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## Advance directives and communication styles in a lower Rio Grande Valley health facility

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ADVANCE DIRECTIVES AND COMMUNICATION STYLES  
IN A LOWER RIO GRANDE VALLEY  
HEALTH FACILITY

A Thesis

by

ARMANDO G. DOMINGUEZ

Submitted to the Graduate School of the  
University of Texas Pan-American  
In partial fulfillment of the requirements for the degree of  
MASTER OF SCIENCE

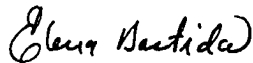
December 2000

Major Subject: Sociology

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Approved as to style and content by:



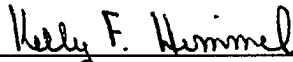
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December 2000

## ABSTRACT

Dominguez, Armando G., Advance Directives and Communications Styles in a Lower Rio Grande Valley Health Facility. Master of Science (MS), December 2000, 54 pp., 2 tables, references, 51 titles.

This study explores physicians' decision-making communication styles at end-of-life and advance directives in a hospital. Participant observation, case studies and a survey questionnaire are used.

Egalitarian communication style is found to have moderate reliability. A .6969 coefficient, is measured by Cronbach's Alpha model. Authoritative communication style, yields a less than moderate alpha coefficient of .4278. Regression analysis using these two variables as the independent variables obtains insignificant results.

However, sixty-three percent of the respondents speak Spanish moderately or very little. Eighty percent of the surveyed sample do not have training to administer advance directives. Twenty-two percent of the respondents have staff trained to administer advance directives. Policy recommendations call for training in advance directives for medical doctors in this particular facility.

## DEDICATION

I dedicate this thesis to the memory of my family and friends who have transcended to a higher place.

## ACKNOWLEDGMENTS

For her intellectual stimulation, I am indebted to Dr. Elena Bastida, my major thesis advisor and mentor. I thank the physicians at Valley Baptist Hospital for their cooperation. I give special recognition to Dr. Tina Briones for her support. I wish to thank the members of my thesis committee, Drs. Kelly Himmel, Uzzer Raajpoot and Israel Cuellar. Special thanks to Dr. Marta Sotomayor and the National Hispanic Council on Aging for her support through the Andrus Foundation Fellowship.

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## CHAPTER I

### INTRODUCTION

This study focuses on prevalent decision-making communication styles and advance directives at a Southmost Texas medical facility. The study originates at the request of the facilities' Board of Directors. They seek insight into the expenditures by Medicare patients at end-of-life. According to the 1998 Dartmouth Atlas of Health Care this facility is third in the nation for expenditures at end-of-life by Medicare patients over the age of sixty-five (86).

The methodology used for the study is a triangulation between case studies, participant observation and survey questionnaire. A case study is defined by Feagin, Orum, and Sjoberg (1991) as an in-depth, multifaceted investigation, using qualitative research methods, of a single social phenomenon. Four case studies are presented. All four individuals in the case studies passed away in a hospital in the Lower Rio Grande Valley. Bailey (1994) notes that observation is preferred when one wants to study in detail the behavior that occurs in some particular setting or institution. The results of participant observation at the medical facility are presented. A survey, according to Bailey (1994), consists of asking questions of a (supposedly) representative cross-section of the population at a single point in time; other characteristics of the survey are that there is a fixed set of questions and responses systematically classified, so that quantitative

comparisons can be made. In this study, there are forty-nine questionnaires, filled out by medical physicians at the research site that are quantitatively analyzed.

Communication style is theoretically defined by Buller and Buller (1987:375) as the way one verbally or paraverbally signals how literal meaning should be taken, interpreted, filtered, or understood in a communication context. Advance directives allow individuals to express and document their treatment preferences at a time when they are competent, and to inform others (i.e. health care professionals) how they would like to be treated in case of incompetency according to Eisemann and Richter (1999:37). Role theory adds sociological perspectives to the interactions of physician-patient in their communication process.

### Organizational Structure

The organizational structure of the study presents an introduction in Chapter One. A theoretical discussion and literature review is in the second chapter. Chapter III outlines the qualitative case studies. Participant observations that took place in the hospital setting are presented in Chapter IV. The results of this study are presented in Chapter V, here the assumptions that guided the study as they relate to communication styles and advance directives are further discussed. Chapter V also presents a synthesis of the main findings and concluding remarks.

