertise, advice and support to achieve the best scholarship possible.

In my life, I have enjoyed the benefit of memorable teachers who have shown me what it is to learn, to search and to grow. I acknowledge two of them at the University of Southern Mississippi-- Dr. Mazharul Haque and the late Dr. Arthur J. Kaul-- for revealing new worlds that had been with me always, unseen.

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### CHAPTER I

### INTRODUCTION

This dissertation was a content analysis of the NBC primetime medical drama, *ER*, to examine end-of-life (EOL) content and to consider the presence of an EOL ideology that may be advanced by the health care system in the United States. For the purposes of this analysis, I asserted that the U.S. health care system is an Althusserian Ideological State Apparatus (ISA), and I deemed components of EOL care (identified in the body of health care EOL literature) as an adequate proxy for an EOL ideology. I wanted to understand better if television shows included content and portrayals that reflect what may be an evolving trend in EOL care. This trend included encouraging people to decide autonomously to limit their own life-sustaining treatment in certain circumstances and persuading families to discontinue life support of an affected family member, earlier at the end of life than has been experienced in the past.

The concept of EOL decision-making has acquired an acuity within American culture that was unprecedented. It appeared in news accounts, was studied by government bodies and panels, and was found in non-news content. Some of the interest in EOL was spurred by real-life situations, including the medico-legal cases of Karen Ann Quinlan (Gavrin, 2007), Nancy Cruzan and Terry Schiavo (Perry, Churchill & Kirshner, 2005) that received worldwide attention and publicity. Quinlan's family was not the first to struggle through EOL decisions, but they may have been the first one spotlighted in headlines. The Cruzan legal challenge set a U.S. Supreme Court precedent in deciding EOL care. Schiavo's case dominated print and broadcast for months, with congressional and White House interventions reported in 2005.

Televised EOL content could play a critical role in American society, as it may create expectations for viewers and prepare them to make decisions in accordance with the dominant power structure. My research impetus in health communication was spurred by professional experiences as a critical care nurse since 1991 and as an organ donation professional since 1997. In those years, I had either participated in or observed hundreds of EOL incidents in hospitals in two states and the District of Columbia. Some processes were codified in policy, but many depended on the idiosyncrasies of medical and nursing staffs for direction. In general, it was the topic avoided, with some health care professionals worried about offending or antagonizing families. After transitioning into organ donation advocacy, my practice was energized with concerns about EOL encounters, as a family's EOL experience can substantially affect the outcomes for organ donation authorizations. That is, families who were dissatisfied with their EOL experience were less likely to agree to donation. In some respects, organ donation professionals were left to re-interpret the EOL experience for families, before counseling them about their options for donation of the deceased patient's organs and tissues.

Along with the professional interest that I have in EOL care, insight into this content has become more important in contemporary culture, as it relates to increasing economic strains on the health care system. These pressures could ultimately make some patient populations, as well as racial, ethnic and cultural minorities, vulnerable to receiving reduced medical services. Some of the vulnerable patient populations consist of the aged, the critically ill, the poor, and those not competent to make their own decisions.

The Quinlan, Cruzan and Schiavo cases all involved patients reported to be in a "persistent vegetative state" who were receiving long-term care in a nursing-home setting. This description contrasted sharply with the vast majority of EOL care dilemmas

that occurred in the fast-paced setting of a hospital's intensive care areas. No judicial, legislative or media attention illuminated these prosaic predicaments in which families and patients had to render some of the most essential and excruciating decisions of their lives. These judgments were made by people who were unequal to the environment, which was foreign, if not hostile, to the uninitiated lay person who trespassed. EOL decision-making was least transparent to those who needed it most, because by definition, EOL care was dominated by sophisticated technology, arcane language and formalized processes that can be invoked for influence, or for control. In other words, an institution with considerable authority (of expertise, access to care and legal power, among others) commanded the particular health care environment where patients and their families were required to participate in choices, decisions, judgments and resolutions that determined the end of a person's life.

Many people faced with EOL dilemmas may never have recognized the influence of the forces that come to bear on their choices. EOL decision-making could be influenced by mediated content that either persuades the viewer to follow a dominant culture ethic about EOL or that misleads through inaccurate representations. The reason I wanted to study EOL in *ER*, in particular is that it could be considered the most influential medical drama in television history, based on the density of its viewership and the length of its popularity, as well as the critical acclaim that *ER* enjoyed.

To fully understand this multi-faceted topic, I incorporated several areas of research within the literature review. First, I discussed the theory that directed my inquiry, including Althusser's ISA and ideology, content analysis and television studies. Then I integrated a clinical and cultural description of EOL, both as a specific process within health care and as a cultural phenomenon.

### CHAPTER II

### LITERATURE REVIEW

# Althusser's Ideological State Apparatus

In this dissertation, I examined ideological content about end-of-life decisions presented in television drama through the prism of Althusser's Ideological State Apparatus. Althusser (1971) described ISAs as entities in society that control, limit, permit and influence what we think and do, to varying degrees, regardless of whether we know they exist. In his original essay on ISAs, Althusser (1971) identified eight different ISAs through history, including: 1) religion, 2) education, 3) family, 4) legislative/legal, 5) political, 6) trade union, 7) communication, and 8) culture. In particular, I considered Althusser's communication ISA, which is composed of all forms of mass media content and institutions. In describing the transition of the most dominant ISA from that of the church to the schools, Althusser suggested that ISAs change over time, taking on different roles and functions from one another. He implied also that new ISAs would emerge (Althusser, 1971).

# ISA v. Repressive State Apparatus

Althusser (1971) originated the concept of ISAs to explain how people's behavior and culture itself are influenced by elements within a society that may not be apparent. He differentiated ISAs from "repressive state apparatuses" (p. 17). The state apparatuses had the power to force or compel individuals to do actions, such as to obey civil and criminal laws, to pay taxes, or to register for conscription. The state had the authority to do violence to people who do not perform those actions, either by brute force or through powers of arrest. ISAs were not *part* of the state but existed instead in the private sphere

and generally did not have the powers of violence that the state may employ. For example, the religious ISA exerted influence when it indoctrinated followers to its belief system. No one was forced by law, in a democratic society, to participate in religious worship, yet many people did so. Himmelstein (1994) wrote that these *institutional* apparatuses (as opposed to a state apparatus) operated with: "a politics of information manifested in battles over content, as government sanctions particular economic postures and social stances taken by dominant media organizations while public-interest advocates... put up a comparatively weak challenge to those sanctions they deem inequitable" (p. 4). This reflected Althusser's supposition that ISAs ultimately functioned to support a dominant power structure. An ISA, therefore, influenced primarily through *ideology*, rather than through the *repressive* and legitimated power, authority and force of the state.

Without using the explicit terminology of the ISA, Chomsky (1992) subscribed to Althusser's understanding of ideological structures that hold up an elitist power formation. Noting that the educational system was the cradle for "developing ideological principles" (Chomsky, 1992, p. 146), Chomsky considered mass media and schools as tools of indoctrination designed "to prevent the population from understanding what they are participating in indirectly through the institutions that they support" (p.17). Chomsky (1992) proposed that people with more access to these apparatuses supported the power structure more ardently, as he asserted "These are groups that are closely associated with power....They share class interests with those who control and in fact own the economic system. They are the cultural commissars of the system of domination and control that's very pervasive" (p. 14). Other scholars considered the influence of ISAs within society in additional ways.

# Influence of ISAs

Gane (1983) noted the scholarship regarding how ISAs are categorized as "those which concentrate on the fact that the ideological structures allow 'nothing' to happen, and those which show that, in fact, something happens in these apparatuses which is decisive for the social formation concerned" (p. 433). Berger (2000) described ISAs as more heuristic: "The social conception of knowledge recognizes that education, the media, our families, and other parts of society play a major role in giving people the ideas they hold" (p. 83). Debate continues about if, why, and how ISAs exist in society, relative to supporting the state or any dominant ideology. According to Hall (1985), Althusser's ISA essay tried to bridge gaps in Antonio Gramsci's work about how civil institutions and not just the ruling power of the State exerted influence in society.

Although Althusser's ideological state apparatus (ISA) emerged from Marxist theory, Althusser diverged from Marx's concepts. Both theorists viewed human behavior as being subject to outside influences that are larger than the individual. Indeed, both theories considered the possibility that individuals may be completely unaware of those influences. Althusser, however, did not accept the concept of *false consciousness* (DeFoster, 2010; Hall, 1985) that, according to Marx, was how ideology is experienced, when the ruling class imposes its vision on the working class, in an exploitative economic system. McPhail (1987) noted Althusser's disagreement over consciousness to be "the recognition of a greater degree of independence of ideology from the economic base" (p. 66). Hall (1985) reevaluated Althusser's ISA to find more application in contemporary capitalist societies. Hall's (1980) encoding-decoding theory retracted the Althusserian supposition that ideology is imposed on a viewer. Instead, he contended that a recipient decodes messages in congruence with how they view their own reality.

# New ISAs Will Emerge

Over time, ISAs changed in importance within a culture and how they worked in concert with each other. Althusser (1971) described the first ISA transition, in what Hirst (1976) labeled the "switch from church/family couple... to school/family couple" (p. 388). Prior to capitalism, according to Althusser (1971), the church apparatus reigned superior in power to all other ISAs. After capitalism, however, he theorized, the educational ISA dominated among the ISAs in "mature capitalist formations" (p. 26). The education ISA was not first in a person's life, however. Neither the church nor the school welcomed a person into the world. That ISA was the family. The family was the ideological structure that, Althusser (1971) wrote, "interpellates" or called to us before our existence on the planet even began (p. 47). Humans were defined as part of some type of family (or the complete absence of one) from the moment a person's existence was acknowledged. Althusser (1971) predicted that this quality of malleability found in ISAs permitted new ones to emerge and to change in status, as I asserted happened with the ascension of the health care system to such importance in contemporary society.

The powerful communication ISA, Althusser (1971) ventured, promulgates dominant ideology to viewers. McPhail (1987) wrote that mass media have emerged as increasingly important in cultural-critical study, because considerations of capitalism's survival "has raised the priority of mass media amongst other" ISAs (p. 67). Selnow (1990) recognized the use of the mass communication ISA in supporting other ISAs, too, as: "...television's lessons are remarkably coherent and congruent with the beliefs of churches, schools, and commercial institutions" (p. 72).

The Health Care ISA (hcISA)

As part of this dissertation, I considered the politically-powerful American health care system as an ISA, as described by Althusser (1971). Although it was a loose confederation of professional and economic interests, the hcISA has grown influential enough in daily American life, to qualify as such an important body. It would join the list of entities (family, cultural, religious, education, legal, political, trade union, and communications) that Althusser theorized to be so influential in culture that individuals could not avoid their sway. Without naming it outright, Kaufman (2005) described what could be considered the emergence of a hcISA in the 1950s, when: "Clinical medicine began to order patients' lives in a new way—managing and delineating the entire life cycle, including death... Medicine's 'new revolution,'...[is] as significant... as the one described by Foucault that brought scientific medicine into existence around 1800" (p. 65). Health care grew in importance within our society as technological breakthroughs created demand for services. At some point, access to the health care system grew into a requirement for participation in society. Simultaneously, however, barriers rose that limited access to affordable and desirable care within it.

In this dissertation, I examined EOL artifacts in the television drama *ER*, to determine if an EOL ideology (that mirrors current EOL clinical research) exists in that content. The potential influence of television messages made the possibility of a hcISA even more compelling, as an EOL ideology (Figure 1) could subtly guide viewers into "understanding" what their roles and expectations are, for EOL care of their own family members or the community at large.

Although there was never a national health care program in the United States, it was almost inconceivable for most Americans not to access the health care system almost

from birth, when a person was acknowledged to be in a family. In contemporary

American society, a physician launched this acknowledgement in a medical setting, by

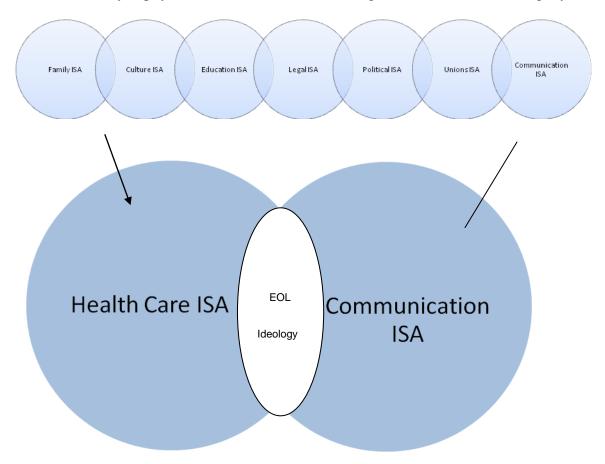


Figure 1. The Spread of an EOL Ideology. The health care ISA developed after the original ISAs, then merged with the communication ISA to spread an EOL Ideology. delivering care to the expectant mother, then to the baby. The hcISA also co-opted other ISAs (mass media) to interpellate people formally to embrace and seek medical care, which is touted as among the best in the world. The penalty for not accepting the ideology by responding to the call was, at the very least, to feel social isolation for not using a new medication that is heavily marketed as beneficial. At worst, a person without insurance (one who did not heed the call to support the hcISA) courted the possibility of

financial devastation through incurring astronomical medical bills for accessing care and paying the costs out of pocket. Kaufman's (2005) description of organized medicine noted these pressures to participate and conform to the expectations of the hcISA—a leviathan in scope and influence—so large it executed irrefutable dominion over *how we die*:

Medicine today is a web of complex social institutions, diverse kinds of knowledge, fragmented systems of care, and a broad array of clinical practices. In all those ways, it has become the most powerful framework in the United States for understanding critical illness and for approaching the dying.... There is widespread demand to have control at the end of life through having greater choice. This presents a paradox, for medicine both provides and constrains that choice. (p. 9)

This dissertation, then, was a consideration of how two ISAs could converge -mass communication and health care-- in the spread of an EOL ideology, via television
medical programming (See Figure 1). If so, it could be argued that the media
representations of EOL prepared millions of viewers to fulfill a silent agenda regarding
the use of EOL care and resources at the end of human life. Indirectly, scholars called for
an examination of this kind, in both the clinical and cultural disciplines. To appropriately
manage EOL in American hospitals, Curtis and McGee (2000) declared that it would
require "a broad reconsideration of medicine's dominant role and our culture's
conflicting values" (p. 347). Lewis (2007) recognized the enormous power that is
centered within the complex of organizations and individuals that delivered health care to
U.S. residents:

... medicine in the 21<sup>st</sup> century is impossible to understand within the modernist discourses of science and ethics alone. Medicine has become so intertwined with media culture (TV shows, magazines, advertisements), with the rapidly expanding biotech sector of the economy, and with the limitless consumer appetite for human enhancement and status, it must be understood as a cultural enterprise. (p. 364)

# *Ideology*

The heart of this analysis was founded in the understanding that the origin of an ISA was rooted in an ideology, which was defined in various ways. According to Althusser (1971), ideology "represents the imaginary relationship of individuals to their real conditions of existence" (p. 36). Althusser's ISA expanded on the work of Gramsci's hegemony, which Berger (2000) called dominant ideology that is "invisible because it is all-pervasive" (p. 74). Lewis (1992) concurred with Althusser that: "Ideology is our *lived* experience in the world. We practice ideology when we use the stock of concepts it provides us with to make our way in the world" (p. 459), i.e., it is less about what we do, but that we are unconsciously steeped in ideology. In a more classic Marxist definition, White (1992) defined ideology as "beliefs that are taken as 'natural' when in fact they perpetuate the status quo and continue the class system of oppression" (p. 165). Haque (2003) wrote that ideology was, fundamentally, "a system of beliefs, values, and behavior that have a dominant position in the society" (p. 36). According to Berger (2000), ideology was "a systematic and all-inclusive sociopolitical explanation of what goes on in a society" (p. 71). He explained that everyone had ideological beliefs, even if they were unaware of them or were unable to express them. Another perspective (Finlayson, 1996) was that ideology contributed to the identity of the person who accepted it, when it

"achieves temporary coherence, unification, when the elements that make up the ideological discourse, the chain of signification, are so connected that each evokes the other" (p. 94). Hirst (1976) wrote that awareness of ideology was "true consciousness in blinkers" (p. 385). Another view by Myers (2005) considered ideology as a sense-making mechanism in which ideology "stitches together a comprehensible narrative out of a complicated and contradictory world, explaining both the nature of that world and our particular place in it" (p. 151).

Hall (1985) applauded Althusser's basic thesis, but he disagreed with the assertion that ideology must be both inserted into "practices" and observed, in order to be considered ideology (p. 100). He defined ideologies as: "the frameworks of thinking and calculation about the world—the 'ideas' which people use to figure out how the social world works, what their place is in it and what they *ought* to do" (p. 99). Himmelstein (1994) suggested that Hall's definition of ideology "implies that the making of social meaning is to a degree at least framed by people's struggles to position themselves in the spectrum of competing 'ideas' about their world" (p. 5). It was this conception of ideology that I thought most suited this analysis. Although there was considerable power exerted by any ISA in contemporary society, individuals still had a degree of choice in what information they accepted.

# Ideology and Mass Media Research

Television and film (defined as part of the original communication ISA) remained popular media that were rich sources for analysis of content containing ideology. In a consideration of ideology in television programming, Gitlin (1987) wrote: "Commercial culture does not *manufacture* ideology; it *relays* and *reproduces* and *processes* and *packages* and *focuses* ideology that is constantly arising both from social elites and from

active social groups and movements throughout the society..." (p. 510). Berger (2000) stressed that it was the responsibility of the ideological critic "to point out the hidden ideological messages in mediated and other forms of communication" (p. 73). White (1992) echoed the call to analyze language and media content for ideological influence, when he explained: "Ideological analysis, then, aims to understand the ways in which meanings are produced by and for individuals within a social formation" (p. 167). Himmelstein (1994) considered television as "one of our society's principal repositories of ideologies/ideology" (p. 5) through its "use of a powerful language comprising images, words, gestures, clothing, settings, music, and sounds..." (p. 5). While disagreeing with the Althusserian thought that ideology is "monolithically imposed" on television viewers, Kellner (1987) noted there was "a new configuration of ideology in advanced capitalism" (p. 472) generated by advances in electronic media, most notably television:

Ideology is often conveyed through images (of country and race, class and clan... individuality and solidarity.) The combination of rational theory with images and slogans makes ideology compelling and powerful. Ideology roots its myths in theories while its theories generate myths and supply a rationale for social domination (if the ideology attains hegemony). Thus ideologies have both 'rational' and 'irrational' appeal, as they combine rhetoric and logic, concepts and symbols, clear argumentation and manipulation. (p. 472)

A well-established body of research existed in mass media that analyzed content for ideological content. Much of it was in newspapers and was applied to news content, e.g., anti-Muslim discourse (Abbas, 2001), portrayals of professional athlete conduct during contract negotiations (Bishop, 2005), British portrayals of American "gun culture" (DeFoster, 2010), San Francisco political campaigns (Glenn, 2003), themes in George

Will's editorials (Goss, 2005) and intellectual repute in political discourse (Proudman, 2005). Ideological analyses in television ranged from advertising themes (Bishop, 2001) to popular prime-time shows (Chesebro, 1991) and dramatic programming (Corcoran, 1987). Newcomb (1996) described television as an "ideology machine" (p. xix) that "played a fundamental part in lives individual and collective" (p. xx). Slater, Rouner, and Long (2006) appealed for research about dramatic content in particular, as "virtually no studies have examined how television dramas might affect viewer support for controversial policy positions" (p. 235). Lembo (2000) noted "...the workings of television—as functional, ideological, or discursive—derive their analytical significance from the fact that they are understood to be linked...with more broad-based forms of power, be they historical, social structural, institutional or discursive" (p. 60). Corcoran (1987) noted the dearth of ideological analysis in television studies because "...the ideological process...is achieved in a very indirect way" (p. 534), but its importance is unmistakable "...because it asks questions of media that previous paradigms have ignored" (p. 548). At the very least, television messages held the potential to influence viewers about their impressions and expectations of EOL care in hospitals.

### **Television Studies**

A multitude of factors governed the potential for and degree of influence that television messages have on viewers. Some groups *depended* on media for health education and information (Brodie, Kjellson, Hoff, & Parker, 1999). Others were even more vulnerable to mediated messages about health, accepting fictional portrayals of health information as accurate or factual (Brodie et al., 1999; Brodie et al., 2001). Therefore, a deeper understanding of the polysemy of EOL portrayals, both on the

surface and within the larger context of ideology was required. Hall (1985) wrote that ideology was certainly inscribed into language, and it was the scholar's call to ferret out the ideology with analysis.

Depending on the questions they asked, scholars analyzed television texts with various methods. One of the most common was content analysis (Harwood & Anderson, 2002; Jo, An, & Sohn, 2011; Kalisch & Kalisch, 1983; Murphy, Hether, & Rideout, 2008; Turow & Gans, 2002). Narrative study was also represented well in mass communication study (Busselle & Bilandzic, 2009; Busselle, Ryabovolova, & Wilson, 2004; Mittell, 2006; Slater et al., 2006), as well as in effects studies (Busselle, 2001; Chory-Assad & Tamborini, 2003; Shapiro & Chock, 2003; Konijn, Van der Molen, & Van Nes, 2009). Cultural and critical studies (Chesebro, 1991; Hurd, 2007, Koven, 2003; Selnow, 1990) brought together a consideration of culture as portrayed in media content.

# Content Analysis

The method of examination that I used in this dissertation was content analysis. Scholars in communication, health care and other fields described the components of and acknowledge the value of both quantitative and qualitative content analysis to expand and clarify research interests. Zhang and Wildemuth (2009) recognized the expansiveness of qualitative analysis as it "goes beyond merely counting words to examining language intensely" to classify "large amounts of text into an efficient number of categories that represent similar meanings" (p. 308). At its foundation, content analysis is used to form "replicable and valid inferences from data to their context" (Krippendorff, 1980, p. 21) and "is a systematic and objective means of describing and quantifying phenomena," (Elo & Kyngas, 2008, p. 108).

In this dissertation, variables were quantified while additional analysis of dialogue allowed me to explore thoroughly the presence of an ideology about EOL that I expected to be present in *ER*. Indeed, discerning themes that answer the question *How?* takes more analysis than simply finding a category for organizing descriptive information that is actually manifest content, according to Graneheim and Lundman (2004).

Manifest and latent content. Krippendorff (1980) stressed that manifest and latent content can and should be analyzed with content analysis. Manifest content was identified on the surface of a text, and latent content concerned the text's underlying meaning (Graneheim & Lundman, 2004), both of which require interpretation of varying depths and "level of abstraction" (p. 106). Qualitative content analysis has afforded the consideration of *latent* content in a text.

Combined quantitative and qualitative approaches. According to Zhang and Wildemuth (2009) qualitative content analysis was generally inductive to reveal "the meanings underlying physical messages" (p. 308). They noted the different perspectives of quantitative and qualitative analysis and appreciate their complementary nature: "The quantitative approach produces numbers that can be manipulated with various statistical methods... qualitative content analysis pays attention to unique themes that illustrate the range of the meanings of the phenomenon... the two approaches are not mutually exclusive and can be used in combination" (p. 309). According to Holsti (1969), a methodological triangulation of this sort gave a more robust appreciation of the studied topic: "It is by moving back and forth between these approaches [qualitative and quantitative] that the investigator is most likely to gain insight..." (p. 11).

Directed versus conventional approach. Several different approaches to qualitative content analysis were identified (Elo & Kyngas, 2008; Hsieh & Shannon,

2005). A directed approach used theory or previous research to guide the formation of a coding process and was considered to be more structured than conventional content analysis in which previous research did not exist and the coding strategy emerges after exposure to the content.

Deduction versus induction. This distinction illustrated also the difference between a deductive approach to analysis and an inductive approach (Hsieh & Shannon, 2005). When a researcher immersed herself in content *first*, categories were identified by induction, to yield fresh perceptions of the research interest. According to Elo and Kyengas (2008), the categories and which content belongs in them, decided through induction, were chosen by a researcher through scholarly interpretation. A deductive method informed the coding process with previous research or a theory pertinent to the topic, and was used to "retest existing data in a new context" (p. 111) or to compare data from points in time. According to Hsieh and Shannon (2005), in directed content analysis, the study began with theory, and codes were defined before and during analysis, with the codes emerging from theory or previous pertinent research. Again: the two approaches were not mutually exclusive. Coding may have begun deductively, but then branched out inductively with repeated exposure to the content, to fill in gaps that were left unanswered with the deductively-derived coding scheme. According to Zhang and Wildemuth (2009), theories, previous research, and the project data, from either an inductive or deductive approach, spawned the coding schemes and categories of qualitative content analysis. One study of health policy issues in multiple television programs (Turow & Gans, 2002) classified data about health policy issues in medical dramas on television, using this dual approach in which the categories were derived from "knowledge of the health policy literature, preliminary viewing of the programs and

conversations with experts" (p. 6). If the content did not fit one of the 67 categories, it was coded other with descriptive notes accompanying it.

An advantage of qualitative content analysis was the opportunity it offered to discern themes that are found in latent content which were the messages underlying the visible or audible or legible message. Graneheim and Lundman (2004) suggested that the creation of themes was part of abstraction, equivalent to making codes and categories for manifest content: "A theme can be seen as an expression of the latent content of the text. Since all data have multiple meanings...themes are not necessarily mutually exclusive" and "...creating themes is a way to link the underlying meanings together in categories" (p. 107). They explained that themes describe the "structure of experience" and were not "...an object or thing. A theme answers the question 'How?"" (p. 107).

# *Television's Popularity*

Television, arguably, functioned as the most prolific source of media content for Americans since the 1950s. Critics described it disparately—from a "vast wasteland" (Barnouw, 1990, p. 300) to being a "repository" (Himmelstein, 1994, p.5) for ideology and culture. The body of media effect research indicated that viewers use television in many different ways with a variety of results. Television was the site of commerce, education, entertainment, information, public debate and myriad other enterprises. The number of channels available for viewing exploded, into a near-limitless selection, far more than the original three major networks in the U.S. during the 1950s. Millions of people each week watched the most popular shows on television, and all age groups spent substantial time viewing television, despite other media being available (Murphy et al., 2008).

The decision to study *ER* was based, primarily, on the density of viewership that the show had, over such a long period of time. *ER* was the longest-running television medical drama in history, gaining unprecedented critical acclaim and popular success in its 15-year, 331-episode run. From 1995-2009, the American Academy of Television Arts and Sciences nominated the show for 124 Emmys, making it the most nominated drama in television history. It won 22 Emmy Awards, including the 1996 Outstanding Drama Series (Academy of Television Arts and Sciences, n.d.). The show's first season garnered the coveted Peabody Award (Peabody Awards, n.d.). Of 375 industry award nominations, *ER* won 116 awards from various organizations, including the Hollywood Foreign Press Association's Golden Globes, the NAACP Image awards and the Screen Actors Guild. TV Guide ranked *ER* as #22 of *TV's Top 50 Shows*. Only one other medical drama, *St. Elsewhere*, placed higher on that list (Associated Press, 2009).

The show's popularity contributed also to the program's longevity. In 1998, the show peaked with 47.8 million viewers (Toff, 2009). *ER*'s two-hour finale garnered one of the largest audiences ever for a network series finale, at 16.2 million viewers (Toff, 2009). *ER* was named *Favorite Television Dramatic Series* by the People's Choice Awards, every year from 1995-2002 (People's Choice Awards, n.d.).

### Health Content in Television

Commercial entities and government authorities, including the health care industry, placed great value in knowing the amount of time that people spend absorbing messages during their television viewing. In fact, televised content was the focus of a number of health groups, in order to put out messages about health topics. A 2004 report of the Henry K. Kaiser Foundation described the process as the entertainment-education (E-E) strategy. E-E has been described as the embedding of "...prosocial messages...that

can have a positive impact on awareness, knowledge, attitudes, or behaviors" (Ye & Ward, 2010, p. 555). The definition of this strategy, then, assumed that television was a vehicle for overt indoctrination. The E-E strategy inserted an "educational message into popular entertainment content in order to raise awareness, increase knowledge, create favorable attitudes, and ultimately motivate people to take socially responsible action in their own lives" (Henry J. Kaiser Family Foundation, 2004, p. 1).

According to Levenson (2000), professional and lobbying groups were interested in getting their messages into television, and they monitored content for the appearance of pertinent health topics, sometimes to counteract it, and at other times to leverage it. The federal government overtly stated its aims to educate and to spread messages about health through television, although some scholars believed that it appears solely as a consequence of the creative process (Murphy et al., 2008). A 2000 Centers for Disease Control and Prevention (CDC) conference instructed participants in how to create a template for using the media in spreading their messages through entertainmenteducation (Centers for Disease Control & Prevention, 2004). In the CDC conference report, many of the recommendations focused on programming for children, but conference materials noted also how desirable entertainment programming is, as a "vehicle for health messages (p. 5)... to achieve their potential and become a vital component of an integrated public health strategy" (Centers for Disease Control & Prevention, 2004, p. 3). Cooper, Roter and Langlieb (2000) described the efforts of Johns Hopkins School of Public Health to reinforce accurate health information following episodes of ER that contained content about particular health topics. Of note, the effectiveness of cardiopulmonary resuscitation was vastly overrepresented in ER and other medical television dramas (Cooper et al., 2000, p. 225), a result that is consistent

with the findings of Diem, Lantos, and Tulsky (1996). Even though *ER* did not portray medical realities accurately, Cooper et al. (2000) found that more than half of its viewers reported they learned "about important health care issues" (p. 225) and some even went so far as to contact their physicians with health concerns.

Researchers observed that programming was filled with ideological cues as well. In a call to examine television's role in the support that viewers may form for policies that are conflict-ridden, Slater et al. (2006) recognized the possibility of "reframing the dramatic situation to reduce the effect of prior ideology and values and by minimizing processing of the story as intentionally persuasive discourse" (p. 235). A longitudinal study of popular television series in the 1990s (Chesebro, 1991) indicated that, although messages contained in them were entertaining, the programs "also contain persuasive messages. Moreover, these persuasive messages were patterned rather than random; they selectively reinforce certain types of communication. As communication systems, these series contain values...which promote certain life orientations and not others" (p. 291). Viewers of Health Content in Television

Television served as a vehicle for health messages, but was used and depended on, in varying amounts and with different levels of trust, by viewers. Brodie et al. (1999) found that three race groups—Caucasians, African Americans, and Latinos—not only depended on television for health care information, they wanted *more* media health coverage and "take personal action as a result" (p. 154) of the health content they view. The same group of participants rated only physicians and health care providers as "highly trustworthy" (p. 158). African Americans in the study said coverage of minority health care issues was inadequate, whereas 40% of Latinos reported they depended on mainstream—not Latino—programming for health care information. Just more than 40%

of Caucasians and 34% of African Americans reported they trust mainstream media either "always or most of the time" (p. 158). Referencing Stuart Hall's encoding/decoding theory of dominant, oppositional and negotiated reading of media content, Lewis (2007) predicted that readings mimicked the real-life behavior of the reader who was being socialized to depend on the medical system for direction, education and advice: "Since readers' identifications follow from their repeated consumption patterns, most readers… will fall into highly, but somewhat ambivalent, medicalized identifications" (p. 375).

Combining entertainment with education also drew the interest of viewers to health (and EOL) content. According to Kendrick and Costello (2000), "There is no doubt that television can play a major role in demystifying much of the fear and anxiety associated with all aspects of health care delivery" (p. 20). They suggested, "Programme makers have it within their gift to produce work that entertains and educates the viewing public" (p. 20). Viewers of ER, the show dubbed by Strauman and Goodier (2008) as "the "benchmark of the 'new doctor show' of the 1990s" (p. 128), displayed an increase in knowledge of particular health issues, at least for some period of time, with 52% saying they were both entertained and educated about important health issues from watching the show (Brodie et al., 2001). A 2001 CDC survey showed similar proportions of viewers who trusted (52%) health information in the media to be accurate and who took action (48%) as a result. Hispanic women (70%), African American women (65 %) and African American men (64%) reported learning about diseases and their prevention from watching day-time or prime-time drama (Centers for Disease Control & Prevention, 2004). ER viewers who reported gaining the most information from the shows were older, less educated and of races other than Caucasian (Brodie et al., 2001). A third of the

group reported getting "information from *ER* that helped them to make health care choices," whereas more than half of regular viewers said "they talked with family and friends about the health care issues" (Brodie et al., 2001, p. 197).

Why Study EOL Messages in Television?

As Schiappa, Gregg, and Hewes (2004) noted: "Because we learn about dying only indirectly by experiencing the death of others, it is reasonable to hypothesize that our attitudes about death and dying could be influenced by mass mediated messages" (p. 460). In a study that examined the HBO series Six Feet Under, Schiappa et al. (2004) found that participants' fear of the unknown was equal to their fear of post-mortem mutilation, prior to viewing the shows. The fears of cremation and of dismemberment decreased, however, after watching the funeral-industry drama. The study's authors concluded: "added to the previous literature exploring death attitudes and mass media, there is reason to believe that mass communication is a potentially important socializing agent with respect to death attitudes" (Schiappa et al., 2004, p. 472). Seale (2005) concurred: "Media organizations appear both to reflect and help construct lay beliefs" about death (p. 968). In 2007, Morgan, Harrison, Chewning, Davis and DiCorcia echoed the recognition that some life experiences came about so rarely, that it was hard to learn about them in our own lives. Televisual images of those experiences, then, turned out to be even more particularly potent and important. "...[O]rgan donation is an excellent example of a 'second-hand reality,' one which can only be formed by exposure to the media" (Morgan et al., 2007, p. 144). Certainly, EOL and death-related issues would fall into this category of second-hand reality.

Television was the site of many health and death-related messages, so it is a rich source for study. Turow and Gans (2002) examined hospital dramas for the presence of

health policy issues, which they defined as "a disagreement or expressed dissatisfaction with government or institutional rules about non-clinical issues in patient care" (p. 4). Although they noted none of the issues were treated in-depth, they found that *ER* had the most health issues portrayed, with a vast majority being about ethical issues (as opposed to clinical or resource issues). An average of one "public policy-focused scene per (hour) episode" appeared, including those that debated whether a "physician's support of a patient's refusal of treatment was tantamount to assisted suicide" (Turow & Gans, 2002, p. 4).

After the topic of medical malpractice, Turow and Gans (2002) found that EOL and patient rights issues appeared with the most frequency. "End-of-life scenes involved characters disagreeing over individuals' legal, ethical or organizational prerogative to make decisions about the care they would receive as they move toward death... scenes (that) reflected actual current national public policy debates" (p. 4). Turow and Gans, (2002), differentiated among several EOL issues: do not resuscitate (DNR), doctor-assisted suicide, hospital stay or leave decision, living wills, quality of life and treatment refusal. Only DNR, treatment refusal and other appeared (p. 4). Murphy et al. (2008) found that health content of major network shows did not reveal any EOL information, although a rigorous quantitative approach may not have exposed the presence of EOL content that a qualitative investigation would have revealed.

One interest of this dissertation was the possibility that death and EOL decision-making were depicted accurately in televised content. If the EOL ideology (amassed from the clinical literature's representation of EOL issues) was shown truthfully, then viewers could have been indoctrinated to its acceptance. If the EOL ideology was portrayed falsely, however, there was the possibility that the content left the impression that the ISA

operates in a different way, engendering more trust of the ISA about death issues. Other studies indicated that the portrayals of medical roles changed over time and may have affected how viewers perceive them. Depictions of physicians were viewed similarly as they changed from being the dominant culture hero during the golden age of physician dramas to less reverent portrayals in contemporary medical programming (Chory-Assad & Tamborini, 2003). If either characterization--as either accurate or fantasy-- was true about EOL ideology in television content, documenting that fact was equally important. Kaufman (2005) noted differences in how EOL discussions appear in documentaries and dramatic programming. She wrote about Near Death, a documentary made at Beth Israel Hospital in Boston that showed conversations between professionals and families of dying patients. She observed how differently the documentary was from entertainment programming: "This is not like the television show ER. The conversations are not short, dramatic, authoritative, or to the point. In fact, they are the opposite—long, tedious, equivocal, repetitive, and without resolution.... the physicians remain entirely evasive about death" (Kaufman, 2005, p. 45).

### American Health Care and EOL

A review of the health care literature provided context for examining the EOL ideology that existed within a health care ISA and that was disseminated through mass media content. Gaining a grasp of the factors that surrounded death within the health care system was essential in order to conduct a cogent examination of the mass media portrayal of hospital death and EOL issues in the United States. Some of these factors about death involved the demographics, economy and practitioners of health care. The health care industry employed a unique lexicon about EOL care. To aid the reader in understanding some of these concepts, I included a glossary of terms in Appendix A.

## Change in Lifespan

Advances in health care technology over the past century corresponded with an increased lifespan in the United States. This means, generally, that more people than ever were dying in a health care environment with all the decisions and resource management that entails, as opposed to dying at home, as was common a century ago. Not surprisingly, the cost of death in the medical system rose every year.

The U.S. population grew larger in number and older, owing to technology and the Baby Boom Generation. In 2000, the U.S. population was 282 million people, with 12.5% being 65 years or older. By 2010, the general population swelled nearly 10% to 308.7 million, with attendant increases in the older population as well (U.S. Census, 2011). In 2011, the first baby boomers turned 65. The last of this post-World War II generation will meet that milestone 20 years later. By 2030, this age group is expected to be 20% of the population (70 million people). The group older than 85 years is predicted to be 8.9 million people in 2030, and nearly half of the U.S. population will have a chronic health problem by then (Rice & Fineman, 2004). People born in 2007 can expect to live 77.9 years (Centers for Disease Control & Prevention, 2011), which is an increase of more than 60 % from a century before, attributed by Mackelprang and Mackelprang (2005) to burgeoning of the health system, including "increases in health care providers, revolutionary development of public and environmental health systems" (p. 315). In 2005, the United States spent \$6,401 per capita for health care, which was 16 percent of the Gross Domestic Product in 2006 (Lewis, 2007).

Improvement of health care technology and access to medical care was associated with a slowing of the death rate for older people. In 2007, just more than 2.4 million people died in hospitals in the United States. The causes of death also reflected an aging

population, with more degenerative disease than in the first half of the century. Starfield (2000) hypothesized that the third leading cause of death (after heart disease and cancer) may be the model of medical care that exists within hospitals. Although a U.S. Institute of Medicine study (Kohn, Corrigan, & Donaldson, 1999) estimated the number of deaths in hospitals that can be attributed to errors at less than 100,000 people, Starfield (2000) disputed that number and hypothesized that medical interventions in the quest for a cure, ironically, were the third leading cause of death—closer to 225,000. The interventions included medication errors, other errors and unnecessary surgery, nosocomial (hospital-acquired) infections and adverse consequences of medications.

Angus, Barnato, Linde-Zwirble, and Weissfeld (2004) estimated that one in five people in the United States will die in, or after receiving care in, an intensive care unit (ICU). This was a staggering concept--that 20% of all people in the United States will die in what was once considered an elite health care environment designed to deliver stateof-the-art lifesaving therapies (Boyle, Miller, & Forbes-Thompson, 2005). In 1999, these terminal admissions that occurred in ICU accounted for the vast majority of costs associated with deaths in a hospital. More than three-fourths (80%) of all costs associated with deaths in a hospital come from the 60% of death admissions that receive ICU care (Angus et al., 2004). The trend toward dying in hospitals began to reverse slightly, however. From 1997 to 2007, the portion of people who died in hospitals dropped an average of 5% for all age groups and races. The number of deaths at home in that time frame rose 50%. In 2007, racial and ethnic minorities, including Asian or Pacific Islanders, African Americans, and Hispanics had the highest rate of death in hospitals. As a group, African Americans were least likely to die at home in 2007 (National Center for Health Statistics, 2010).

Although everyone dies, there were discernible differences in how people die, along the lines of gender, race and economics. For example, in 2001, the death rate for African Americans was 1.3 times higher than for Caucasians (Crawley, 2005). According to Barnato, Berhane, Weissfeld, and Chang (2006), although African Americans were treated less intensively for many procedures and diagnoses including lung cancer and renal transplantation, they were more likely to die in a hospital (than Caucasians) and incur more spending during the last year of life (compared to Caucasian people). African American women outlived men by about six years (70 years and 76 years). Caucasian women also lived five years longer than Caucasian men (75 years and 80 years). Health care scholars attributed the disparity in death rate to a lack of access to care as well as a history of racism that contributes to mistrust of health care institutions. Crawley et al. (2000) wrote:

The legacy of slavery, abuses in medical experimentation, economic injustices, racial-profiling practices, and the disproportionate numbers of incarcerations... reflect societal and ethical misconduct that has led to a general loss of credibility of many institutions, including the health care system. Death has often been associated with these societal patterns. (p. 2518)

They suggested that, even though a psychological denial of death in the African American population may have obstructed end-of-life care goals, this repudiation was actually a healthy response to generations-old biases that have existed within society against African Americans' survival (Crawley et al., 2000).

### Economics of Health

Health care in the United States represented a substantial portion of the American economy. Gapenski (1999) noted that health care finance, as an economic structure, is

second only to real estate in the United States. Health care encompassed services (personnel, providers and practitioners), insurance, managed care, equipment and supplies, pharmaceuticals and biotechnology, as well as private and public research entities and consultants. To this description, Weissert and Weissert (1996) added another dimension: government oversight, regulation and authority. They described the "embedded government role" necessitated by the "system's complexity" (p. 2).

Feldstein (1999) proposed that government intervention in health care created demand for health care services that brought about almost crippling increases in health care spending. Until Medicare and Medicaid were authorized in 1965, 80% of health care expenditures were paid by individuals' insurance companies. The charge-based reimbursement system of the government payers encouraged hospitals to grossly expand services and facilities. Health care technology exploded in this rich culture, and practitioners were encouraged to provide more and varied health care services to patients who had access to private insurance or government programs. In the 1980s, however, spiraling costs burdened private and public payers, so cost-containment measures, including diagnosis-related groups for reimbursement, were put into place. At this point, Feldstein (1999) pointed out, physician practice patterns were identified as contributing to a hospital's costs and became a concern. Studies from the 1990s indicated that Medicare spent four times more for care rendered in the last year of life of an elderly person than was paid out in survivors benefits for that person (Rice & Fineman, 2004). Care delivered to people in the last year of life was deemed to be expensive sick care. From 1992-1996, medical care delivered to people in the last year of life represented about a third of all Medicare costs, 25% of Medicaid spending and 22% of all medical expenses in the United States (Rice & Fineman, 2004).

## Death in a Medical Setting

End-of-life was evolving, as a contemporary social phenomenon. Although death has always been, how it occurred changed significantly. Even before recorded history, Campbell (1997) suggested, the prospect of death was so destabilizing to the human psyche that the "first function of myth...was to conquer death" (p. 43). Mythology remained present throughout current representations of death, too, as Campbell wrote: "Both the great and the lesser mythologies of mankind have, up to the present, always served... to bear the aging back to nature and on through the last dark door" (p. 223).