### 1998 Dartmouth Atlas of Health Care

In its explanation of expenditures on beds by Medicare patients in the end of life, The 1998 Dartmouth Atlas of Health Care focuses on technology. By focusing on the technological, the cultural correlates that may be causally related to the sequences leading to these expenditures are missed. This project proposes an examination of decision-

making communication styles as an explanation to end of life expenditures by Medicare patients in a hospital referral region of South Texas.

The Dartmouth Atlas of Health Care proclaims modern technology has vastly extended the ability to intervene in the lives of patients, most dramatically so when life itself is at stake (1998:82). Macionis (1999:74) describes technology as knowledge that a society applies to the task of living in a physical environment. He adds, technology ties the world of nature to the world of culture (Macionis 1999:74). According to Barger-Lux and Heaney as cited in Weiss and Lonnquist, Western cultures subscribe to a belief system that prioritizes 'technical rationality'--a mind-set that essentially all problems are seen as manageable with technical solutions, and rationality (reasonableness, plausibility, proof) can be established only through scientific means using scientific criteria (1986). Many social scientists believe that technology not only is influenced by cultural values but, in return has a powerful and deterministic effect on culture and social structure-a theory known as technological determinism (Weiss and Lonnquist). Introducing an argument for caution, critics point out that if we have the technological capability to do something, then we should do it...(it) implies that action in the form of the use of an available technology is always preferable to inaction (Freund and McGuire 1991). These technologies now allow medicine to diagnose almost every disease and to reverse many which would have caused death forty years ago (Liberson 1993:2).

The problem, as outlined in The Dartmouth Atlas of Health Care, is that the American experience of death varies remarkably from one community to another (1998:82). For example, in 1994-95:

The chance that when death occurred, it occurred in a hospital, varied more than twofold among hospital referral regions, from as few as 20% of deaths to more than 50%.

The chance of being in an intensive care unit one or more times during the last six months of life varied by a factor of more than 5, from 9% of deaths in one region to about 48% in another.

The number of days Medicare enrollees spent in hospitals during the last six months of life varied by a factor of more than 5 in 1995, from an average of 4.4 days in one hospital referral region to 22.9 days in another.

The number of days Medicare enrollees spent in intensive care units during the last six months of life varied by a factor of more than 9 in 1995, from an average of 0.5 days in one hospital referral region to 4.9 days in another.

The price-adjusted reimbursements by the Medicare program for hospital (inpatient) care during the last six months of life varied by a factor of 2.8 in 1995, from \$5,831 per decedent in the least costly hospital referral region to \$16,571 in the most costly region.

The Wall Street Journal reported a local regional medical facility third in the country, in end-of-life expenditures by Medicare patients, next to the Bronx and Miami.

As noted in The Dartmouth Atlas of Health Care, like other medical decisions, end-of-life decisions about the use of resources, are usually influenced by the available supply (1998). The amount of acute care hospital resources allocated to residents of hospital referral regions has a strong influence on the American experience of death. (DAHC :1998). For some patient this progress has resulted in prolonged dying, accompanied by substantial emotional and financial expense (JAMA 1995).

#### Historical Overview of the Patient's Self-Determination Act

In response, the judiciary, and a president's commission have advocated more emphasis on realistically forecasting outcomes of life-sustaining treatment and on

improved communication between physician and patient (JAMA 1995).

The Patient's Self-Determination Act, signed into law by President Bush on November 5, 1990...to ensure that the new constitutionally protected right 'to self-determination in health care decisions ' be given force by ensuring that individuals were given an opportunity to indicate their wishes with clear and convincing evidence. (The Annenberg Washington Program:1994).

The Act requires health care providers 'to provide, individually or with or others, for education, for staff and the community on issues concerning advance directives (The Annenberg Washington Program 1994). It also requires the Secretary of Health and Human Services to 'develop and implement a national campaign to inform the public of the option to execute advance directives and of a patient's right to participate in and direct health decisions. (AWP 1994).

Accordingly, The Health and Safety Code of the Texas Department of Health defines directive as an instruction...to withhold or withdraw life-sustaining procedures in the event of a terminal condition (Chapter 672). It further describes terminal condition as:

an incurable or irreversible condition caused by injury, disease, or illness that would produce death without the application of life-sustaining procedures, according to reasonable medical judgment, and in which the application of life-sustaining procedures serves only to postpone the moment of the patient's death (Chapter 672).