Contrary to the present-day concept of death as a private moment attended to by family and health care professionals, death was a public event until relatively recently. According to Kaufman (2005), in the 15th century, the model for death was one of spiritual passage. With the development of medicine, by the late 18th century, death became "located in the body" and "The dying person was transformed into the patient" (Kaufman, 2005, p. 63). In the mid-20<sup>th</sup> century, nurses were on "deathwatch... the vigil during which they kept a close watch on patients known to be dying" (Kaufman, 2005, p. 93). The purpose was to never leave the patient alone, to control symptoms and to keep the family at bay, as they were "rarely present at the patient's bedside at the moment of death" (p. 93). With the sweeping changes that technological advances brought, the vigil was replaced by machines that sensed and recorded a patient's life forces by telemetric vital sign monitoring, by laboratory results that revealed the chemical make-up of the bloodstream, and by diagnostic procedures that seemingly foretold the demise of organ systems. And all of this was contained within the seclusion of a hospital room (Kaufman, 2005).

The introduction of organized medicine and physicians into the death process was a significant agent for change in the shaping of EOL process and dilemmas. Chronicling this movement through history, Curtis and McGee (2000) described periods where physicians reigned as omnipotent in death and other phases when they absented the care of dying people. In medieval times, a combination of Hippocratic and Christian ideology "resulted in the physician's being both practical and secular" (Curtis & Magee, 2000, p. 342), so that their choice in not treating the dying patient was "reinforced... out of necessity for maintaining his social status and economic well-being" (p. 342). Until the conclusion of the 19th century, the physician had a place in the dying process. When death beckoned, however, the clergy's role crystallized, with attention focused on the person's spiritual issues at death's approach. So physicians receded from the deathbed "as the focus was on spiritual, not physical or medical salvation" (Curtis & Magee, 2000, p. 342).

In the next period, Curtis and Magee (2000) explained, "the possibility that people were prematurely buried brought about a heightened attention to the signs that death had occurred" (p. 343), and most physicians were repelled by the chance they would be part of abbreviating a patient's life. By the 20th century, physicians took up at the helm of treating the fatally ill (Curtis & McGee, 2000).

Through the 1900s, ethics and medical practice transformed and were transformed by the death process. Whereas, until as late as the 1970s, physicians withheld the news from a patient of her terminal diagnosis (Nuland, 1994), especially if it was cancer (Candib, 2002), the concepts of autonomy and justice emerged in the EOL consideration. In the early 1990s, the federal government mandated that all patients, who were admitted to hospitals that accepted Medicare reimbursement, were to be advised of their right to

designate what sort of care they would receive at the end of their lives—the Patient Self-Determination Act (Gavrin, 2007). Specifically, according to Teno, Gruneir, Schwartz, Nanda, and Wetle (2007), this was information to encourage patients "to participate in and direct their own health care decisions, to accept or refuse treatment, to prepare an advance directive (AD), and to be informed of the health care facility's policies on the use of these rights" (p. 189).

# Legal Cases Shaping EOL

This national effort to include people in their own treatment was a result of EOL court decisions that began in the 1970s and now extend to discussions of the seeming paradox of a good or healthy death. One case began in the 1970s. Karen Ann Quinlan's terminal care during a vegetative state may have been the most public assertion that dying had become problematic in contemporary society. The court cases surrounding the decisions of her treatment acuity, according to Kaufman (2005), "moved the topic of medical decision-making—the question of who best represents the patient's interest and, most important, the fear of a lingering and grotesque death—squarely into the public domain. The question became 'What do we do about her?'" (p. 64). This person is "a new kind of person—not fully alive and not quite dead—created by the confluence of high-tech machinery, attentive medical and nursing care, and the influence of the law on medical practice" (Kaufman, 2005, p. 64). The Quinlan case transformed death into "a matter of deciding when a person should be and when a person should be considered dead" (Kaufman, 2005, p. 65).

The Terry Schiavo case brought intense media and public attention on EOL decisions, most notably surrogate decision making and discontinuation of nutritional support. It was not the proto-typical EOL situation, as the more common EOL dilemma

was when a patient was in a hospital and receiving mechanical ventilation and chemical support of blood pressure and other vital signs. More typically, family and physicians, without court intervention, were most often left in the position of deciding what to do for the ill or injured patient. In the Schiavo case, the Florida legislature, the Florida Supreme Court, the U.S. Congress and President George W. Bush made formal, unprecedented decisions and interventions to allow and to prevent removal of life-support measures in the form of a feeding tube (Perry et al., 2005). She died on March 31, 2005, following the final removal of a tube that delivered enteral nutrition.

This exodus of death from home to hospital—the *medicalization* of death-meandered in a complicated journey with benefits that possibly equaled the
disadvantages for all involved, related to technological improvement and the dignity of
one's last days of life. Certainly, it affected how death occurred, was experienced and
was witnessed, according to Kaut (2002):

Albeit a natural and expected part of our existence, death is still viewed as failure—an affront to modern medical science. Although we are the beneficiaries of remarkable advances in modern health care, the prospect of death remains; moreover, the very nature of dying has changed. (p. 221)

Additionally, Gavrin (2007) noted a fundamental change in direction for physicians and medicine that occurred in the same time frame that death was relocated to the hospital:

Technological innovations during the last several decades have shifted the focus on medicine from simply caring for sick individuals to curing or alleviating most diseases. The skills we have acquired have become so sophisticated that we can chase away death, postpone it, and slow it down. (p. S92)

Good Death, Bad Death, Healthy Death: Cultural, Clinical Perspectives

With the power to delay death, as Kaufman (2005) wrote, the potential to elongate suffering or abbreviate existence loomed as a mixed blessing. This power was the difference between a good death and a bad death. Kaut (2002) explained that the oxymoron of good death may be "incompatible with prevailing notions of death as failure; however, the holistic care perspective, with its respect for spiritual awareness, may be essential in managing death anxiety and spiritual pain... thereby promoting spiritual health near the end of life" (p. 232). Conversely, other scholars pointed to the almost categorical absence of spirituality in EOL situations in hospitals (Breitbart, Gibson, Poppito, & Berg, 2004; Herman, 2007; Wenger & Carmel, 2004).

The 10 components of a healthy death, according to Gavrin (2007), across all spectra of care (but particularly in ICU), did not include explicit spiritual perspectives and were identified as:

the presence of significant others, 2) physical expressions of caring, 3) desire for truth, 4) control in decision making, 5) discussion of practical issues such as funerals and wills, 6) the opportunity to review the past, 7) maintenance of personal appearance and hygiene, 8) avoidance of inappropriate prolongation of the dying process, 9) relieving burden, and 10) strengthening relationships with loved ones. (p. S91)

Kaufman (2005) countered that the hospice approach, which would presumably embrace these 10 concepts, is the "contemporary symbol of the Anglo-American, middle-class idea of 'the good death'... in which the foci... are personal comfort for the patient... support for family and friends, while the patient knowingly and reflexively declines toward death" (p. 70).

Field and Cassel (1997) wrote that a federal study commissioned to examine EOL and death defined good death as: "one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (p. 4). They noted that the committee's definition of bad death is a bit more ambiguous, as a death "characterized by needless suffering, disregard for patient or family wishes or values, and a sense among participants or observers that norms of decency have been offended" (p. 4). Mularski et al. (2006) identified symptoms that may predict a poorquality death in ICU: 1) pain, 2) breathing difficulty, 3) agitation, 4) anxiety, 5) depression, 6) confusion and 7) fatigue.

# How EOL Appears in the Clinical & Hospital Setting

Within television content, I observed how EOL discussions and decision-making are treated. The bulk of these observations were words, delivered by characters of *ER*. In the clinical EOL literature, words about EOL are noted prominently—both what was and was not said. In this section, I explained briefly what the health care literature revealed, in order to illustrate what the state-of-the-science is perceived to be, as well as what was reported to have happened.

Best practices in EOL care. In 1997, the Robert Wood Johnson Foundation initiated a national program to examine the deficient practices in EOL care and to upgrade the delivery of palliative care to dying patients, called Promoting Excellence in End-of-Life Care. It sought to span age, race, geographic and practice location, ethnicity and economics to support pilot projects across the United States. The project was seminal for the production of literature about EOL experience in American hospitals. Of the 22

projects that the program funded, 20 of them were continued or expanded by the host institutions (Byock, Twohig, Merriman, & Collins, 2006).

A review of these studies as well as others gave a picture of EOL in the hospital and critical care setting. Based on this review, the broadest summary of how EOL often occurred there is: An older patient was admitted to an ICU, unconscious, with no written indication of their wishes for treatment or its termination. The patient was dependent on a ventilator for breathing and could not communicate with his or her physician or nurses. Several family members were present who understood nothing of the patient's prognosis, the expectations for their participation, or the meaning of much of the information given to them by physicians and nurses. Serious communication mismatches occurred between providers and the family, in terms of frequency, timing and vocabulary. These disparities complicated any EOL decision-making process that emerged, if it did at all. Tremendous anxiety resulted for family members who did not have a clear understanding of their role or what was happening to their ailing family member. Decisions were made in an excruciatingly drawn out fashion or in a staccato, chaotic environment.

Differences in acute care hospitals. Teno, Mor, Ward, and Roy (2005) compared EOL care in a high-intensity health service area (HSA), which included large, university-based hospitals with many medical specialties and where the majority of the nation's ICU beds were located and EOL care in a community hospital. They found that the patients who received more physician visits, with more specialists caring for them in hospitals did not have better family perceptions of care, related to important indicators of good EOL care. In lower-intensity HSAs, patients had more advance directives, but the care was noted to be less consistent with the wishes of the deceased. Ironically, in the lower-intensity HSAs where there were more advance directives, family members had more say

about the patient's care--despite the ADs--and were more likely to report that lifesustaining treatment was administered at the appropriate level (Teno et al., 2005.)

In another study (Mularski et al., 2006), family members rated the quality of life as 32 out of a possible 100 for the patient's last seven days of life before dying in an ICU. Only 47% said pain was controlled adequately, and the same portion discussed their wishes for care with a physician. Roughly a third perceived the dying person kept their dignity and self-respect and felt at peace with dying. A mere 3% reported the patient was breathing comfortably. Families who perceived pain control as adequate reported higher scores for the quality of the dying experience in an ICU.

As other scholars (Boyle et al., 2005; Rady & Johnson, 2004; Vig, Taylor, Starks, Hopley, & Fryer-Edwards, 2006) noted, critically-ill patients rarely make their own medical decisions, with 75% of them being made by surrogates. Five bases for decision-making that were identified by surrogates: 1) conversations, 2) advance directives, 3) shared values/experience with loved one, 4) surrogates' own beliefs, values and preferences about when "life is not really life anymore", and 5) turning to others for input and help (Vig et al., 2006, p. 1690). Perhaps predictably, Azoulay et al. (2005) found that a third of families reported symptoms consistent with Post-Traumatic Stress Disorder (PTSD), after their loved one died in an ICU or was discharged from a critical-care setting. Vastly more (80%) of those families involved in EOL decision-making reported the PTSD symptoms (Azoulay et al., 2005).

Psychology of the ICU death environment. The phenomena of "death denial" or a "rescue culture" (Nelson, 2006, p. S326) commonly detected in ICUs combined with unrealistic expectations by families, were found to contribute to patient care in that setting. Nelson (2006) wrote that nurses have reported that patient families don't

understand "what the phrase 'life-saving measures' really means" (Nelson, 2006, p. S325). ICU directors believed that the single greatest barrier to delivering optimal care to dying patients was: "patient/family demands for all possible treatment at the end of life" (Nelson, 2006, p. S325). Others suggested "public education to reflect the reality that 'modern medicine' cannot always fix what is broken" (Nelson, 2006, p. S325). It is possible that television content about EOL may be a family's only roadmap for the confounding terrain they will traverse, described poignantly by Gavrin (2007):

The essential workings of the ICU—all the participants, the hierarchies, the machines, the medical code [jargon], the severity of illness—are completely foreign to lay people; they have nothing in their experience, educational or otherwise, to use as an anchor for making sense of their surroundings....Patients and families become culprits, the more so because they do not have sophisticated training that is required of the workers in the ICU; they do not understand. (p. S90)

They do not understand. Indeed, ICUs may be the battlefield for an EOL ideology that can only be comprehended by a small, elite group of health care professionals, and families have become the enemy who is inferiorly armed for the fight.

Psychology of the professionals. According to Nelson (2006), the psychology of health care providers to reject death as a failure may simultaneously have made the early address of EOL issues to appear unseemly and premature, right up until it is almost too late for them to be managed. Levy et al. (2005) suggested that physicians and nurses were often at odds over EOL care in the nation's ICUs. They noted that physicians never thought their patient's death was prolonged, which "supports the hypothesis that attending physicians believed that the management was the most appropriate possible"

(Levy et al., 2005, p. 1780). Physicians and family members rated the death experience as more satisfactory than did nurses or residents, perhaps because the physician and family felt "a sense of responsibility for a 'good death'" (Levy et al., 2005, p. 1780). Black (2007) found that physicians reported fearing death more than nurses and social workers. The groups who brought up EOL with families most often were social workers and any health care professional with a recent death incident (Black, 2007).

Female physicians thought about death more and reported more comfort in dealing with families and patients about death than their male colleagues, according to Curtis and McGee (2000). These researchers found also that female physicians exhibited more depression over a patient's death and believed that physicians referred dying patients to other physicians, in order to avoid caring for a terminal patient.

Barton, Aldridge, Trimble, and Vidovic (2005) reported that obstetrician-gynecologists and psychiatrists handle death worst in a clinical setting whereas oncologists dealt with it the most comfortably, followed by neurologists. Curtis and McGee (2000) identified the factors that are important in how physicians approach and handle a patient's death. They included the physician's personal values, practicing in an urban setting instead of a rural setting, ethnicity and religiosity of physician.

Registered nurses in the ICU are sometimes viewed as the patient's strongest advocate, as well as the catalyst for stimulating EOL decision-making that shortens a patient's existence. Nurses are first to conclude that EOL care needs to be instituted. Levy et al. (2005) recounted that "most nurses (78%) thought that dying ICU patients received inadequate analgesia and 40% indicated that they acted against their conscience in caring for dying ICU patients" (p. 1780). Robichaux and Clark (2006) noted also that nurses experienced profound ethical discomfort when they perceived that excess

treatment prolonged the dying process. These authors also recognized the intertwined control and conflict of the health care professional providing care at the bedside, a phenomenon that seemed to assume a hcISA exists: "Acting for the patient poses the greatest ethical challenge at the intersection of 2 manifestations of power, the personal and the institutional, because a nurse can choose to act for institutionalized medicine as well as for the patient" (p. 484).

Gavrin (2007) considered the nurse's dilemma in EOL bedside care, which resonates as part of the power structure that can decide death's moment and manner. He wrote that, although nurses are often not consulted about the plan of care, they are left to carry out a physician's orders. The physician was free to avoid family interactions, leaving the nurse trapped at bedside delivering care that seemed futile and, thereby, immoral to the nurse.

Support termination decisions. Although EOL care is not only about termination or limitation of life-supporting therapies, termination of support was the most obvious issue closest to the time of death. Gavrin (2007) suggested that physician idiosyncrasy dictated the sequence in which these decisions are made. In general, recent therapies were stopped first. Then, organs that have failed naturally were not supported, and expensive therapies were halted sooner or avoided altogether. Gavrin (2007) wrote that the usual order for support termination is: "1) stop dialysis, 2) no new diagnostic tests, 3) stop blood pressure supporting medication, 4) stop IV fluids, 5) cease vital signs monitoring, blood tests and antibiotics, 6) stop infused feedings, 7) discontinue mechanical ventilation " (p. S90).

### Communication in EOL.

Studies of EOL care in ICUs indicated that families often cited communication from physicians and other health care team members as unsatisfactory and contributing to the stress of the situation (Lautrette, Ciroldi, Ksibi, & Azoulay, 2006). Communication with physicians was identified as the single biggest flaw in EOL care. In physician-authored research (Boyle et al., 2005), however, communication was only one among many problems perceived as impediments to managing EOL situations with families. Communication was identified as a tool that physicians may use as a means to the end of maintaining the appearance of being in control (Boyle et al., 2005). One study revealed that people of all races wanted "more jargon-free, understandable information regarding the patient's health status and expected outcomes" and were frustrated about their "inability to get doctors to talk to them" (Braun, Beyth, Ford, & McCullough, 2010, p. 271). In particular, Braun et al. (2010) found that African Americans preferred a physician to show more sensitivity and honesty by "easing family into the bad news" (p. 271).

In a discourse analysis of EOL discussions, Barton et al. (2005) noted that greetings and introductions were used to "establish the authority of the physician conducting the discussion" (p. 3). Families were more satisfied when the EOL discussion was led by a physician who was in charge of the patient's care. Boyle et al. (2005) found that, during meetings, "family members' ratings of satisfaction with physician communication increased as the ratio of family members' to physicians' speaking time increased" (p. 303). Perhaps unfortunate, then, may have been the finding that physicians spoke approximately 73% of the time in the EOL discussions (Levy & McBride, 2006)

that Vig et al. (2006) reported to be a source of conflict for families with the clinical staff about half the time.

Families unprepared for the shock. EOL discussions were complicated by the shock of an ICU admission to families. Boyle et al. (2005) wrote that the complications were compounded by the fact that no more than 10% of patients had advance directives in place or had the capacity to participate in EOL decisions. Lautrette et al. (2006) found that, in less than five percent of the time, EOL decisions were made with direct input from the patient who was dying. In Rady and Johnson's (2004) study, no patient who died after being treated in an ICU had discussed "palliation or end-of-life care as an alternative treatment" (p. 705) compared to 25% of patients who died on general wards after having discussed the topic. The ICU patients had less pain control, more invasive treatments and incurred charges nearly four times as high as the general ward patients.

Vulnerable patient populations. One patient population particularly vulnerable in the application of EOL measures was dementia patients who were at a distinct disadvantage in communicating their own wishes. Richardson, Sullivan, Hill, and Yu (2006) reported that, during the last month of life, a dementia patient received far less aggressive treatment than those without it. Patients with dementia were less likely to: 1) be admitted to an ICU, 2) be placed on ventilator, 3) receive dialysis treatments, 4) have invasive vital sign monitoring, or 5) receive a cardiac catheterization. In civilian hospitals, patients with dementia were admitted to ICUs less often than at VA hospitals, but they were more likely to get ventilator and dialysis services as well as to have highly-invasive pulmonary artery monitoring of cardiac status (Richardson et al., 2006).

Ironically, in the VA setting, dementia patients who either fractured a hip or developed

pneumonia received as many painful or uncomfortable procedures as cognitively intact patients.

Influences of past century. The intersection of economics, technology and political power shaped how health care was delivered over the past half-century in the U.S. Decades ago, the standard was, according to Feldstein (1999), Fuchs' "technological imperative" in which no matter "how small the benefits were to the patient, or how costly the benefits were to the insurer, the physician would prescribe the best medical care that was technically possible" (p. 36). The pendulum appears to swing now toward the side where EOL decisions are demanded by government authorities, with sooner-rather-than-later being the preference. Field and Cassel (1997) bluntly attributed the reason for increased concentration on EOL care to the fact that the largest payer of health care monies in the United States—the federal government—was responsible for taking care of the oldest and sickest populations. As they wrote: "One reason for the attention to the cost of care at the end of life is that such care is, in considerable measure, funded through Medicare, Medicaid, veterans, and other public programs" (p. 3).

Adjustments in reimbursement mechanisms heralded a change in the teaching of health-care providers, most prominently physicians. Dickinson (2002) noted a culture change in medical schools was slowly beginning to take into account that death is unavoidable. Rich (2007) suggested that the embedded concept of "death as a cosmic shame... is quite consistent with the reigning curative (in contradistinction to the palliative) model of medicine, which views death as the ultimate enemy and the essence of medical failure" (p. 63). Medical schools began to offer death education, with an increase in schools offering a death and dying course from 7% in 1975 to 18% in 2000

(Dickinson, 2002). Curricula for these courses emerged as well (Ellison & Radecke, 2005).

Implications for racial and ethnic minority communities. Although best practices for EOL practice would not be a panacea for all people and all groups, it would presumably fit the majority's goals and needs—people and institutions supported by and maintaining a dominant power structure. This would include people and institutions with similar backgrounds and perspectives. But what about groups who are not in the majority? One area well researched in health care was racial disparity in health care access and utilization. A report of a 2002 federal study (Smedley, Stith, & Nelson, 2003) regarding racial and ethnic disparities highlighted misconceptions about health care usage and the fatal results of the lack of access by racial and ethnic minorities. Describing the disparities as "remarkably consistent across a range of illnesses and healthcare services," the report's authors wrote that "a significant majority of Americans believe that blacks... receive the same quality of healthcare as whites" (Smedley et al., 2003, p. 2). In fact, according to the report, minorities did not get an array of appropriate medical and surgical therapies and interventions at nearly the same rate as Caucasian people and "these differences are associated with greater mortality among African-American patients" (Smedley et al., 2003, p. 3). Sources for inequality of health care service delivery, according to the U.S. Institute of Medicine report (Smedley et al., 2003) include: 1) changes in finance and payment systems, 2) individual misunderstanding and mistrust of providers and the system, 3) provider bias and prejudice, and 4) strained resources, including patient-provider time of interaction.

Researchers explored mistrust of the medical system by African Americans, noting that it may have limited their utilization of needed health care services (Chandler,

2010; Shelton et al., 2010). This mistrust grew from a number of reasons, including: 1) a lack of "cultural competence" (Kennedy, Mathis, & Woods, 2007, p. 58) by health care professionals in understanding the specificity of African American experiences within society, 2) a deficit of African American and other minority physicians and other health care providers with whom vulnerable patients could develop a relationship of trust, and 3) an abusive history of unethical medical research that used African Americans as unwitting participants (Kennedy et al., 2007). Examples of this unscrupulous research included the United States Public Health Service's Tuskegee Syphilis Study, conducted in Macon, Alabama, from 1932-1972 (Green et al., 2011; Katz et al., 2008; Reverby, 2010), as well as other ways that African Americans were used opportunistically by medical professionals, such as for the development of the first immortal human cells for research (Skloot, 2010).

The medical system may be viewed as part of the larger dominant political structure in the United States. Some authors surmised that African Americans have less confidence in government because of the "historical marginalization of Blacks in every element of American society" (Haider-Markel, Delehanty, & Beverlin, 2007, p. 587). As members of the "dominant biomedical culture" (Candib, 2002, p. 213) physicians were blinded, perhaps to the possibility that other ethnicities could hold long-standing values in opposition to relatively-new ones about EOL. This phenomenon "becomes problematic for patients from cultures who place a higher value on family connectedness than on individual autonomy and from cultures who may value life at all costs over an easy death" (Candib, 2002, p. 213). An understandable mistrust of health care institutions and professionals by the largest minority group in the United States would likely affect this

group's acceptance of a dominant EOL ideology in the health care setting and any acquiescent participation in EOL decision-making that reflects the dominant ideology.

Brain death and organ donation. An additional area of exploration that I included was that of organ donation and brain death, simply because these areas often co-exist in EOL considerations. Brain death, by virtue of its nature, is an accepted concept that is associated with EOL decisions, such as ventilator removal and other support termination (Derse, 2000).

Brain death was a relatively rare occurrence, being 2-6% of deaths. When a person met all the criteria for neurological death, as demonstrated by examinations revealing no brain function or blood flow to the brain, a ventilator can continue supplying oxygen to the brain dead patient's lungs. This support allowed the heart and the rest of the body to continue functioning for an indefinite period of time. A patient who is declared to be brain dead may become an organ donor (Wijdicks, 2001). Vital organs such as the heart, lungs, liver, kidneys, and pancreas, may be recovered only from a person who is dead. This discussion does not include the donation of a kidney or a portion of another organ that a person may give while still living. It also does not include Donation After Cardiac Death (DCD), which is estimated at less than 10% of all organ donation (Tuttle-Newhall et al., 2009) in the United States.

Some hospitals had policies that allow or require physicians to stop the ventilator after brain death is pronounced. However, most families were part of the discussion and the timing of that event. In between brain death pronouncement and termination of support was when organ donation decisions were made and the recovery of organs was effected. The U.S. Department of Health and Human Services' Center for Medicare and Medicaid Services (CMS) oversees both hospitals and the organ donation infrastructure.

Over the past decade, there were several federal initiatives designed to increase organ donation in the United States. CMS' Organ Donation Breakthrough Collaborative began in 2003 (Tuttle-Newhall et al., 2009) and focused on improving the consent rates gained for organ donation at the time of a patient's death. These best-practice interventions focused on discussions with family members after a death occurred—not the autonomous decision made by an individual prior to death. A few years later, the aim was focused on creation of organ donor registries in every state whereby a person registers his or her autonomous decision to be an organ donor in a database, to be honored at the time of death. No family authorization would be required. So, brain death and organ donation have a rightful place in the consideration of EOL care and decision-making, as they are very present in the ICU death locus and are overseen by the dominant power structure. *Identification of Research Problem* 

A great challenge in the study of EOL has been to define it. A 2004 federal report about EOL care in 2004 by the Agency for Healthcare Research and Quality (AHRQ) effectively retreated from the attempt to define EOL, sufficing to say there are components that make up EOL. For the purposes of this study, I considered the second section of components as an adequate definition for this consideration of EOL as portrayed in television programming focused on critical care areas:

...The evidence supports the following components: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death. (p. 3)

Why study such a somber topic—the antithesis of health—as it is portrayed in medical/health programming? Is there any crucial need for understanding what is inevitable for all people, yet dreaded? On a macro level, the U.S. is reaching a state of near calamity in paying for all health care, with particular distress regarding options for an aging population of Medicare recipients who were born just after World War II. Some scholars defined EOL as a public health issue (Rao, Anderson, & Smith, 2002) verging on crisis and in need of systematic, educational address. The U.S. Institute of Medicine (Field & Cassel, 1997) decried the lack of consistency or cogency in how care at the end of a human's life is decided:

Legal, organizational, and economic obstacles conspire to obstruct reliably excellent care at the end of life... Traditional financing mechanisms—including arrangements based on discounted fees—still provide incentives for the overuse of procedural services and the underprovision or poor coordination of the assessment, evaluation, management, and supportive services so important for people with serious chronic or progressive medical problems. (p. 5)

This review of the literature indicated there was a virtual absence of scholarship about the portrayal of EOL care in televised dramatic programming. I wanted to know how a person's end of life is shown in influential television programming. I believed that mass media scholars should investigate how this content affects viewers, no matter if it mimics reality or is dramatically beautified. Scholarship value exists in appreciating the frequencies with which demographics and behaviors that are involved in EOL are represented in television programming. So, I posed the following questions to determine these frequencies, to assess for the proxy of a dominant EOL ideology represented by

definitions and terminology of EOL found in clinical research and government policies and to probe for deeper, latent meanings in the way EOL is portrayed in *ER*.

Research Questions

RQ1: How often do EOLIs occur in ER?

RQ2: How much time is taken up by EOL discussions depicted in ER?

RQ3: Where do EOL discussions take place in *ER*?

RQ4: What diseases were most common for patients in the EOLIs?

RQ5: How often is medical jargon observed in EOLIs in *ER*?

RQ6: What legal terminology about EOL appears in the EOLIs in ER?

RQ7: What age group was most common for EOLI characters in *ER*?

RQ8: How often were women depicted as characters within EOLIs in *ER*?

RQ9: Which racial group was represented most often in the characters depicted in EOLIs in *ER*?

RQ10: How are health care professionals depicted in EOLIs in *ER*?

RQ11: What are the outcomes of EOLIs depicted in *ER*?

RQ12: Which topics, observed in the heath care literature about EOL, appear in EOLIs in *ER*?

RQ13: How is a federal definition of EOL—"(1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death" (Agency for Healthcare Research and Quality, 2004, p. 3) -- depicted in *ER*?

RQ14: What cultural practices regarding death and dying appeared in the EOLIs in *ER*?

RQ15: How is mistrust of medical professionals and institutions depicted in the EOLIs in *ER*?

#### CHAPTER III

#### METHODOLOGY

In this dissertation, I used both a deductive and an inductive approach to content analysis. I viewed a purposive sample, consisting of every episode in the 15-season, primetime television drama, *ER*, to determine which episodes contained EOL situations. Then, I analyzed those episodes to determine both the manifest content, including how frequently particular aspects of EOL are portrayed and also latent content that could indicate the presence of an EOL ideology. The benefit of qualitative interpretation is the permission to describe and to be unfettered by a yes/no choice. This latitude allows researchers to observe freely and to expand theoretical horizons and simultaneously document phenomena for future study. This study, then, was a cross-disciplinary approach to interpretation of "the deeper meanings that lay just beneath the surface of a culture's artifacts" (Campbell, 1995, p. 13). According to Holsti (1969), a methodological triangulation of this sort gives a more robust appreciation of the studied topic: "It is by moving back and forth between these approaches [qualitative and quantitative] that the investigator is most likely to gain insight..." (p. 11).

#### **Procedure**

I viewed every episode in the 15 seasons to identify which ones contain EOL content. Then I assigned the EOL content into pre-determined categories, completing a coding instrument for each situation in which characters communicate EOL content. A second coder was trained in use of the coding instrument. She viewed 10% of the EOL-containing episodes or an approximation of that amount. She was a registered nurse who worked in the field of organ donation for 10 years and was a graduate student of ethics in health care. Several sessions of training for this coder gave her a grounding in the

logistics of completing the coding instrument (Appendix B & Appendix C). The co-coder was well-versed in the topics that are included on the coding instrument, both by virtue of professional experience and scholarly research.

### Coding Instrument

The coding instrument yielded frequencies that are "the objective, systematic, and quantitative description of the manifest content" (Berelson, 1952, p. 18). Some of these variables of interest were programming characteristics such as airdate, demographics of the characters, as well as the areas of EOL care mentioned above, used in the EOL ideology proxy. Virtually every item (gleaned from the health care literature review) that was included on the coding instrument was operationalized by a definition that was listed in Appendix A. Others were listed only in the coding book. For example, "jargon" was defined as "the technical terminology or characteristic idiom of a special activity or group" (Jargon (Def. 2), n.d.)

In addition, the qualitative analysis, as well as an abstraction of an EOL ideology proxy, seen in Figure 2, was used to reveal patterns, themes and undercurrents of thought that could indicate the presence of an EOL ideology. In particular I assessed for the presence of an EOL ideology that is indicated by: 1) EOL definition components, 2) aspects of EOL care found in the health care literature and 3) legal issues that pertain to EOL found in the health care literature. In Figure 2, I illustrated the level of abstraction that I used to investigate the research questions. The items on the far left labeled "Sub-Category" were the variables of interest that I labeled for the coding process. These items were used for the consideration of an EOL ideology.

## Sample

I chose a census sample, according to Krippendorff's (1980) definition, of all *ER* episodes in order not to miss any EOL references in the longest-running medical drama in U.S. television. The value of considering this sample is that it affords me the opportunity to analyze a larger volume of EOL content than would be accomplished by a random sample. The sample also allows me to observe any changes that occur in the portrayal of EOL content over a 15-year span of time. This could contribute to the consideration of any emergence or solidification of an EOL ideology over time.

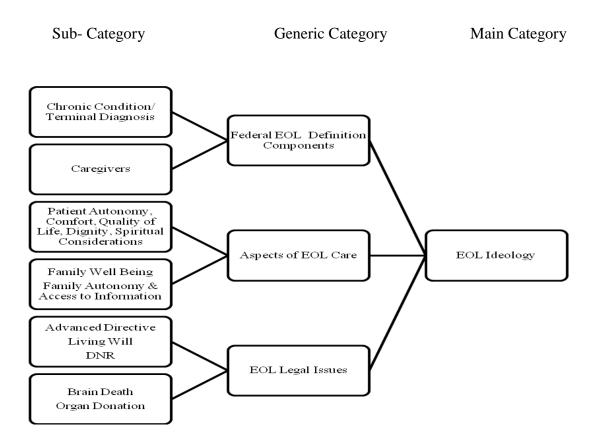


Figure 2. EOL Ideology Proxy Abstraction. From left to right, the specificity of each category lessens, demonstrating that an ideology is made up of concepts that describe practices in the culture. The concept of abstraction was adapted from Elo & Kyngas (2008) to illustrate how an ideology may be formed and identified.

### Unit of Analysis

The unit of analysis in this content analysis was an EOL incident, (EOLI), which is any part of a scene in which EOL content is discussed by any character in an episode of *ER*. This meant that more than one coding sheet was completed for each episode that contains EOL content. A participant coding sheet was completed for each character who was involved in the EOLI. This procedure captured as much of the information as possible about EOL discussions, including perhaps the most important—the characters and the relationships between them, e.g. physicians and their patients. This was the core of my research—to determine if power imbued in members of a dominant power structure influenced the EOL care of a person outside of the power structure.

Similarly, Elo, and Kyngas (2008) defined a unit of analysis in qualitative studies as variously as "a letter, a word, sentence, portion of pages or words, the number of participants in discussion or time used for discussion" (p. 109). Graneheim and Lundman (2004) advised that a unit of analysis should be "large enough to be considered a whole and small enough...to keep in mind as a context for the meaning unit" (p. 106), which in this study was any reference to EOL: components of a definition, aspects of EOL care or legal issues pertaining to EOL decisions. All of these items were language structures that were connected by "their content and context" (p. 106).

The "meaning unit" (Graneheim & Lundman, 2004, p. 106) was the words used about EOL contained in the EOLI, about issues, care or decision-making, whether an offhand remark or a lengthy discussion, found in *ER*. These references were considered an EOL "theme (that)...might be expressed in a single word, a phrase, a sentence, a paragraph, or an entire document... expressions of an idea," according to Zhang & Wildemuth (2009, p. 310). The notes that I made about each episode served as a source

of information about themes that emerge over time in the content. Again this added robustness to my study as it yielded more knowledge about EOL in television content than was gained within the confines of coding on the data collection instrument.

\*Reliability\*

Utilizing a second coder to view content and complete the coding instrument allowed me to gauge reliability. Intercoder reliability was assessed using Holsti's (1969) formula. This formula was 2M/N<sub>1</sub>+N<sub>2</sub>, in which M is the total items agreed upon by the coders, and N is the numbers of decisions made by each coder. Holsti (1969) noted that a criticism of this measure is that the possibility of agreement by chance is not included in it. Reliability was reported for each EOLI coded by each coder. Overall, the interrater reliability coefficient was .96 for the EOLIs, combined, which is acceptable. Many items had a coefficient of 1, which indicated no disagreement between the coders. On the low end of the agreement scale, several items had coefficients less than 90—three of the EOLIs, treatment refusal, patient autonomy and family well-being. All coefficients were listed in Appendix D.

### **CHAPTER IV**

## QUANTITATIVE RESULTS

All of the quantitative results pertained only to EOLIs in ER, not the entire show.

RQ1: How often do EOLIs occur in ER?

EOLIs appeared in 34% (n=114) of the 331episodes that aired in 15 seasons of *ER*. As defined, EOLIs sometimes occurred more than once per episode, although most EOLIs in a single episode related to one specific patient-centered circumstance. In the 114 EOLI-containing episodes, 222 EOLIs were observed and described on an EOLI Coding Instrument, supplemented by descriptive notes. The basic information about the viewed content is summarized in Table 1. Appendix E contains a list of all episodes, their airdates and if EOL content was noted in them.

Table 1

Frequency of EOLIs

Description	Number of times observed
Total episodes viewed	331
EOLIs, total	222
Characters in EOLIs	232
Total character appearances	748

RQ2: How much time is taken up by EOL discussions depicted in ER?

Half (50.5%, n=112) of EOLIs lasted less than a minute, with 49% (n=109) lasting 1-5 minutes, and only one lasting longer than 11 minutes. Another way that EOLIs were measured involved how in-depth the discussion was, in one of seven ways:

1) brief comment by HCP, 2) discussion between/among HCPs, 3) discussion between

patient and HCP, 4) discussion between family and HCP, 5) discussion including patient, family and HCP, 6) discussion between family members, or 7) other. The portions of EOLIs that were in each of these descriptions are found in Table 2.

Table 2

The Depth of Discussion in EOLIs

Type of Discussion	Portion of EOLIs	Number of EOLIs	
Brief comment by HCP	3.6%	8	
Discussion between/among HCPs	35%	78	
Discussion between patient & HCP	19%	42	
Discussion between family & HCP	37.8%	84	
Discussion among patient, family & HCP	3.6%	8	
Discussion among family members	.5%	1	
Other	.5%	1	
Totals	100	222	

RQ3: Where do EOL discussions take place in *ER*?

Some of the data described, in general, how an EOLI *looks*, most notably the location of the EOLI. In Table 3, the locations were noted. Overwhelmingly the most common location was an ER treatment room. EOLIs occurred least often in a chapel, medication/supply room and a health care professional's office. Other locations included a physician's home and other locales away from the Chicago hospital where *ER* was located. They made up 3.6% (n=8) of the locations. All locations are listed in Table 3.

Table 3

Location of EOLIs

Location	Portion of EOLIs	Number of EOLIs
ER treatment room	62%	138
Hallway	17%	38
Nurse's desk	5%	11
Waiting room	4%	9
Outside hospital entrance	2.3%	5
Patient care ward	2.3%	5
ICU patient room	1.4%	3
Hospital patient room	.5%	1
Conference room	.5%	1
Medication/supply room	.5%	1
Chapel	.5%	1
HCP's office	.5%	1
Other	3.6%	8
Totals	100	222

RQ4: What diseases were most common for patients in the EOLIs?

Each patient was diagnosed with an illness or injury. Closely-associated diagnoses, such as brain injury and neurological disease were combined for simplicity. The most common patient diagnosis was brain injury, including stroke (36.5%), followed by cancer (21%), trauma (10%), and respiratory disease (9% each) and heart failure (6.8%). Cancer was the second most common diagnosis in the CDC data for 2000, for

2010 and in *ER*. Cardiac disease and heart failure was grossly underrepresented in *ER*, when compared to the CDC data for 2000 and 2010. The complete list of death-related diagnoses is found in Table 4.

Table 4

Comparison of Causes of Death by CDC in 2000 and 2010 and in ER EOLIs from 1994-2009

Number	CDC 2000	CDC 2010	ER 1994-2009
1	Heart Disease	Heart Disease	Brain Injury & Neurological Disease (36.5%)
2	Cancer	Cancer	Cancer (20.7%)
3	Cerebrovascular	Cerebrovascular	Trauma (10.4%)
4	Chronic Lower Respiratory Disease	Cerebrovascular	Respiratory Disease (9%)
5	Unintentional Injury	Unintentional Injury	Heart Failure (6.8%)
6	Diabetes Mellitus	Alzheimer's Disease	HIV/AIDS (3.6%)
7	Influenza and Pneumonia	Diabetes Mellitus	Sepsis (2.3%)
8	Alzheimer's Disease	Influenza	Kidney Failure (1.4%)
9	Nephritis	Nephritis	Liver Failure & Lupus (.9%)
10	Septicemia	Suicide	Dementia, Diabetes, Pertussis, Genetic Disease

Asian patient-characters had the fewest diagnoses, with only brain injury, cancer, or HIV/AIDS. African American patient-characters had brain injury, cancer, diabetes, kidney failure, heart failure, pertussis, respiratory disease, or sepsis. Caucasian patient-characters had the most variety in diagnosis, with all in Table 4 (except for pertussis) being represented in that race category.

Pearson Chi-Square tests in cross-tabulations revealed relationships between issues documented in the health care literature about EOL and patient diagnoses. They are listed in Table 5. When one variable was dependent on another variable, indicating a Table 5

Relationship	Between	<b>EOLI</b>	Topics	and	Patient	Diagno	osis
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EOLI Topic	Patient Diagnosis
Terminal Diagnosis	AIDS/HIV (75%), brain injury (28%), cancer (63%), liver failure (50%), neurological disease (70%)
DNR	Cancer (33%), diabetes (100%), heart failure (34%), liver failure (100%), sepsis (60%), trauma (26%), respiratory disease (80%)
Patient Autonomy	Respiratory disease (55%), sepsis (80%)
Patient Comfort	AIDS/HIV (50%), cancer (35%), heart failure (20%), liver failure (50%), neurological disease (30%)
Spiritual Considerations	Brain injury (41%), kidney failure (33%), trauma (44%)
Advance Directives	Dementia (100%), heart failure (13%), neurological disease (10%), pertussis (100%)
Treatment Refusal	AIDS/HIV (50%), liver failure (50%), lupus (100%), neurological disease (35%)
Brain Death	Brain injury (41%), trauma (44%)
Organ Donation	Brain injury (54%)

relationship, the level of significance throughout this study was generally p < .01 or better, but those that were only significant to p < .05 were accepted. Several correlations between the issues and patient diagnoses reached statistical significance. Brain death was linked strongly to brain injury and trauma. The topic of organ donation was linked

strongly to brain injury as a diagnosis. Terminal diagnosis was a topic most often in AIDS/HIV, followed by neurological disease, cancer and liver failure. Patient comfort was also linked to AIDS/HIV, cancer, liver failure, heart failure and neurological disease. Spiritual considerations, which came up rarely in the EOLIs was linked to brain injury, kidney failure and trauma. Respiratory disease and sepsis were the only two diagnoses correlated with the topic of patient autonomy.

RQ5: How often is medical jargon observed in EOLIs in *ER*? This study of *ER* episodes revealed that half (49.5%, n=110) of the EOLIs contained jargon, either predominately or paired with layman's terms, in the EOLIs. Only 14.4% (n=32) of the EOLIs were dominated by technical jargon. Jargon was more likely to be used in the EOLI when physicians spoke most ( $\chi^2 = (24, n = 222) = 47.71, p < .01$ ). When patient comfort was discussed, jargon was less likely to be employed, in a correlation that reached statistical significance ( $\chi^2 = (3, n = 222) = 15.61, p < .01$ ). In EOLIs that included patient comfort, only 3% (n=4) had technical jargon predominate, whereas 19% (n=42) had mostly layman's terms. Conversely, when brain death was a topic, jargon predominated in those EOLIs, in a correlation that reached statistical significance ( $\chi^2 = (3, n = 222) = 18.73, p < .01$ ).

RQ6: What legal terminology about EOL appears in the EOLIs in ER?

In this study, content for legal terms that pertain to EOL and that appear in the health care literature were examined. Each of these terms was defined in a glossary included in the Appendix A. Overall, 291 mentions of legal terms occurred in the 222 EOLIs. DNR and patient autonomy were the most frequent terms observed in use, while living will appeared the least frequently. Of all the patient demographic descriptions, patient age reached statistical significance most often with the topics discussed in the

EOLIs. Mentions of organ donation and patient age were related. One-fourth of organ donation mentions were in the 12-21 year group, and 47% of organ donation mentions were in the 22-40 year group. All legal terms are summarized in Table 6.