Compliance with the educational requirements by both public and private organizations has been uneven at best (AWP 1994). It is by focusing on these advance directives and how they are communicated that the shift from technology to culture is instrumented. The theoretical explanations of statuses and roles clarifies these social interactions.

## CHAPTER II

### THEORETICAL PERSPECTIVES AND LITERATURE REVIEW

In a seminal review of the literature on doctor-patient communications (Ong, et al., 1995:903) state:

In the past two decades descriptive and experimental research has tried to shed light on the communication process during medical consultations. However, the insight gained from these efforts is limited. This is probably due to the fact that among inter-personal relationships, the doctor-patient relation is one of the most complex ones. It involves interaction between individuals in non-equal positions, is often non-voluntary, concerns issues of vital importance, is therefore emotionally laden, and requires close cooperation.

They suggest that to more fully understand why communication between doctors and patients is such a powerful phenomenon, it is important to look at:

- (1) the different purposes of medical communication;
- (2) the analysis of doctor-patient communication;
- (3) the specific communicative behaviors displayed during consultations; and
- (4) the influence of communicative behaviors on certain patient outcomes (1995:903).

Ong et al. distinguish three purposes of communication between doctors and patients. These are creating a good inter-personal relationship, exchanging information and making treatment related decisions (1995:903).

### Creating a Good Inter-Personal Relationship

According to Kreps and Thronton (1992:45) strong interpersonal relationships are based upon the fulfillment of needs by relational partners. It is stated by Roter, Hall and Rand (1981:18) that “medicine is an art whose magic and creative ability have long been recognized as residing in the interpersonal aspect of the patient-physician relationship” Cockerham adds that “medical treatment usually begins with a dialogue” (1998:171). In medical care talk is the main ingredient and it is the fundamental instrument by which the doctor-patient relationship is crafted and by which therapeutic goals are achieved (Roter and Hall 1992).

Parsons (1951) explains that the relationship between a physician and his or her patient is one that is oriented toward the doctor helping the patient to deal effectively with a health problem. There are different opinions among communication researchers on how to define a good interrelationship. Necessary ‘ingredients’ are: laughing or making jokes, making personal remarks, giving the patient compliments, conveying interest, friendliness, honesty, a desire to help, devotion, a non-judgmental attitude and a social orientation according to Ong, et. al (1995:904).

Kreps and Thronton (1992:47) claim “the more therapeutic interpersonal communications is the more the communication helps individuals involved increase their levels of health”. Carl Rogers distinguishes basic ‘core conditions’ he considers elemental to the efficacy of the therapy: empathy, respect, genuineness, unconditional acceptance, and warmth Lazarus (1979). Physician empathy and effective physician communication skills increase patients’ satisfaction, improve patients’ compliance and enhance physicians’ ability to diagnose and treat their patients (Neuwirth:606).



According to Porritt (1994) empathy is about being able to take the client's perspective and understand how they might be feeling. Cassell (1995) explains, information can be an effective therapeutic tool in medical situations if it meets three tests: (1) reduces uncertainty, (2) provides a basis for action, and (3) strengthens the physician-patient relationship. The 'patient-centered' method of doctor-patient relationship is viewed as egalitarian by Hensbest and Stewart (1989). They define it as doctors' responses which enable patients to express all their reasons for coming, including symptoms, thoughts, feelings and expectations. According to Weston, Brown and Stewart (1989) a main approach is to follow the patients' leads, and understand patients' experiences from their point of view. "The ideal medical interview integrates the patient-centered and physician-centered approaches: the patient leads in areas where he is the expert (symptoms, preferences, concerns), the doctor leads in his domain of expertise (details of disease, testament)" (Smith and Hoppe 1991:141). Roter and Hall (1992) call this 'mutuality'. Exchanges in which the doctor facilitates patient participation, and exchanges which reflect the doctor's roles as an interpreter and synthesizer, comprise 10% of physician talk Roter, Hall and Katz (1998). The growing number of publications concerning 'shared' decision-making can be seen as a result of a growing interest in doctors and patients as equal 'partners' in the relationship Ong (1995:904).