Table 6

Legal Terminology in EOLIs

Legal Term	Number of times mentioned	
Advance Directive	16	
Brain Death	42	
Do Not Resuscitate	68	
Family Autonomy	48	
Living Will	6	
Patient Autonomy	68	
Treatment Refusal	43	
Total	291	

Patient age and advance directive were related, in that 56% of the mentions of advance directive were for patients ages 41-60; 18% were for patient ages 61-80, and 13% were for those older than 80 years. Patient age and living will were related, as half of this topic's mentions occurred in the patient age group > 80 years, and 17% were in ages 61-80. The topic of DNR is related to age, in that 42% occur in the groups above age 60. Patient age and patient autonomy were related, in that 43% of the mentions of patient autonomy were in the age groups above age 60, and 25% was in the 41-60 year group. Family autonomy was also related to patient age. A third of the mentions of family autonomy were when the patient was 12-21 years old and 15% when the patient was a

child under 12. Ten percent of the family autonomy mentions occurred in those over age 80. All correlations between patient demographics and topics discussed are summarized in Appendix G.

RQ7: What age group was most common for EOLI characters in *ER*?

*Patients*. Patients in EOLIs accounted for 44% of all of the 232 characters. Most patients were 22-40 years old (23%, n=24). The next largest age group was 41-60 years old with 21% (n=22) in it. Children from 12-21 years were 14.4% (n=15) of the patient group. Children younger than 12 years were about 10.5% (n=11) of the group. People over the age of 80 were 8.7% (n=9) of the patient-characters.

*Physicians and nurses.* Among physicians, 31% (n= 10) were 41-60 years old, with the remainder in the 22-40 years old category. Most nurse characters (62%, n=8) were in the 22-40-year-old category. Five were 41-60 years of age. None appeared to be older than age 60.

RQ8: How often were women depicted as characters within EOLIs in *ER*?

Overall, women made up about 45% of characters in EOLIs. Of the 104 patient characters, 30% (n=31) were female. In EOLIs, 13 nurse characters (5.5% of total) made 5% (n=37) appearances (out of the total 748 character appearances). The nurse character set was overwhelmingly female (85%, n=11). Of the 31 physician characters, a dozen (39%) were women. Wife characters numbered 10 and appeared 16 times. In the EOLIs, there were 15 characters who played the mothers of patients. When DNR was discussed in the EOLI, the patient was more likely to be a female, with 53% of the DNR discussions involving a female patient.

RQ9: Which racial group was represented most often in the characters depicted in EOLIs in *ER*?

Characters in the EOLIs were more likely to be Caucasian (78%, n=181). These Caucasian characters accounted for approximately 85% of all appearances in EOLIs. African American characters totaled 13% (n=31) of all characters, and they made only 9% of the 748 character appearances (n=69). Ten Asian characters appeared 21 times, which was 4% of the total characters and 2.8% of the total appearances. Hispanic characters were least represented, with 2% (n=5) of the characters making eight appearances (1%) in EOLIs.

Patients. The race of patients in the EOLIs observed was overwhelmingly Caucasian (77%, n=80). Asian patient characters made up 1.9% (n=2) of the patient-characters, and the same was true for Hispanic patient-characters. In 15 years of the series, EOL experiences were written for 12 (11.5%) African American patient characters. They made 8.5% of the total patient character appearances in EOLIs, which was 3% of all character appearances. Hispanic EOL situations accounted for the least of all patient appearances, with three (1%) of the 222 EOLIs featuring two (1.9%) Hispanic patient characters. Unnamed patient characters appeared as 9 (8.6%) characters in 15 (5.5%) appearances. Some of these appearances took place through the dialogue of another character, so that their demographic descriptions were not available (5%, n=5).

Physicians. Five of the physician characters in EOLIs were African American. Only three had recurring roles over multiple seasons. The five African American physician characters (16% of physician-characters) made 35 of the 748 character appearances (5%) in EOLIs. One physician character, an Asian female, assumed her given first name, which was a traditional Chinese name, during the series. This sole Asian American physician accounted for 3% of physician characters. She made five appearances out of 748, for a total of .7% of appearances by an Asian physician character

in EOLIs. No Hispanic physician characters appeared in EOLIs in *ER*. All other physician characters in EOLIs were Caucasian (n=24, 77%), except for a single character of Indian heritage (3%) who appeared six times (.8%) out of 748 character appearances in EOLIs.

*Nurses*. The race of the patient and health care professional groups is summarized in Table 7.

Table 7

Race of Selected Character Groups in EOLIs

Characters	Race	Proportion of Characters (n=232)	Proportion of all appearances (n=748)
All Characters	Caucasian	78%	85%
	African American	13%	9%
	Asian	4%	2.8%
	Hispanic	2%	.9%
	Undetermined	4%	1%
Patients (n=104)		45%	36%
	Caucasian	77%	24%
	African American	11.5%	3%
	Asian	1.9%	.9%
	Hispanic	.9%	.4%
	Undetermined	2%	1.2%
Physician (n=31)		6%	5%
	Caucasian	38%	2.7%
	African	23%	06%
	American		
	Asian	15%	.4%
	Hispanic	15%	2.7%
	Undetermined	8%	.3%

RQ10: How are health care providers depicted in EOLIs in ER?

Physician presence dominated EOLIs. Physicians were the most numerous health care provider in EOLIs, with 31 separate characters, followed by 13 nurse characters. Physicians spoke most in the EOLIs. In 64% of the EOLIs (n=142), physicians spent more time speaking than any other character. Conversely, nurse characters spoke the most only 4% of the time. Other health care providers spoke most only .9% of the time. Based on screen-time alone, physicians had the most influence in EOLIs, among all health care providers. Few other health care providers played dominant roles. A social worker, a physician's assistant and an organ donation coordinator made scant appearances. The organ donation coordinator was treated with disdain by other health care staff. One character began the series as a nurse (who had quit medical school earlier). She returned to her medical residency, so she became a physician character. Also, two physician characters evolved into patients, as they suffered illness and injury themselves.

RQ11: What are the outcomes of EOLIs depicted in *ER*?

Most often, the outcomes of EOLIs portrayed in *ER* were nebulous, without a definite resolution. Nearly half (45%, n=99) were categorized as unclear or unstated. When the outcome was apparent, 21% (n=47) were coded to accelerate care, and 15% (n=33) were gauged as wait and see. The remainder was divided among gradually decelerate care at 8% (n=18) or immediate termination of support (4%, n=8). Only 3% were turfed to another physician. Five percent (n=11) of EOLI outcomes were coded other.

RQ12: Which topics, observed in the heath care literature about EOL, appear in EOLIs in ER?

As seen in Table 5, participants discussed terminal diagnosis most often in the 222 EOLIs, followed by DNR and patient autonomy, family autonomy and information access, organ donation, treatment refusal, brain death, patient comfort and quality of life. The topics that cropped up with least frequency included living will, spiritual considerations, family well-being, advance directive, dignity, and plan to communicate with family. Some diagnoses were predictive of the topics that arose in the EOLIs, and these relationships are noted in Table 5, along with the frequency of occurrence.

RQ13: How is a federal definition of EOL—"(1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death" (Agency for Healthcare Research & Quality, 2004, p. 3)--depicted in *ER*?

Although no overt references to this federal definition of EOL were observed in the EOLIs, indications that a general understanding of this concept existed. Patients were admitted to the hospital for amelioration of symptoms of diseases such as cancer, renal failure and chronic respiratory disease. These patients required care that was paid, professional. Very few patients were considered hospice patients in the EOLIs, which would presume a longer progression of the disease. Patients who suffered traumatic injury or a rapid diagnosis of fatal illness did not fit within this definition as neatly, however, but could be considered close to its broad confines. Functional impairments that persist encompassed virtually every patient's condition who was admitted for care.

#### CHAPTER V

## QUANTITATIVE DISCUSSION

As defined in this study, an EOL ideology was evident in *ER*, and the health care system in the United States would fit the definition of Althusser's Ideological State Apparatus. Although there was no indication that the ideology leaned toward limiting care to patients near the time of death, the mere fact that EOL was addressed repeatedly throughout 15 years of programming indicates an ideology was present. An ample amount of EOL content conflicted with any trend toward abbreviating life-saving therapies, i.e. it embraced the technical imperative to sustain life at all costs. The outcomes of EOLIs were least likely to be terminate support immediately. The mere presence of this volume of EOLIs within *ER*, however, demonstrated that viewers received substantial exposure to the concepts and vocabulary of EOL. So, a mass media product in *ER* effectively delivered an EOL ideology that is found in the scholarly body of work produced in the hcISA.

EOL decision-making is neither good nor bad. Cogent reasons exist for a person to participate in decisions about their own EOL care and for family members to make decisions for someone who is not able to make their own. The possibility exists, however, that a dominant power structure, such as health care authorities within the federal government, pushed along incentives to curtail costs in hospitals by increasing awareness of and adherence to an EOL ideology that rejects use of critical-care services for the dying. If people participated in this ideology knowingly and voluntarily, then it could be interpreted as a reflection of cultural values. If those affected by the EOL ideology did not realize that their behavior was being influenced covertly by a power structure, without concern for their individual welfare, the ideology was coercive. The compelling

reason for studying all of the ways that EOL were portrayed in an influential television series was to see if an ideology misled and persuaded viewers that they know what to do about EOL, instead of explaining the realities of EOL.

A fictionalized example follows of how components of EOL decision-making could be misunderstood by an everyday person and used against her best interest. A healthy 70-year-old widow with no understanding of the critical-care medical environment signed a legal document, a DNR, and had it entered into her medical record when she had a minor surgery. The woman was a dedicated viewer of television dramas. She believed, based on what she had heard and been told in the media, that the document would protect her from being kept alive on machines. That phrase meant to her a humiliating existence of struggling in pain, with no dignity or autonomy intact-- an outcome that she dreaded. By age 80, she had been diagnosed with lung cancer but was being treated successfully and was able to live independently without any family. She looked forward to flying across the country to her granddaughter's college graduation in the spring and other important events in her life at church and in volunteer work. While taking down her Christmas decorations, the woman fell off a step-ladder, breaking her hip. Living alone, she languished on her living room floor for two days, in pain, and became dehydrated and delirious. A neighbor checked on her, found her barely conscious and called 911. After admission to the emergency room, however, physicians were reluctant to transfer her to an ICU for support, primarily because she had a DNR in her record, which they understood to mean no extreme measures that would be the core of therapies in the ICU. The woman was not able to communicate with those who delivered health care to her. The decision they made to begin palliative care were based on: 1) lack of family present, 2) an aged patient who could not communicate, 3) a cancer diagnosis,

which was interpreted as a fatal condition, no matter how many years the woman could live with treatment, and 4) most important was the DNR she had signed earlier. She died within 48 hours, of respiratory failure, in a non-critical patient care area, with a continuous infusion of pain medication for the broken hip pain. Distant relations arrived as she slipped deeper into a coma, to the news that her DNR was being respected, and there was nothing else to do. Did the right thing happen? Did this woman understand that she would not be given the opportunity to heal from a broken hip, if she had a DNR and a lung cancer diagnosis? Did an EOL ideology found in television dramas influence a viewer to *do the right thing* and declare that she did not want to be resuscitated? A clear answer does not exist, but no one should make those decisions based on inaccurate representations of EOL that advocate an EOL ideology that is not out in the open. At the very least, DNR and other EOL concepts are open to interpretation by health care providers, based on a number of factors. All of the quantitative data collected in this study was used to determine if an ideology could be at work.

# Summary of Research Questions Addressed

### Definition of EOL

In this examination of EOLIs in *ER*, I found a covert demonstration of the definition of EOL that I use, which is: "(1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death" (Agency for Healthcare Research & Quality, 2004, p. 3). No dialogue directly referred to the definition, but by implication, each EOLI did meet the criteria set out in the definition. Each EOLI included a patient who experienced a functional impairment by virtue of a

diagnosed illness or injury. Also, each patient received care in a formal health care setting or with health care professionals in attendance.

## EOL Topics in ER and Outcomes

Whereas some topics, including patient dignity and spiritual considerations, almost never emerged, a density of EOL-related topics and legal issues gleaned from the clinical literature were mentioned in the 222 EOLIs. Terminal diagnosis, DNR and patient autonomy arose most frequently. Most often, the outcome remained unclear. When the outcome was definite, care was escalated more often than not, which seemed to fly in the face of any organized effort in health care to decelerate care at the end of life.

Studying the social, economic and political forces brought to bear on EOL decision-making is essential now, as there is a push to control the costs of health care in the United States that gains momentum steadily. For the first time ever, physicians have financial incentive to counsel patients during office visits about EOL. Health care reform efforts have come and gone, with no highly-publicized imprint on EOL, until the Obama administration brought to fruition the President's health care reform plan. This plan included language in federal rules that guided and potentially codified how EOL decisions were effected, with an emphasis on science-based medicine. Ethicists, political pundits, religious leaders and many others generated a rhetorical furor when the concept was broached in 2009, and the term *death panel* entered the American lexicon. In 2010, however, the Obama plan was signed into law, with compromise wording about EOL that reimbursed physicians for addressing EOL decision-making in wellness visits for Medicare recipients (Pear, 2010). This provision represented a fairly innocuous change, when compared to the inflammatory concept of death panels or any sort of apparatus that would have forced patients or families to limit hospital care for the dying. It was,

however, a substantial variation in how EOL care was approached by medicine. A monetary incentive was brought into existence for physicians-- the professionals who decided how resources are used-- to reduce care provided to the dying. The reimbursement scheme was one more step in the plan that can be traced over the past quarter-century or more to increase patient autonomy and provide good EOL care while reducing the ever-burgeoning costs of dying in a hospital (Agency for Healthcare Research & Quality, 2004; Dickinson, 2002; Field & Cassel, 1997; Johnson, 2009; Levenson, 2000; Mackelprang & Mackelprang, 2005; Osman & Perlin, 1994). The federal Centers for Medicare and Medicaid Services' reimbursement change augmented the shift toward influencing patients and families to believe that there should be an end to the therapies that can be delivered in the acute-care hospital setting or perhaps never to pursue those therapies at all. No matter what ethics or personal preferences were applied to EOL decision-making, no doubt can be entertained that this signified an escalation in the evolution of federal ideology regarding the decisions that affect the end of a patient's life.

# Legal Aspects of EOL

Presumably, one option that physicians will address with patients in EOL discussions during wellness visits will be an old, but not well-used concept, of advance directive (AD). According to Teno et al. (2007), patients with an AD were less likely to die in an ICU, so their care was less expensive. Even though nearly half of the study population that did not have an AD died in a hospital, only 34% of those with an AD died there, leading to the assumption that hospice was utilized more. Nevertheless, 47% of the AD patient-families reported the patient did not receive adequate emotional support,

whereas pain relief and breathing difficulty were reported as better for patients with AD (Teno et al., 2007). AD came up less than 8% of the time in EOLIs in *ER*.

Although this dissertation was not based solely on quantitative data or a comparison of television EOLIs to the experiences in real life, some value resided in noting differences and similarities within these two spheres. I compared data points, including diagnosis and demographic information, to find similarities and differences.

In one comparison, the underrepresentation of heart disease in *ER*, compared to the incidence of that disease in the United States, was apparent. Brain injuries (including stroke) were overrepresented in *ER* than in the population, which may account for how frequently organ donation and EOL issues, in general, arose in the episodes. Also of note: fairly rare disease conditions that are highlighted in *ER* episodes (genetic syndrome Trisomy18, Pertussis, Lupus) would not appear in a CDC list of most common diseases. This may be explained by the edu-tainment agenda of health-information groups, in getting their disease and education interests into dramatic television scripts (Cooper et al., 2000; Henry J. Kaiser Family Foundation, 2004).

# Demographics of EOLI

The participants of the EOLIs were more likely to be Caucasian and male, with a noted scarcity of Hispanic participants (and no Hispanic physicians), and few African American EOLIs. Nurse-characters were less likely to be Caucasian than physicians. The most common family-character was a parent.

Patient age contrasted moderately with the most current census. U.S. Census data for 2010 indicated that males were 49% of the population. The population over 80 years was less than 4%, and the portion of children under the age of 14 was 21%. The segment of the U.S. population that was between 18 and 44 years was 40%. So, the EOLIs over-

represented males, as well as each end of the age spectrum. In contrast, the most common age group in the U.S. was under-represented.

In 2010, U.S. Census data indicated that Caucasian people were 72% of the population. Slightly less than 13% were African American, and Asian people were 4.8% of the census. More than 16% of people in the 2010 Census identified themselves as of Hispanic heritage. So, when compared to census data, content about EOLIs in *ER* included more Caucasian people, fewer African American people, Asian people in nearly representative proportions, but far fewer Hispanic people than in the U.S. population.

In my examination of *ER*, I found two areas that differ substantially from my review of the clinical literature about EOL. Communication about EOL and the racial and ethnic perspectives of death and dying were portrayed dissimilarly than the literature indicated for death in hospitals. I thought both of these topics were of particular interest in contemporary society. Communication controls virtually every segment of human enterprise, both individual spoken words, as well as mass-mediated content. The ways that EOL were addressed in *ER* generally involve the communication of characters through dialogue that was created intentionally by script writers. This determined how physician characters communicated about EOL with other characters, including family characters. Scripts allowed vicarious demonstration of EOL interaction, again in fiction that was designed to appeal as a real-life drama.

The reason that racial and ethnic differences in EOL were important to note was that they represent a growing portion of the United States' population viewpoints. It will be incumbent on all those dealing with EOL issues, whether individually or in a mass-communication context to pay attention to these differences, as well as to other population changes, including age. Curtis and McGee (2000) prescribed: "Examination of

the complexities of medical technology, an aging society, and cultural confusion about how to solve ethical end-of-life decisions must continue, and a broad reconsideration of medicine's dominant role and our culture's conflicting values is needed to truly allow people to die with dignity (p. 347)." Creators of mass communication content, including television dramas, need to consider these areas carefully when incorporating EOL information.

### Setting and Jargon

EOLIs occurred more often at the patient's bedside, with physicians speaking the most, in short exchanges of less than a minute, employing technical jargon half of the time.

#### Communication

The way in which an EOLI is communicated within *ER* provided a bounty of content to analyze. The body of health care research spoke to the individual speech communication of participants in real-life EOLIs. This study analyzed how mass mediated content portrayed the individual speech communication about EOL in a television drama, which were EOLIs as mass media messages.

The literature about EOL discussions in a clinical setting indicated that physicians speak most, and the more time a clinician spoke, the less satisfied were family members with the interaction (Curtis, 2004). Also, families of patients who did not have an advance directive reported more issues with physician communication and with staying informed (Teno et al., 2007). Nearly all (95%) patients who die in an ICU could not communicate, in order to tell the health care professionals what to do about resuscitation (Curtis, 2004), so these topics were seldom addressed by the patient. The discussions would fall to their families and designated decision-makers. In *ER*, however, the portion

of patients who were talking to their families and health care professionals about their EOL experience is excessively high. Out of 222 EOLIs, 53 contain scenes in which 35 of the patients were able to talk, question, request, demand and explore what their EOL care should be. This fact alone helped account for the density of topics that are probed within the dramatic content about EOL in *ER*. It also may have added to the misperception that most people will be autonomous about their own EOL decisions in a hospital.

Although families reported they wanted to receive information from the patient's physician, they also reported dissatisfaction with the interactions. Novak and Axelrod (1979) suggested that it was a difference in culture that may make this communication interaction unsatisfying for patient-families. "The speech of scientistic medicine, because it has separated its practice from human concerns, too often speaks not to the needs of the people (the sick and suffering) but to medical science's own internally generated problems (disease)," (Novak & Axelrod, 1979, p. 160). The problems associated with technical jargon as defined in this study may have stemmed less from a difference in vocabularies than from a worldview held by the medical establishment that diverged ominously from those who entrust their care to that discipline. "The tyranny of linguistic obfuscation, where sickness is defined as disease, where suffering is defined as pain, and cure is defined as successful treatment, dominates medical practice," (Novak & Axelrod, 1979, p. 160). In ER, jargon was most often associated with brain death, but was not used perhaps as often or to lay people's disadvantage as in a true clinical setting. The entertainment value of the drama would have suffered, if jargon had dominated.

Within *ER*, the EOLIs did not provide any template for optimal communication strategies. Only one episode "An Intern's Guide to the Galaxy," (Zwerling & Albert, 2004, Season 11, Episode 5) addressed any communication protocol for physicians to

discuss EOL decisions with a family. An intern clumsily and selfishly stumbled through a checklist of topics to be addressed called a care pathway (Zwerling & Albert, 2004, Season 11, Episode 5) with a dazed family member, when he was forced to do so, by a social worker. In that process, the intern thought the family member had given consent for organ donation, when she clearly did not understand that she was agreeing to that. It was unclear if the mass mediated content in this episode criticized the concept of an organized approach to EOL decision-making. It demonstrated how uncomfortable EOL is for many people, and the need for preparation and education about addressing it.

In ER, physicians overwhelmingly managed EOLIs, with RNs contributing in only minor-- although powerfully humane-- roles from the sidelines. Could this televised depiction of a physician's role have set expectations for viewers who experienced death vicariously via television much more often than in their real lives? Shapiro and Chock (2003) suggested that television viewers may indeed have expectations of their real lives set by the viewing experience of a television drama such as ER. "... in processing media stories, people are unwilling or unable to devote a lot of thought to making perceived reality judgments... Fictional dramas often make more real connections with our lives particularly our emotional lives—than presentations that are arguably more real" (Shapiro & Chock, 2003, p.167). So, the role of physician, as depicted in EOLIs in ER may have been misleading, when compared to their roles as described in the clinical literature. The body of research indicated that physicians avoided death-related interactions in a criticalcare setting (Puntillo & McAdam, 2006), were described by families as controlling and that they tended to continue treatments, in a sort of therapeutic inertia (Robichaux & Clark, 2006). Nurses, on the other hand, were seen as dealing with death day-in, day-out, in a care perspective that was described as holistic versus the technological imperative of

physicians, and they often felt abandoned by the physician who avoided the death and dying situation (Robicaux & Clark, 2006).

Racial and Ethnic Differences in EOL

Viewers of television content rated only physicians and other health care personnel as highly trustworthy, with Caucasian people more trusting of the mediated images than were African Americans, the latter of which thought there was a dearth of programming about health issues in their race (Brodie et al., 1999). Forty percent of Latino people who were surveyed said they depended on mainstream media for health information, over Spanish-language television, also. People in all racial groups reported relying on mainstream media for health information, when they wanted that information (Brodie et al., 1999).

Regarding EOL in the health care setting, scholars including Duffy, Jackson, Schim, Ronis, and Fowler (2006) and Rao et al. (2002) reported there were distinct differences in how racial minorities preferred to approach EOL. If the way in which racial and ethnical minorities experience EOL differed from the way that Caucasian people (as the dominant culture in the United States) did, their experiences could be considered an alternative or oppositional reading of EOLIs. Lewis (2007) wrote that those readings deserve heightened attention, rather than blurring into the dominant reading. It makes sense that "Drawing attention to negotiated and oppositional possibilities increases the likelihood of those alternative readings" (Lewis, 2007, p. 372). Without an oppositional reading (which was composed of the subtle differences found in racial and ethnic minority EOL experience), the alternative was diminished, if not erased. So, too, would be the meaningful history and knowledge that have produced the different response by minority communities to EOL in a hospital.

The EOLIs in *ER* virtually ignored the special characteristics that make up a cultural or ethnic response to death and dying. This effectively denied the culture or ethnicity, as inferior or unimportant. Even though it may seem more appropriate to downplay or to erase the idiosyncrasies that make up cultural rituals, especially if those characteristics are considered problematic in the dominant culture, it sends the message that the dominant culture's practices are the only acceptable ones. That is the task of an ideological state apparatus (ISA) — to spread the dominant culture's ideology through institutions within society. An unconscious act on the part of a show's creators, perhaps, but the effect is the same— to diminish the power of any opposition to the dominant ideology, and to reinforce the dominant ideology. In this case, the ideology may be that death should occur according to the same criteria that meet the ISA's needs, without regard for race, ethnicity, heritage or history— a deeply marginalizing concept for those who do not fit into the dominant culture. It also contributes to wrong beliefs held in the dominant culture that will continue to devalue the health needs of minorities.

The mistake made when followers of a dominant culture hold inaccurate beliefs harms society as a whole. For example, polls indicate that most Americans believed that African Americans "receive the same quality of healthcare as whites... Behind these perceptions, however, lies a sharply contrasting reality" (Smedley et al., 2003, p. 2). The reality is that minorities do *not* get a variety of appropriate medical and surgical therapies and interventions at nearly the same rate as Caucasians and "these differences are associated with greater mortality among African American patients" (Smedley et al., 2003, p. 3). An analysis of health care resource usage in the clinical literature revealed disparities in health care resource allocation and usage between minorities and Caucasian people, throughout the lifespan that extends to EOL. Many large-scale studies did

indicate that minorities (including African American and Hispanic people) use more services and therapies at the end of life than Caucasian people do. It is important to remember, however, that racial and ethnic minorities access health care services in all other stages of life much less than their Caucasian counterparts. Without context, this fact alone could contribute to harmful stereotypes of these communities in EOL, by health professionals and in society. Perhaps this explained why the creators of *ER* made racial and ethnic minority EOLIs so generic and devoid of cultural specifics. It is feasible to expect a television drama with broad appeal to millions of people to be careful not to reinforce racial, ethnic or cultural stereotypes. For this examination, however, I thought there was value in considering the clinical data about EOL differences by race and ethnicity, along with placing that data within a context to promote understanding of what occurs in the real world and how it was portrayed in television drama.

Even though studies have shown that a person's socioeconomic status does not forecast the use of EOL-related apparatuses such as DNR, AD, hospital admission and feeding tubes, "ethnicity remained a significant predictor for each outcome" (Shrank et al., 2005, p. 703). Hanchate, Kronman, Yinong, Ash, and Emanuel (2009) reported that Medicare costs in the last six months of life were 32% more for African American people, and 57% higher for Hispanic people. In southeastern states, however, costs were lowest and virtually *the same* for African American and Caucasian people. The highest costs appeared in urban areas, where the cost disparity was greatest among races. "At life's end, black and Hispanic decedents have substantially higher costs than whites. More than half of these cost differences are related to geographic, sociodemographic, and morbidity differences" (Hanchate et al., 2009, p. 495). Studies cited by Duffy et al. (2006) also suggested different preferences between race groups and gender for EOL

care. Some of these included the reluctance of racial and ethnic minorities to agree to advance directives, hospice care and withdrawal of therapies, as well as African American males' mistrusting physicians more than any other race and gender combination. A qualitative study reported by Rao et al. (2002) revealed that residents of an African American community said they wanted to die in a hospital to lessen their family's burden and memories of an at-home death. This dovetailed with other studies that indicated the "level of acculturation (movement toward mainstream American culture) does not alter findings related to cultural influences on end-of-life preferences" (Duffy et al., 2006, p. 150). In other words, culture was a legacy handed down for safekeeping, despite the dominant culture's attempts to recruit for assimilation to the mainstream.

Again, context tells the fuller story. Welch, Teno, and Mor (2005) wrote that African American family members rated care as very good or excellent 60% less often than Caucasian people. A review of numerous studies revealed that: "...after adjusting for socioeconomic status and access-related indicators, African Americans are less likely than whites to have a primary care provider, to receive analgesia after fracturing a bone, to receive resource-intensive hospital care when seriously ill, and to receive ...cardiac treatments" (Welch et al., 2005, p. 1145).

This contrasts sharply for the last months of life, when African Americans used emergency services, ventilatory support and feeding tubes at higher rates than Caucasian people, and used nursing home services less. African Americans were roughly twice as likely to receive care from family, friends, and home health care workers. African Americans used all or most of the decedent's savings for health care more than twice as often as Caucasian people (Welch et al., 2005). So, paradoxically, African Americans use

fewer health resources than Caucasian people for all of the years that they live, up to the final year of life.

Another explanation for the phenomenon of higher-cost EOL care for African Americans centered on the large, urban hospitals where most care was delivered to African Americans. Care delivered in those hospitals simply cost more than in smaller, community hospitals (Barnato et al., 2006; Hanchate et al., 2009). Patients did not control the charges that a hospital set, so if the hospital closest to their home charged the most, African Americans were forced to incur higher-cost care, based on geography.

In interviews about their expectations and preferences for EOL care and a hospital experience that the authors (Shrank et al., 2005) cautioned should not be used to create "stereotyped communication blueprints" (p. 707) based on ethnicity, African American family members spoke about the need for faith or religious intervention during EOL. They referred to the chance of a miracle occurring, which would make necessary all interventions to keep a patient alive indefinitely so that the miracle can take place. One African American member said, "We want to put him on the ventilator regardless of how long because [we] believe faith is so strong it will bring them through" (Shrank et al., 2005, p. 707). The authors noted the theme that "prayer 'heals' patients... (and) the importance of 'faith in God' when addressing end-of-life issues" (Shrank et al., 2005, p. 705). In contrast, Caucasian participants did not expect a "health care worker to bring up spiritual issues" and "a spiritual advisor would not be helpful in the decision making" (Shrank et al., 2005, p. 706) but would "provide support and not answers" (Shrank et al., 2005, p. 707).

Within *ER*'s treatment of EOL, virtually none of these specific characteristics associated with cultural or ethnic differences were included. African American families'

needs and experiences practically mirrored Caucasian characters. The concepts of fairness in health care access as well as trust in the medical establishment were identified as issues that affect the health outcomes of minorities in the United States, most particularly African Americans (Crawley, 2005). Yet, none of the EOLIs contained content that even hinted at a mistrust of the medical establishment in any minority community. Caucasian family characters in several EOLIs, including those found in episodes "Friendly Fire" (Green & Alcala, 1997, Season 4, Episode 3) and "Last Rites" (Orman & Alcala, 1999, Season 6, Episode 2), articulated their mistrust of the medical professionals when egregious mistakes were exposed. No minorities ever voiced the same misapprehensions, however.

Welch et al. (2005) found that African American families were almost two and a half times as likely as Caucasian people to want to speak to a physician during the EOL experience but did not get that opportunity. As a consequence, African Americans were roughly twice as likely as Caucasians to note problems with: 1) physician communication, 2) keeping the family informed and 3) emotional support of the family. African Americans were 70% less likely to have communicated specific treatment wishes prior to hospitalization and were 60% less likely to have an advance directive document prepared (Welch et al., 2005).

In interviews with families about their expectations of EOL and ICU experiences, Shrank et al. (2005) found two preferences that were the same for both African Americans and Caucasian people. Both races expressed the desire for autonomous decision-making and preferred a physician to be honest and kind and use language that was understandable to the family. That is where much of the similarity ended, in EOL preferences. They wrote that: "... white participants were more exclusive" about

including family members in EOL discussions, some of whom they described as more "trustworthy" than others, with only the "closest" to be included (Shrank et al., 2005, p. 703). Caucasian participants wanted more "medical information and cost implications... and expressed more concern with quality of life" (Shrank et al., 2005, p. 706). The Caucasian families in the study wanted information about the patient's prognosis before deciding about starting a ventilator for support. However, they thought it appropriate to maintain a patient on a ventilator so the "family can be assembled" (Shrank et al., 2005, p. 707) to say their final good-byes or to formulate a care plan. Almost without exclusion, Caucasian families did not want a spiritual leader included in the EOL discussion. By contrast, African American participants wanted a spiritual leader included, with more family and friends. They valued "protection of life at all costs" (Shrank et al., 2005, p. 703) and expected prayer to be part of the equation. A large portion of the African American participants "specifically identified prayer as an important component of the end-of-life process" (Shrank et al., 2005, p. 706). One female participant said that she was moved, when a physician prayed with her for her husband's recovery, after the physician had discussed the patient's condition with his family. African Americans specifically said they wanted to be "acknowledged" (Shrank et al., 2005, p. 705) but not pressured or rushed by physicians, which was one of their concerns. African Americans in the study identified trust in the physician and health care system as a unique challenge with almost half of the group expressing "concern about their physician's inability to predict patient outcomes" (Shrank et al., 2005, p. 706).

These differences in preference were nowhere to be found in the EOLIs of *ER*.

Only 12 episodes incorporate African American characters in EOLIs, and only a couple of Hispanic characters appear in EOLIs. So, it might be difficult to show the fine

distinctions of ethnic and cultural differences in death and dying in this scarcity of opportunity. Spiritual aspects were virtually ignored as well. One of the few instances where faith was mentioned in an EOLI occurred in the episode "Last Rites" (Orman & Alcala, 1999, Season 6, Episode 2). A Latina patient who was dying of congestive heart failure adamantly denies wanting a priest at her bedside. As she neared death, however, she believed a nurse had already summoned a priest and wanted last rites to be administered to her. Without time to summon a priest, a physician on the unit posed as a priest and speaks a form of Latin to her that sounds plausible in her delirium. So, the need for spiritual guidance, although dictated by the patient's requests, took on an air of showmanship and pretense. The desired absolution sought through a sacred ritual was faked, to comfort a dying person, which can be interpreted as extremely caring to the person but somewhat disrespectful of the place that religion and faith would take.

None of the EOLIs that included African American characters featured issues of faith or religion. One episode showed an African American father struggling on his own, to care for a young son who had survived for two years with a tragic brain injury after being hit by a car. In "Luck of the Draw," (Manning & Holcomb, 1995, Season 1, Episode 13) the father sought no religious guidance, did not refer to prayer and wanted his son's, as well as his own, suffering just to end. He wanted a DNR order for his son, which was interpreted as no care at all, including food and water, much to the dismay and disapproval of all the health care personnel involved. When compared to the indications in the clinical literature, this depiction would seem to stand on its head any cultural or ethnic differences in EOL care. I did not expect that every EOLI that included racial or ethnic minorities could match the clinical literature about differences in EOL and death.

It does stand to reason, though, that at least a portion of EOLIs could have included these subtle yet important distinctions.

#### CHAPTER VI

## **QUALITATIVE ANALYSIS**

The quantitative counting of words and descriptions provided a foundation for this study and launched a deeper qualitative analysis of EOL content in ER. More observations may be made beyond or between the counted words. The latent meanings within the collected data—or even an absence of content in the dramatic scenes--are important in this consideration of the portrayal of EOL in a television drama. Some of this qualitative observation required a comparison of the EOL content in ER to data found in the clinical literature. Some of it was gained from copious note-taking during viewing. Through these notes, passages of dialogue led to the discovery of themes that possibly would not fit into the categories on the pre-constructed EOL Coding Instrument.

The qualitative examination derived from narrative notes made about EOLIs in *ER* supported the two issues of consequence that were noted in the quantitative results: communication and race/ethnicity. Basically, the communication about EOL in a hospital setting was over-simplified, which was not unexpected with the time limitations of a television drama. Within this oversimplification, however, power and status were conferred on the physician role in dictating and resolving EOL crises. Although the physician role conflicted occasionally with the authority and system in place within the series, all of those scenes and dialogue cemented the physician's power by virtue of his or her expertise, access to resources and legitimate authority as the head of the patient care realm.

RQ14: What cultural practices regarding death and dying appeared in the EOLIs in *ER*?

ER did not ignore entirely race, ethnic and cultural differences in the EOLIs, but differences were not portrayed well and equally. I contend that this poor treatment of racial, ethnic and cultural differences in EOL demonstrates Althusser's (1971) supposition that ISAs support the dissemination of ideology almost invisibly. Althusser (1971) proposed there was a process by which a person participated in ideology—that ideology began with an idea, a belief or an inclination that may or may not be consciously held by a person. The idea led the person to engage in actions. The actions became practices. The practices evolved into ritual. Ritual solidified to indoctrination, which coincided with the evaporation of the idea. The original idea became invisible to the person, Gane (1983) explained, but "beliefs remain" (p. 445).

Althusser (1971) illustrated this seamless quality in the spread of ideology in an ISA with the example of religious instruction leading to the ritual of liturgical worship in a church setting. Once the liturgy was accepted and entrenched, there may have been little inspection of the beliefs that were inculcated in the religious instruction. He wrote: "...the ideologies were *realized* in institutions, in their rituals and their practices, in the ISAs" (p. 58). Along these same lines, Hall (1985) warned of the complex dynamism inherent in ideology, that ideology occurred "... in discursive chains, in clusters...As you enter an ideological field and pick out any one nodal representation or idea, you immediately trigger off a whole chain of connotative associations. Ideological representations connote—summon—one another" (p. 104). All of the scenes analyzed in this section fall into this understanding of ideology propagation. Exposure to the EOL content within a dramatic television series is a subtle form of contact with an EOL ideology purveyed through the communication ISA.

For example, "Sticks and Stones" (Sachs & Alcala, 1999, Season 5, Episode 17) brought in Asian cultural differences associated with death and dying, albeit in a somewhat stilted stereotypical fashion that would lead a viewer to reject any alternative forms of EOL than the dominant one. An elderly Asian woman was dying of cancer. Her family asserted themselves in her care by refusing and not allowing her health care providers to tell Mrs. Fong that she has cancer. They withheld the information so that she would not lose the will to live by hearing the bad news. The family was juxtaposed against a young resident, who is appalled at their stance. She yearned to use all of the tools within her control to keep the woman alive, no matter how briefly or in what condition. By comparison, however, the family's beliefs appeared eccentric and wrongminded, which amounted to a diminution of the Chinese culture they adhered to, even after immigrating to the United States. The resident acted as a conduit of the ideology that Althusser (1971) asserted animates an ISA.

By contrast, the episode "And Baby Makes Two" (Kenney & Glatter, 1995, Season 2, Episode 5) encourages a viewer to think that the mother of an infant infected with AIDS has done the right thing by following a physician's guidance to take the baby home to die. Although it was clear that her character spoke English as a second language, indicating possible recent immigration to the U.S., no allusion to cultural rituals and practices about EOL were mentioned. On the contrary, this episode illustrated two themes identified (among the 39 listed in Table 8) in the episodes. One is called *You Have to Shock Them with the Bad News* that alludes to the harsh manner in which a physician explains to the mother that no treatment will prolong her son's life. The other theme in this episode was *No Miracles Allowed* in which one physician was angered that the overly-candid physician effectively eliminated any possibility that the baby boy could

experience a miraculous response to the meningitis treatment and return home to spend more time with his mother. Neither of these themes in EOLIs addressed any cultural idiosyncrasies in death

Table 8

Themes Identified in EOLIs and the Number of EOLIs Containing Them

Number	Theme	Times Observed
1	Organ DonationNot as Easy as It Looks	39
2	Brain Death is Really Hard to Understand	15
3	When Personal & Professional Worlds Collide	12
4	Autonomy of Pt in DNR	10
5	Exactly What Does DNR Mean, Anyway?	7
6	Omniscient Physician	6
7	We Have to See the DNR in Writing	6
8	Seventeen-Year-Olds Don't Get to Decide	6
9	Doctor Knows Best?	6
10	Hospice Means You'll Just Have to Stand the Pain	5
11	Who Doesn't Deserve an ICU Admission	5
12	Home Is Where I Want to Die	5
13	When Life Partners Aren't Spouses	5
14	Death Denial by Family	4
15	DNR means Do Not Treat???	4
16	Final Wishes	4
17	Family Grief Disappoints Hospital Staff	3
18	Hospital is Best for Pain Management	3
19	You Have to Shock Them with the Bad News	3
20	Coma Is Not Brain Death	3
21	Physician Assisted Suicide	3
22	Culture Collision of Values	3
23	Spiritual Worries	3
24	Staging EOL	3
25	DNR is a Defeat to You People	3
26	No Miracles Allowed	2
27	Mistrust Earned Thru Experience	2
28	Long Illness Before Death	2
29	Make a Patient a Donor with a Card	2
30	Quest for Personalization	1
31	De-personalize the Nearly Dead	1
32	The Uncomprehending Family	1
33	DNR Panics at HomeThen ER	1

Table 8 (continued).

Number	Theme	Times Observed
34	EOL Burnout	1
35	EOL & DNR are Messy at Times	1
36	It's Not My Fault!	1
37	DNR vs. Dialysis	1
38	Death Monologue	1
39	Organ Donation Saves Lives	1

rituals. The second episode almost diametrically opposed the first Asian family's death experience, as if the normal or expected outcome was a culturally-sanitized death encounter with a patient who acquiesced to the dominant physician's suggestion.

The only other EOLI that involved an Asian family and actually referred to cultural dictates revolved around an ER physician, her physician father and physician assisted suicide (PAS). In "Twas the Night" (Hebert & Hebert, 2004, Season 11, Episode 9), the ER physician told her colleague that she was obligated by cultural imperatives to follow her father's orders. Her father had sustained brain and other injuries in a car accident that killed her mother. He was exhausted but seemingly competent and told his daughter she must help him die with a lethal injection of sedative and painkillers. In the sole example of a health care provider who acknowledged and observed minority cultural practices linked to EOL and death, the physician participates in assisted suicide, an illegal act in most states. This episode contrasted how differently physicians responded to EOLIs when it was in their own family, instead of a patient, in a theme identified as When Personal & Professional Worlds Collide. The dominant culture interpretation of physician-assisted suicide demands it to be judged as murder, which may adhere to Hall's (1980) description of a preferred reading. This scene required a higher ruling, in the form

of an ethnic culture dictate, to make the act tolerable. If the characters had been Caucasian (and within the dominant culture), their decision to end a life outside of the medical establishment would have been inexcusable. The scapegoat for this act is the Asian-ness of the influences on Dr. Chen's decision-making, which went beyond the marginalization of cultural traditions and principles, to disparagement of the culture itself by being linked with an act that is criminal in most of the United States.

Another EOLI that could have expanded on the differences in how EOL is viewed in different cultures was in "Get Carter" (Gemmill & Glatter, 2004, Season 10, Episode 13). In this near-tragically comic EOLI, a physician directed a French-speaking woman to ask the adult daughter of a Caribbean immigrant (who was dying of pertussis), if her mother had an advance directive. The episode capitalized on an opportunity to highlight the transmission of communicable diseases that are contained in the U.S. through mass vaccinations. It gave no consideration, however, to the possibility that a person from a multi-cultural island world would have any special needs, opinions or beliefs about dying and EOL. In fact, the physician applied the dominant culture standards in EOL care without hesitation to a family who could be considered vulnerable to influence, merely by being in a foreign environment, without fluency in the dominant language. Althusser (1971) noted that no ISA is purely ideology and functions with some degree of repression available to those who operate within its confines. The physician in this incident could be considered to have wielded such repressive authority. At best, within this EOLI, there was a missed opportunity to highlight characteristics of dying and EOL in cultures other than the dominant one.

RQ15: How is mistrust of medical professionals and institutions depicted in the EOLIs in ER?

Mistrust of medical professionals and institutions got scant treatment within EOLIs in *ER*, despite the copious documentation of this phenomenon within the health care literature. With racial and ethnic minority characters, the topic did not arise as a specter that influenced perceptions of the characters prior to the patients' care.

Considering Althusser's (1971) and other theorists' work about ideology, one way that the mass communication ISA supports the hcISA (and ultimately the dominant power structure) occurs by leaving out any possibility that organized medicine and the hcISA had warranted mistrust by racial and ethnic communities. Although ISAs were separate from state power, Althusser (1971) argued, the state's function and power were, ultimately, furthered by the ideologies inculcated through an ISA, such as the mass communication ISA: "It is by the installation of the ISAs in which this ideology is realized and realizes itself that it becomes the ruling ideology" (p. 59). In essence, the state and ruling powers could not have existed without the ISAs' nurturance of ideologies through the people within society.

When it arose at all, mistrust seemed to come from the individual situation, i.e. the patient and family mistrusted because of something that happened to them *in this event*. For example, in "Sticks and Stones," (Sachs & Alcala, 1999, Season 5, Episode 17) the family became very agitated with a physician who revealed inadvertently to their mother that she had cancer. At that point, they expressed mistrust. They blame the resident, telling her: "This is your fault! All your fault!" (Sachs & Alcala, 1999, Season 5, Episode 17).

Although there is no verbalization of mistrust of the professionals and institutions in EOLIs that included African American characters, some of the events in them leave an

impression that the system is so hectic and chaotic that trust should not have been given, but there is really no choice for those who need critical care.

In "Under Control," (Baer, Sachs, & Misiano, 2000, Season 6, Episode 16) two surgeons discussed the care of an African American man who had end-stage cancer. One of them accidentally perforated his colon during surgery. The man had colon cancer and wasn't expected to live months, if not weeks. The senior surgeon explained the hole might seal off, but if not repaired with surgery (that would take eight weeks to recuperate from), he would probably develop a life-threatening infection—peritonitis. The patient said adamantly he wanted no additional surgery. The senior surgeon advocated for the patient's quality of life, since he had such a short life expectancy. The resident, however, viewed the patient's care as an opportunity to show off her skills to her peers, to be able to fix her mistake. The patient's care at the end of his life presented a secondary concern.

There was no scene in "Under Control" (Baer, Sachs, & Misiano, 2000, Season 6, Episode 16) in which the surgeon who had inflicted the injury admitted her error to the patient, along with the options available to him, so that he could make a decision for himself. Again, the creators ignored an opportunity to include information about mistrust of the medical system, based on historical data that indicates how African Americans could conceivably not trust mainstream medicine. By doing so, the state's ruling ideology (Althusser, 1971) was supported, since any mention of unethical medical experimentation performed on African Americans at the hands of health care providers and researchers was sidestepped.

The opportunity to lay bare sources of conflict and mistrust in racial and ethnic minorities that may animate EOL situations in real hospitals every day was missed, perhaps because African Americans in *ER*'s EOL episodes appear so infrequently. A lack

of trust in the providers of care would be very pertinent in any EOL circumstance.

Having so few EOLIs that include African American patient characters hampered the chance of demonstrating any cultural differences expressed in African American lives as well as their EOL experiences.

Television remains an obvious vehicle for ideology dissemination, used by power structures in society. The way that mistrust of the medical system is either portrayed or omitted entirely in the EOL content of ER is one way the Marxist and Althusserian reproduction of means occurs. Viewers—both minorities and those of the dominant culture—remain unaware that mistrust of the medical system (portrayed in ER) should be even a possibility. This lack of awareness maintains support for the dominant culture ideology about EOL within a health care setting. The ideology is that EOL should be experienced identically across the board, in a fashion deemed acceptable by the hcISA. In Althusser's (1971) essay, he considered how a post-capitalist society reproduces the means by which the economic society continues, i.e. the workers or "labour" (p. 6). He asserted that ideology played as pivotal a role in the reproduction of means as an educational system that transferred work skills to employees. Althusser (1971) considered the "submission to the ruling ideology" (p. 6) as crucial to supporting a dominant power structure, which must also have the means to "manipulate the ruling ideology correctly" in order to stay dominant 'in words'." (p. 7)

Any cultural differences associated with racial and ethnic minorities that play a part in their health care were effectively blunted or outright ignored in the *ER* episodes. I interpreted this absence as having latent meaning. The absence or blurring of important differences in the health care beliefs and death rituals of ethnic groups acted to marginalize these groups. Treating EOL and death as the same for all groups of people

sterilized the topics and said, to some degree that this is how everyone should behave. It prescribed the preferred method for dealing with perhaps the most powerful and intimate topic in a person's or family's existence. That method, within *ER*, was distinctly dominant culture. The cultural differences that are depicted singled out as backward anything other than Western and Caucasian.

### Themes Identified

By viewing each episode and taking copious notes about the depictions in each one, 39 separate themes were recognized that recurred within the 15 seasons. Their frequencies were noted in Table 8. Themes for 83% (n=184) of the 222 EOLIs were identified. Many of these themes may not have been identified by a lay audience, but as a health communication scholar operating as a cultural critic, I identified recurring, underlying premises that arose in many episodes. These themes ordered into categories the important information about the EOL content that did not fit into the predetermined coding sheet and would have been lost for interpretation.

Organ donation. Ironically, the most common theme that arose was only an associated topic for EOL. Organ donation encompassed all of the aspects of EOL that are found in the definition, but added layers of complication to the issue. Organ Donation...Not as Easy as It Looks occurred 39 times. The title referred to the fact that organ donation was often treated in such a way that serious errors in fact or practicality occurred in the episodes. Most often, the writers created scenes that made organ donation appear to be something wrapped up by a physician who performed all of the tasks that, in reality, an organ donation professional, assigned by the hospital's organ procurement organization (OPO) would accomplish. In the only episode that included an OPO employee, a nurse called her the "grim reaper" (Orman & Toberen, 1998, Season 4,

Episode 16). In "My Brother's Keeper" (Orman & Toberen, 1998, Season 4, Episode 16), the nurse's hackneyed phrase indicated her opinion of the organ recovery coordinator as opportunistic and lacking compassion for a patient in a tragic situation. This most-common theme offered a rich resource of depictions of a topic that was interesting to many people but was beyond the scope of this dissertation. Other issues that arose under *Organ Donation...Not as Easy as It Looks* included crudely-effected attempts at family authorization for organ donation, as well as clumsy portrayals of the interactions between hospital staff (who acted in an organ donation professional role) with transplant medicine professionals. A few other themes were closely associated with *Organ Donation...Not as Easy as It Looks*. These included *Brain Death is Really Hard to Understand*, which occurred 15 times. *Coma Is Not Brain Death* was in three EOLIs. *Make a Patient a Donor with Their Donor Card*, showed up in two EOLIs, and *Organ Donation Saves Lives* was in one EOLI. Altogether these themes made up a third of the themes identified.

theme was *When Personal and Professional Worlds Collide*. This theme alluded to how differently the health care professionals behaved, when EOL invaded their personal lives. Three regularly-recurring physician characters and one visiting physician who needed health care all experienced this cognitive dissonance, away from their professional milieu. Most poignant, perhaps were the EOLIs in which a physician's father is dying of lung cancer. In "Under Control" (Baer et al., 2000, Season 6, Episode 16), the physician went to his colleague (who was also his wife) and asked her to persuade his father to undergo chemotherapy for stage-four lung cancer. He had been resistant and wanted to go into hospice, away from his son. The physician's wife advocated for her husband to accept his father's wishes. The father had already made his DNR status known and

wanted to enter hospice care, so he would not disrupt his son's life. The episode "Loose Ends" (Baer & Hooks, 2000, Season 6, Episode 20) juxtaposed this father's death to how death happened in the ICU/ER. Instead of chaos, pained decision-making and conflict in an environment devoid of privacy, he experienced a so-called *good death*. He made his last wishes known to his family, who respected them. His family was solicitous of his comfort and needs. He was in his son's home with oxygen therapy, IV fluids and antibiotics. Their last hours together had import, when they said their final good-byes and told each other they loved one another. When the physician awoke from a nap, he found that his father had died. The physician remained calm, until later, when he broke down in tears with his wife.

When another physician discovered that her long-lost birth mother was in the final stage of life, she reversed her professional stance of staunchly abiding by a patient's stated or written wish for EOL care. Although this physician did not always favor personally the patient's wishes in her clinical role, she abided by them. At times, she pushed for the technical imperative to save a life at all costs. At others, she fought fellow physicians to ensure that a written DNR order was respected, as in "Last Rites" (Orman & Alcala, 1999, Season 6, Episode 2). With her own mother, however, this physician clearly acted as an adult child who happened to have specialized access to medications and knowledge that would increase her mother's time to live. In "Point of Origin," (Mack & Misiano, 1999, Season 5, Episode 18) she goes to a board and care facility where she had tracked her biological mother through a private detective. The jagged dialogue that occurred between the physician/daughter and the assisted living staff showed how different were the stakes for this physician and for the daughter that she was-- one who

never got to resolve the pain of her early life with the woman who gave her up for adoption:

Weaver: Call 911.

Staff: She's DNR. You're not her doctor.

Weaver: No, I'm her daughter. (Mack & Misiano, 1999, Season 5, Episode 18) Even though the physician had been blind to these sorts of issues in the families under her care, she immediately understood what the finality of a loved one's last days and death would mean to her. Later she discussed her mother's care with a nurse who disagreed with the physician's approach. The physician intentionally invoked her privilege as a physician to decide what is best for the patient, when, in actuality, she was treating the patient for her own needs:

Hathaway: The chart says you pushed some Lidocaine.

Weaver: That's right.

Hathaway: Did her DNR status change?

Weaver: Do Not Resuscitate does not mean Do Not Treat.

Hathaway: You treated an arrhythmia.

Weaver: Yeah, that's not resuscitation.

Hathaway: So you won't intubate.

Weaver: Carol, she's my patient, and I'll make a judgment call if it comes to that.

(Mack & Misiano, 1999, Season 5, Episode 18)

DNR. Among these identified themes, DNR appeared in several. The most common one was Autonomy of the Patient in DNR, which showed up in 10 EOLIs. In "Last Rites," (Orman & Alcala, 1999, Season 6, Episode 2) a young woman overrode her own DNR order while her father was out of the room. She told the physician that she did

not "want to die today" (Orman & Alcala, 1999, Season 6, Episode 2). Another physician disagreed vehemently, saying the patient was not competent to do so, because her cancer had metastasized to her brain. Other DNR themes were *DNR Means Do Not Treat???*", *We Need to See the DNR in Writing, DNR Is A Defeat to You People*, and *Exactly What Does DNR Mean, Anyway?* Taken collectively, these themes demonstrated how ambiguously concepts in EOL were portrayed within *ER*.

Grief in EOL. Although most of the EOLIs involved interactions between patients or their families and health care providers, some of the themes spoke specifically about the response of these two groups to the EOL. One of these was Family's Grief

Disappoints Staff in the episode "Luck of the Draw" (Manning & Holcomb, 1995, Season 1, Episode 13). The theme Death Denial by the Patient or Family was exactly how it sounds-- when the patient or family hung on to any hope, no matter how extravagant, to stave off the reality of death approaching. In "Day One," (Wells & Leder, 1994, Season 1, Episode 2) an octogenarian husband could not accept the thought of losing his wife of many decades. He thought he could convince the physicians to treat her more aggressively, if they would understand how important she was-- not just to him, but to her 13 grandchildren. This scene was also coded as another theme, Quest for Personalization:

Mark Greene: Our options are limited. Her condition is terminal. If we put her on a respirator, we may not be able to wean her off it later. We would be prolonging her life in a vegetative state. Or we can make her comfortable. Give her fluids, antibiotics. Let nature run its course.

Mr. Franks: You mean let her die?

Mark Greene: She'd die in peace.

Mr. Franks: Put her on the respirator. (Emphatically.)

Mark Greene: Mr. Franks, are you sure that's what she'd want? (Mr. Franks turns away from Dr. Greene.)

Mark Greene, to RN: We'll hold off until we get another blood gas. Hopefully, things will improve with the nebulizer treatment.

To a retreating Doug Ross, MD, Mr. Franks said: She has 13 grandchildren. Did you know that?

Doug Ross: No, sir. I didn't know that.

Mr. Franks: I just thought you should know. (Wells & Leder, 1994, Season 1, Episode 1).

Pain management. The concept of pain management materialized in two themes that sound similar but were portrayed in stark contrast. The themes were Hospice Just Means You Have to Stand the Pain, and Hospital is the Best for Pain Management. In the episode "Feb. 5, 1995," (Wells & Hayman, 1995, Season 1, Episode 15) a breast cancer patient was admitted to the emergency room from her residential hospice facility, in intractable pain. Ultimately, her ER physician learned that she gave custody of her daughter to her ex-husband before entering hospice and believed she would die very soon. She did not die, however. She wanted to return to hospice, but the physician promised her he could give her more painkillers than the hospice would be able to administer, if her agony increased. Nevertheless, her pain was managed inadequately, and she begged the physician to kill her and end her suffering. An opposite theme was Hospital is the Best for Pain Management which sounded as if pain could be obliterated in the hospital setting (in contrast to the breast cancer patient's experience). It was illustrated in the episode "Everything Old is New Again," (Wells & Leder, 1995, Season

1, Episode 25) when a physician cautioned the lover of an end-stage AIDS patient from taking him home with a bowel obstruction that would not be treated surgically. The physician told him that if the patient regained consciousness "...it could be rough. Here, we can manage his pain" (Wells, & Leder, 1995, Season 1, Episode 25).

Although the episode "Time of Death" (Zabel & Chulack, 2004, Season 6, Episode 11) was counted only once in this study as an EOLI, its qualitative value tallied much higher in demonstrating what goes well and what is disastrous, when EOL occurs in a hospital setting. A patient was dying of liver failure. He delivered a 44-minute soliloguy, which captured with literary poignancy the specter of EOL from a patient's perspective. Instead of staccato, breakneck exchanges, this monologue exposed and shared the last 44 minutes of a man's life. The focus remained unflinching until its end. Intensely personal, all of the staff, terminology, procedures and decisions were portrayed through the prism of a patient's life. All of the things that the health care professionals would not know, in a real EOL situation, were revealed to the viewer. The patient's choices, mistakes, joys, losses, triumphs, and regrets in his life distinctly came to bear on the EOL decision-making process. The art of television drama demonstrated many of the concepts and conflicts of EOL in this one potent episode much better than could ever be revealed in a real-life EOL situation. About EOL, in particular, however, ideology was present, in that the message to the viewer was: EOL is an issue—an issue that affects the viewer.

#### CHAPTER VII

#### CONCLUSION

#### **Overall Impressions**

This study of end-of-life content in a historic television medical dramatic series reveals that viewers are given subtle but potent ideological cues about the management of death in a hospital setting. The consequences of these cues remain unclear, but their mere presence poses questions to be addressed by scholars of mass media and health care, as well as policymakers, educators and health care administrators. The possibility existed that this ideology would embrace the view that life-saving therapies should be ended sooner for critically-ill patients. I found no obvious indication of the content directly suggesting that care should be abbreviated prematurely or earlier than has occurred historically. However, an EOL ideology existed in ER throughout the 15 years that it enjoyed high viewership and critical acclaim. The fact that this one topic—EOL-- was portrayed 222 times, appearing in every third episode of the show, connotes its significance. The density of its appearance told the viewer *This is important... something* to think about. EOL care has emerged as a phenomenon within contemporary society, so that its appearance in dramatic television would be expected. The content may not tell a viewer how to think about EOL, but this preponderance of depictions does tell a viewer what to think about—EOL. The influence of an EOL ideology in ER did not end when the series concluded in 2009, either. The show was released on DVD and was broadcast in syndication on cable channels and was available on on-demand Internet streaming media services. A web site dedicated to the series and maintained by the NBC television network was maintained after the show ended. It included links to federal web sites about EOL care.

As noted in the introduction, my research interest in health communication was preceded by careers as a critical care registered nurse and as an organ donation professional. As an organ donation professional, I practiced outside the sphere of any single hospital, acting in numerous hospitals as an adjunct health care staff member whose role was required by federal regulatory law. In this position, I was privileged to talk to scores of families about their hospital EOL experience, not only while they were going through it but also in the weeks, months and years after their loss. They revealed many things about their lives, their expectations, and their perceptions of death in a hospital. Learning about their experiences informed my perceptions of the content that I examined and analyzed in *ER*.

The EOLIs that I viewed in the 331 episodes bear a passing resemblance to those that I experienced in the real world of American health care. That is not to say that the writers and producers did a bad job. Their work was compelling and was designed to draw a viewer into intense dramatic scenes. It did that, and then some. I believe the task of recreating precisely the complexity of an EOLI nears virtual impossibility. The charge of the television content creator rests in distilling the essence of an EOLI to fit into the abbreviated format that defines the television drama series. This essence would convey the excruciating nature of EOL decision-making characterized by: 1) the emotional chaos that paralyzes any family facing the unthinkable loss of a loved one and all the decisions that entails, 2) the incomprehensible environment of a hospital intensive care setting that is not necessarily geared to handle death and dying issues well for anyone, especially racial and ethnic communities that do not meet the expectations of health care providers, and 3) the psychology of health care providers who may be permanently fatigued with their roles in an inert process for EOL that does not serve anyone well, including patient,

family, provider and institution. All of this complexity would need to fit into brief segments devoted to EOL within a 45-minute weekly episode—a goal not easily achieved.

Areas for Future Research and Accomplishment

Despite these challenges and despite how well *ER* entertained, opportunities were missed in *ER* that I hope are not ignored in current or future television programming. The creators of medical dramatic television programming have a chance to improve the portrayal of a topic that may be the only education a viewer ever gets about EOL prior to encountering it in his or her own life. Most notably, I would prescribe the incorporation of real issues and concerns related to EOL that are part of racial and ethnic communities, with a regard that engenders understanding, esteem and acceptance of differences. Just as important, I expect that the inclusion of the specificities of racial and ethnic lives, overall, would lead to a greater understanding of the range of communities that make up the United States. Otherwise, television deludes a viewer into either expecting all peoples to be of the dominant culture or concluding that television content remains irrelevant and inaccurate. The latter possibility looms as a serious matter for the future of television drama.

From months of exposure to the content in these episodes of *ER*, I think that several specific areas may bear further research. The first I have mentioned already—the depiction or absence within television of racial, ethnic and cultural differences related to death, dying and EOL. Perhaps the lack of these depictions in a 15-year television drama will stand as an anomaly, but I do not believe so. Mass media scholarship should remain vigilant in examining and recognizing content that contributes to the marginalization of racial, ethnic and cultural groups in any society. The most natural extension of this study

presents itself in media effects research. Since ideology appears in the content, looking into the effect of these portrayals on viewer attitudes and behavior would be the next step. Some examples follow. How is the absence of Latino physicians perceived by viewers in search of role models? How do African Americans perceive their stature in society, based on the dominant culture study of the characters in *ER*? How prepared do viewers perceive themselves to be in making EOL decisions, based on this content?

The second area for further inspection would be the portrayal of organ donation activities in television content. Although a substantial portion of the EOL content in *ER* revolved around organ donation, its portrayal was somewhat slanted and unrealistic. I will not hypothesize here on any viewer perceptions of this content, or what the effect may be for organ donation decisions, either positive or negative.

The third area that calls for future research is the themes that I identified throughout the EOL content in *ER*. They convey myriad forces that operated within the dramatization of EOL content. Again, these themes may be unique to *ER*, but determining if they are found in other television content, especially at later dates, could augment an understanding of EOL, death and dying that continues to evolve in mass communication, health care and other disciplines.

#### *Limitations of Study*

Every study contains limitations and opportunities to improve. I acknowledge the most serious limitations of this study here. One was my inability to find a study that looked for exactly the content that interested me. Although I was not able to test another scholar's findings, this work was informed by them. One such work was the Turow & Gans study (2002) of several television shows for health care content. Their findings about *ER* led me to consider it for examination.

There was sufficient interrater reliability when using the EOL Coding Instrument, but it had not been tested before. The two coders were both Caucasian, female, registered nurses and have substantial exposure to EOL in a clinical setting.

Although each episode of the 15-year-long series *ER* was examined, only this particular series was included in the study. There is no basis for comparison or contrast with another series. This limitation, however, co-existed with a strength of the study, which was immersion in the EOL content found in *ER*. This study combined two disparate disciplines—health care and mass media scholarship. The benefit of the combination was a robustness added to a mass communication study about health care that reviews the scholarship of both disciplines.

#### APPENDIX A

#### GLOSSARY OF TERMS FOR USE WITHIN THE EOL STUDY

Accelerate care. This is the outcome of an EOLI in which a patient is delivered more critical care services or therapies.

ACLS (Advanced Cardiac Life Support). Intravenous fluids, drugs to maintain heart rhythm and blood pressure, defibrillation, endotracheal intubation and ventilation that are employed to maintain the circulation of oxygenated blood throughout the body, to organs and tissues.

Advance directive. A legal document that describes what therapies a person wants to receive or forego at the end of life. It may also include instructions to physicians or to other decision makers.

Autonomy. Self-government or self-direction; moral independence.

Brain death. Cessation of all brain and brainstem function.

*Comfort.* This is to "give strength and hope to" (Comfort, [Def. 1], n.d.) or "to ease the grief or trouble of" (Comfort, [Def. 2], n.d.).

Deceleration of care. The outcome of an EOLI in which a patient's critical care services or therapies are discontinued.

Dignity. "The quality or state of being worthy, honored, or esteemed." (Dignity [Def. 1]. n.d.)

*DRG* (*Diagnosis-Related Group*). DRGs are "any of the payment categories that are used to classify patients and especially Medicare patients for the purpose of reimbursing hospitals for each case in a given category with a fixed fee regardless of the actual costs incurred." Its first known use was in 1977. (Diagnosis-Related Group, n.d.)

*DNR* (*Do Not Resuscitate*). This means that a patient will not receive components of Advanced Cardiac Life Support, in order to maintain hemodynamic stability of blood pressure and heart pumping. This may include: 1) medications to increase blood pressure, 2) electrical stimulation to the heart by a defibrillator, and 3) cardiac compressions, in which the sternum is pushed down upon the heart, to move blood in and out of the heart.

EOLI (End-of-life incident). Any words within an episode of ER that pertain to a variety of concepts that describe the events and decisions occurring in a patient's terminal admission to a hospital.

Family. The relatives of a hospital patient who may or may not participate in EOL decision-making.

Health care provider. This is generally a paid health care professional who delivers health care to a patient, including nurses, physicians, therapists, etc.

*Immediate termination of support*. This is when therapies that have been sustaining a patient's blood pressure, respirations and cardiac activity are stopped.

Layman's terms. These are words that would be used by or for "a person who does not belong to a particular profession or who is not expert in some field." (Layman, n.d.)

Organ Donation. This is the act of authorizing and effecting the removal of organs from one human being for transplantation into another human being who is dying of organ failure.

Patient. This is "an individual awaiting or under medical care and treatment" (Patient, Noun, Def. 1a, n.d.)

Quality of life. This is a "degree of excellence" (Quality [Def. 2a], n.d.) or a "superiority in kind" (Quality [Def. 2b], n.d.) related to one's existence. At the end of life,

quality of life connotes a desirable amount of autonomy and comfort that is desired by a person facing their mortality.

Refer to another physician. This is similar to "patient dumping" (Patient dumping, n.d.), a term in use since 1973, according to Merriam-Webster @ w-m.com. Referring to another physician in this manner is when a doctor transfers a patient to another physician or hospital, without the explicit consent of the accepting physician or institution (Dumping, n.d.)

Spiritual considerations. This may refer to concerns and questions about religion, sacred matters or supernatural phenomena, that may be of paramount concern at the end of life.

*Jargon*. "The technical terminology or characteristic idiom of a special activity or group" (Jargon, [Def. 2]., n.d.).

Terminal diagnosis. This is when a patient's condition is identified as not survivable and soon will be the cause of death.

Treatment refusal. This is when a patient either rejects recommended treatment at EOL, or less often, when a physician does not allow a patient to receive therapies that may have uncertain value at EOL.

# APPENDIX B

### EOLI CODING INSTRUMENT

1. Episode Season:	
2. Episode Number:	
3. Title:	
4. Airdate:	
5. Location of EOL mention. (Circ note that in the lined area.) Locati	cle one. If multiple discussions occurred, please
1- ICU pt room	8- Hallway
2- Hospital pt room	9- Outside of hospital entrance
3- Waiting room	10- "Nurse's desk"
4- Conference room	11- ER Treatment Room
5- HCP office	12- Patient Care Ward (Added after viewing
	Epi.1)
6- Chapel	13- Other;
7- unidentified	
6. Characteristic of EOL menti	
1- brief comment by health	•
2- brief comment by patien	
	y or other person associated with patient
4- discussion between/amo	
<del>-</del>	ent and health care provider ily and health care provider
	ient, family and health care provider
7- discussion including par	ient, family and hearth care provider
7. length of time discussion tal	ses. (Circle one.)
1- <1 minute	
2- 1-5 minutes	
3- 6-10 minutes	
4- >11 minutes	

8. Who spoke the most in this discussion?

1- Physician	5- Non-family but may have legal standing
2- Nurse	6- Chaplain
3- Other health care provider	7- Equal amounts by all
4-Family member	8- Unsure
	9- Other
9.Information included in discussion. (Cir	cle all that apply. Make notes as
necessary).	
1- Terminal diagnosis	
2- Plan to communicate with family	
3- Advance directive	
4- Living will	
5- DNR	
6- Treatment refusal	
7- Patient autonomy	
8- Patient comfort	
9- Quality of life	
10- Dignity	
11- Spiritual considerations	
12- Brain death	
13- Organ donation	
14- Family well-being	
15- Family autonomy & access to info	ormation
16- Other	
10. In general, was the language used by I	HCPs in "layman's terms" or technical
jargon?	
1- Layman's terms	
2- Technical jargon	
3- Equal amounts of each	
4- Unsure	
11.Outcome of the discussion. (Circle one	e. Make notes as necessary).
1- "wait and see"	<del>-</del> /
2- refer to another physician for care	

3- gradual deceleration of care

	4- immediate termination of support: ventilator, blood pressure support, medications, feedings.
	5- Unclear or unstated.
	6- Other
12. Pa	rticipants:
a.	Total number of participant/s:
	Characteristics of participants: (Complete a Participant Characteristic form, for ch participant.)

#### APPENDIX C

#### **EOL PARTICIPANT CHARACTERISTICS**

1. Episode Season/Number/ Season/Titl	e/ Airdate:
2. Participant #	
3. Relationship to patient:	
a. Nurse	f. parent
b. Physician	g. child
c. Other health care provider (HCP)	h. friend- not family, not HCP, ma
have legal stand.	• ,
d. Husband	i. self (patient)
e. wife	j. other:
4. Age (best estimate): a. < 12 years b. 12-21 years c. 22-40 years	<ul><li>d. 41-60 years</li><li>e. 61-80 years</li><li>f. &gt; than 80 years</li></ul>
5. Gender:	
1= female	
2=male	
6. Race:	
1=Asian	
2=Black	
3= White	
4=2 or more races	
5= unknown	

### CODING INSTRUCTIONS for EOL DISCUSSION

- 1. View assigned episode. Provide the identifying information for each episode.
- 2. Complete each answer, by circling the choice.
- 3. Any information that you believe is not captured in the multi-choice sections may be included as a narrative note, in provided lines or on the back of the page.

Fill out a separate Participant Characteristics sheet for each participant in the discussion.

## APPENDIX D

### INTERRATER RELIABILITY RESULTS

Interrater Reliability Coefficients of EOLI, Description Items and Information Included in 28 EOLIs

in 20 EOLIS		Intomoton Daliability
		Interrater Reliability
	AUTOLI	Coefficient
Overall Rate	All EOLIs	.96
EOLIs in Season 1	1	.97
	2	.94
	3	.98
	4	.94
	5	.78
	6	.94
	7	1
	8	1
	9	1
	10	1
	11	.94
	12	.97
	13	.97
	14	1
	15	.88
	16	1
	17	.97
	18	1
	19	1
	20	.93
	21	.94
	22	.94
	23	.94
	24	.93
	25	1
	26	1
	27	.79
	28	1
Information Included in EOLI:	Terminal	1
	Diagnosis	-
	Patient Comfort	1
	Quality of Life	1
	Brain Death	1
	Family Autonomy	1
	DNR	1
	Organ Donation	.95
	Organ Donadon	.)3

	Plan to Communicate Treatment Refusal Patient Autonomy Family Well Being	.91 .86 .80 .75
Description Items	Location Characteristic	.93 .96
	Length of Time	.96
	Participant Spoke	.96
	Most	
	Jargon	1
	Outcome	.96

# APPENDIX E

## ALL EPISODES OF ER, 1994-2009

Title	Airdate
True Lies*	1/25/1996
It's Not Easy Being Greene	2/1/1996
The Right Thing	2/8/1996
Baby Shower	2/15/1996
The Healers*	2/22/1996
The Match Game	3/28/1996
A Shift in the Night	4/4/1996
Fire in the Belly	4/25/1996
Fevers of Unknown Origin	5/2/1996
Take These Broken Wings	5/9/1996
John Carter, MD*	5/16/1996
Season 3	
Dr. Carter, I Presume	9/26/1996
Let the Games Begin	10/3/1996
Don't Ask, Don't Tell*	10/10/1996
Last Call	10/17/1996
Ghosts*	10/31/1996
Fear of Flying*	11/7/1996
No Brain, No Gain	11/14/1996
Union Station	11/21/1996
Ask Me No Questions, I'll Tell You No Lies	12/12/1996
Homeless for the Holidays	12/19/1996
Night Shift	1/16/1997
Post Mortem	1/23/1997
Fortune's Fools	1/30/1997
Whose Appy Now?*	2/6/1997
The Long Way Around	2/13/1997
Faith	2/20/1997
Tribes	4/10/1997
You Bet Your Life	4/17/1997
Calling Dr. Hathaway*	4/24/1997
Random Acts	5/1/1997
Make a Wish	5/8/1997
One More for the Road	5/15/1997
Season 4	
Ambush*	9/25/1997
Something New	10/2/1997
Friendly Fire*	10/9/1997
When the Bough Breaks	10/16/1997

Title	Airdate
Ground Zero*	11/6/1997
Fathers and Sons	11/13/1997
Freak Show	11/20/1997
Obstruction of Justice	12/11/1997
Do You See What I See?	12/18/1997
Think Warm Thoughts	1/8/1998
Sharp Relief	1/15/1998
Carter's Choice	1/29/1998
Family Practice	2/5/1998
Exodus	2/26/1998
My Brother's Keeper*	3/5/1998
A Bloody Mess	4/9/1998
Gut Reaction*	4/16/1998
Shades of Gray*	4/23/1998
Of Past Regret and Future Fear*	4/30/1998
Suffer the Little Children	5/7/1998
A Hole in the Heart	5/14/1998
Season 5	
Day for Knight*	9/24/1998
Split Second	10/1/1998
They Treat Horses, Don't They?*	10/8/1998
Vanishing Act	10/15/1998
Masquerade	10/29/1998
Stuck on You	11/5/1998
Hazed and Confused	11/12/1998
The Good Fight*	11/19/1998
Good Luck, Ruth Johnson	12/10/1998
The Miracle Worker*	12/17/1998
Nobody Doesn't Like Amanda Lee	1/17/1999
Double Blind*	1/21/1999
Choosing Joi*	2/4/1999
The Storm 1*	2/11/1999
The Storm 2*	2/18/1999
Middle of Nowhere	2/25/1999
Sticks and Stones*	3/25/1999
Point of Origin*	4/8/1999
Rites of Spring	4/29/1999
Power	5/6/1999
Responsible Parties	5/13/1999
Getting to Know You	5/20/1999

Title	Airdate
Season 6	
Leave It to Weaver	9/30/1999
Last Rites	10/7/1999
Greene with Envy	10/14/1999
Sins of the Fathers	10/21/1999
Truth & Consequences	11/4/1999
The Peace of Wild Things*	11/11/1999
Humpty Dumpty	11/18/1999
Great Expectations*	11/25/1999
How the Finch Stole Christmas	12/16/1999
Family Matters	1/6/2000
The Domino Heart*	1/13/2000
Abby Road*	2/3/2000
Be Still My Heart*	2/10/2000
All in the Family	2/17/2000
Be Patient	2/24/2000
Under Control*	3/23/2000
Viable Options*	4/6/2000
Match Made in Heaven*	4/13/2000
The Fastest Year	4/27/2000
Loose Ends*	5/4/2000
Such Sweet Sorrow*	5/11/2000
May Day	5/18/2000
Season 7	
Homecoming	10/12/2000
Sand and Water*	10/19/2000
Mars Attacks	10/26/2000
Benton Backwards*	11/2/2000
Flight of Fancy	11/9/2000
The Visit	11/16/2000
Rescue Me	11/23/2000
The Dance We Do	12/7/2000
The Greatest of Gifts	12/14/2000
Peace of Mind*	1/14/2001
Rock, Paper, Scissors*	1/11/2001
Surrender	2/1/2001
Thy Will Be Done*	2/8/2001
A Walk in the Woods	2/15/2001
The Crossing*	2/22/2001
Witch Hunt	3/1/2001

Title	Airdate	
Survival of the Fittest	3/29/2001	
April Showers*	4/19/2001	
Sailing Away	4/26/2001	
Fear of Commitment	5/3/2001	
Where the Heart Is	5/10/2001	
Rampage*	5/17/2001	
Season 8		
Four Corners	9/27/2001	
The Longer You Stay	10/4/2001	
Blood Sugar Sex Magic*	10/11/2001	
Never Say Never*	10/18/2001	
Start All Over Again	10/25/2001	
Supplies and Demands*	11/1/2001	
If I Should Fall from Grace	11/8/2001	
Partly Cloudy, Chance of Rain	11/15/01	
Quo Vadis?*	12/13/2001	
I'll Be Home for Christmas	1/10/2002	
Beyond Repair	1/10/2002	
A River in Egypt*	1/17/2002	
Damage is Done	1/31/2002	
A Simple Twist of Fate	2/7/2002	
It's All in Your Head	2/28/2002	
Secrets and Lies	3/7/2002	
Bygones	3/28/2002	
Orion in the Sky*	4/4/2002	
Brothers and Sisters*	4/25/2002	
The Letter*	5/2/2002	
On the Beach	5/9/2002	
Lockdown	5/16/2002	
Season 9		
Chaos Theory	9/25/2002	
Dead Again	10/3/2002	
Insurrection*	10/10/2002	
Walk Like a Man	10/17/2002	
A Hopeless Wound*	10/31/2002	
One Can Only Hope*	11/7/2002	
Tell Me Where It Hurts*	11/14/2002	
First Snowfall*	11/21/2002	
Next of Kin	12/5/2002	
Hindsight*	12/12/2002	
A Little Help from My Friends	1/9/2003	
r		

Title	Airdate
The	1 maute
A Saint in the City*	1/16/2003
No Good Dead Goes Unpnished	1/30/2003
No Strings Attached	2/6/2003
A Boy Falling Out of the Sky*	2/13/2003
A Thousand Cranes*	2/20/2003
The Advocate	3/13/2003
Finders Keepers*	4/3/2003
Things Change*	4/24/2003
Foreign Affairs	5/1/2003
When Night Meets Day*	5/8/2003
Kisangani	5/15/2003
Season 10	
Now What?	9/25/2003
The Loss	10/2/2003
Dear Abby*	10/9/2003
Shifts Happen*	10/23/2003
Out of Africa	10/30/2003
The Greater Good*	11/6/2003
Death and Taxes*	11/13/2003
Freefall	11/20/2003
Missing	12/4/2003
Makemba	12/11/2003
Touch and Go	1/8/2004
NICU*	1/15/2004
Get Carter*	2/5/2004
Impulse Control*	2/12/2004
Blood Relations	2/19/2004
Forgive and Forget*	2/26/2004
The Student	4/1/2004
Where There's Smoke	4/8/2004
Just a Touch	4/22/2004
Abby Normal	4/29/2004
Midnight	5/6/2004
Drive*	5/13/2004
Season 11	
One for the Road*	9/23/2004
Damaged	10/7/2004
Try Carter*	10/14/2004
Fear*	10/21/2004
All Intern's Guide to the Galaxy*	11/4/2004

Title	Airdate	
Time of Death*	11/11/2004	
White Guy, Dark Hair*	11/18/2004	
A Shot in the Dark	12/2/2004	
Twas the Night*	12/9/2004	
Skin	1/13/2005	
Only Connect*	1/20/2005	
The Providers	1/27/2005	
Middleman	2/3/2005	
Just as I Am	2/10/2005	
Alone in a Crowd*	2/17/2005	
Here and There	2/24/2005	
Back in the World	3/24/2005	
Refusal of Care*	4/21/2005	
Ruby Redux	4/28/2005	
You Are Here	5/5/2005	
Carter Est Amoureux	5/12/2005	
The Show Must Go On	5/19/2005	
Season 12		
Canon City	9/22/2005	
Nobody's Baby*	9/29/2005	
Man with No Name	10/6/2005	
Blame It on the Rain	10/13/2005	
Wake Up	10/20/2005	
Dream House	11/3/2005	
The Human Shield	11/10/2005	
Two Ships*	11/17/2005	
I Do	12/1/2005	
All About Christmas Eve*	12/8/2005	
If Not Now	1/5/2006	
Split Decisions*	1/12/2006	
Body & Soul*	2/2/2006	
Quintessence of Dust	2/9/2006	
Darfur	3/2/2006	
Out on a Limb	3/16/2006	
Lost in America*	3/23/2006	
Strange Bedfellows	3/30/2006	
No Place to Hide	4/27/2006	
There Are No Angels Here	5/4/2006	
The Gallant Hero & the Tragic Victor	5/11/2006	
Guns	5/18/2006	

Title	Airdate	
Season 13		
Bloodline	9/21/2006	
Graduation Day	9/28/2006	
Somebody to Love*	10/5/2006	
Parenthood	10/12/2006	
Ames v. Kovac	10/19/2006	
Heart of the Matter*	11/2/2006	
Jigsaw	11/9/2006	
Reason to Believe	11/16/2006	
Scoop and Run	11/23/2006	
Tell Me No Secrets	11/30/2006	
City of Mercy	12/7/2006	
Breach of Trust	1/4/2007	
A House Divided	1/11/2007	
Murmurs of the Heart	2/1/2007	
Dying is Easy	2/8/2007	
Crisis of Conscience*	2/15/2007	
From Here to Paternity	2/22/2007	
Photographs and Memories	4/12/2007	
Family Business	4/19/2007	
Lights Out	4/26/2007	
I Don't	5/3/2007	
Sea Change	5/10/2007	
The Honeymoon is Over	5/17/2007	
Season 14		
The War Comes Home*	9/27/2007	
In a Different Light	10/4/2007	
Officer Down	10/11/2007	
Gravity	10/18/2007	
Under the Influence	10/25/2007	
The Test*	11/1/2007	
Blackout	11/8/2007	
Coming Home	11/15/2007	
Skye's the Limit	11/29/2007	
300 Patients*	12/6/2007	
Status Quo	1/3/2008	
Believe the Unseen	1/10/2008	
Atonement	1/17/2008	
Owner of a Broken Heart	4/10/2008	
As the Day She was Born	4/17/2008	

Title	Airdate
Truth Will Out	4/24/2008
Under Pressure	5/1/2008
Tandem Repeats*	5/8/2008
The Chicago Way*	5/15/2008
Season 15	
Life After Death*	9/25/2008
Another Thursday at County	10/9/2008
The Book of Abby	10/16/2008
Parental Guidance	10/23/2008
Haunted	10/30/2008
Oh, Brother	11/6/2008
Heal Thyself	11/13/2008
Age of Innocence	11/20/2008
Let It Snow	12/4/2008
The High Holiday	12/11/2008
Separation Anxiety	1/18/2009
Dream Runner	1/15/2009
Love Is a Battlefield	1/22/2009
A Long, Strange Trip	2/5/2009
The Family Man	2/12/2009
The Beginning of the End	2/19/2009
T-Minus-6	2/26/2009
What We Do	3/5/2009
Old Times*	3/12/2009
Shifting Equilibrium	3/19/2009
I Feel Good	3/26/2009
And in the End*	4/2/2009

## APPENDIX F

### RELATIONSHIPS BETWEEN TOPICS DISCUSSED

## AND DIAGNOSIS OF EOL PATIENT

Topics Discussed	Topics Discussed & Percentage of Times They Appeared in These Diagnoses	Pearson Chi Square
Terminal Diagnosis	AIDS/HIV(75%), brain injury (28%), cancer (63%), liver failure (50%), lupus (50%), neurological disease (70%)	$\chi^2 = (15, n = 222) = 40.34, p < .001$
DNR	Cancer (33%), diabetes (100%), heart failure (34%), liver failure (100%), sepsis (60%), trauma (26%), respiratory disease (80%)	$\chi^2 = (15, n = 222) = 53.02, p < .001$
Patient Autonomy	Respiratory disease (55%), sepsis (80%)	$\chi^2 = (15, n = 222) = 47.41, p < .001$
Patient Comfort	AIDS/ HIV (50%), cancer (35%), heart failure (20%), liver failure (50%), neurological disease (30%)	$\chi^2 = (15, n = 222) = 47.16, p < .001$
Spiritual Considerations	Brain injury (41%), kidney failure (33%), trauma (44%)	$\chi^2 = (15, n = 222) = 59.80, p < .001$
Advance Directives	Dementia (100%), heart failure (13%), neurological disease (10%), pertussis (100%)	$\chi^2 = (15, n = 222) =$ 30.16, $p < .05$
Treatment Refusal	AIDS/HIV (50%), liver failure (50%), lupus (100%), neurological disease (35%)	$\chi^2 = (15, n = 222) = 59.80, p < .001$
Brain Death	Brain injury (41%), trauma (44%)	$\chi^2 = (15, n = 222) = 55.27, p < .001$
Organ Donation	Brain injury (54%)	$\chi^2 = (15, n = 222) = 82.79, p < .001$

APPENDIX G

RELATIONSHIPS BETWEEN EOLI VARIABLE & TOPICS DISCUSSED

EOLI Variable	Topics Discussed	Pearson Chi Square Results
Patient Age	Advance Directive Living Will DNR Patient Autonomy Organ Donation Family Autonomy	$\chi^2 = (6, n = 222) = 17.78, p < .01$ $\chi^2 = (6, n = 222) = 15.49, p < .05$ $\chi^2 = (6, n = 222) = 23.73, p < .01$ $\chi^2 = (6, n = 222) = 29.34, p < .001$ $\chi^2 = (6, n = 222) = 29.22, p < .001$ $\chi^2 = (6, n = 222) = 14.24, p < .05$
Female Patient Male Patient	DNR Treatment Refusal Patient Comfort	$\chi^2 = (2, n = 222) = 8.91, p < .05$ $\chi^2 = (2, n = 222) = 8.43, p < .05$
Lack of Jargon Presence of Jargon	Brain Death	$\chi^2 = (3, n = 222) = 15.61, p < .01$ $\chi^2 = (3, n = 222) = 18.73, p < .001$

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