### The Exchange of Information

While relational concerns are important, most researchers maintain that the primary objective in these conversations is information exchange (Cegala, et. al., 1996). Beisecker and Beisecker (1985) state that information can be seen as a resource brought to the verbal interaction by both parties. The exchange of information consists of

information-giving and information-seeking Bensing (1991). Patients bring information to the consultation that needs to be shared. “In relation to decision making patients bring three perspectives to the problem: information, expectations, and preference”. Llewellyn-Thomas (1995:101). Physicians need to be able to find and evaluate current evidence Greenwald and Nevitt (1992:591). Mechanic (1998:281) postulates that “effective communication allows the physician to understand the patients’ expectations and concerns; to obtain accurate information, thereby facilitating diagnosis; to plan and manage the course of treatment; and to gain the patient’s understanding, cooperation, and adherence to treatment”.. As quoted in Cockerham (1998:175), Waitzkin, a physician and medical sociologist states:

studied information given in medical care found that social class differences were the most important factors in physician-patient communication. Cockerham (1998) further notes Waitzkin in stating that information often provides a basis for power by those who have it in relation to those who do not. Waitzkin determined that doctors did not usually withhold information to exercise control over their patients. Rather, doctors from upper-middle-class backgrounds tended to communicate more information to their patients generally than doctors with lower-middle- or working class origins. Moreover, patients from a higher class position or educational level usually received more information. Socioeconomic status thus emerged as a determining factor in both providing and receiving medical information.

Boulton et. al. (1986:328) explain that the influence of social class on the doctor-patient relationship is best understood in terms of social distance. She continues, patients who are similar to physicians in social class are more likely to share their communication style and communicate effectively with them; those with dissimilar class backgrounds are

likely to find communication more difficult because their communication style differs from that of the doctor and they lack the social skills to negotiate the medical encounter effectively (1986).

### Medical Decision-making

Another purpose of medical communication, according to Ong, et. al., (1995), is to enable doctors and patients to make decisions about treatment. Theories about decision making suggest that people do not have stable and pre-existing beliefs about self interest but construct them in the process of eliciting information or deciding a course of action. The way information is provided by the physician is therefore crucial in assisting patients to construct preferences (Hibbard 1997).

Traditionally the ideal doctor-patient relationship was paternalistic: the doctor directs care and makes decisions about treatment. During the past two decades, this approach has been replaced by the ideal of 'shared decision-making' (Beisecker and Beisecker 1990).

As cited in Cockerham (1998:179) Shorter:

has traced the social history of the doctor-patient relationship. First, he explains how the medical profession evolved from being a relatively low-status occupation to a highly respected scientific field. The image of the ideal doctor-patient relationship-the caring physician and the trusting patient-was not lasting; it had ended, in Shorter's view, by the 1960's. Doctors had become increasingly distant in interacting with patients, while patients, in turn, had evolved from being willingly passive to active, informed clients who wanted to participate more equally in their care.

It appears logical that in order to make such decisions, patients need information Ong (1995:905). This interaction between medical decision-making and

patients' informational needs has received much attention according to Ong (1995). As an example they cited a study that indicated patients suffering from various chronic diseases expressed a strong desire for medical information. However, the same study indicated that patients also placed responsibility for medical decision-making by their doctor (Beisecker and Beisecker 1990). According to Sutherland, Llewellyn-Thomas, Lockwood et al. (1989) the desire for information about diagnosis, prognosis and treatment is especially great among patients who suffer from a life-threatening disease.

### Analysis of Doctor-Patient Communication

'Interaction analysis systems' (IAS), also called observation instruments, have been developed to analyze the medical encounter (Wasserman and Inui 1983:279). According to them systematic analysis of this encounter can be defined as the methodic identification, categorization and quantification of salient features of doctor-patient communications. The rationale for this analysis, as suggested by Wasserman and Inui (1983), is that aspects of these interactions can modify important components of the health care process.

According to Ong et. al., (1995:906), an underestimated problem in research on doctor-patient communication is the influence of a-theoretical decisions on concrete research. .Bensing (1991) points out that such a system is often chosen because of its availability and/or proven high reliability and thus without much further thought. He identifies two types of interaction analysis systems: 'cure' systems which are meant to capture the instrumental (task focused) behavior, and 'care' systems which are meant to measure affective (socio-emotional) behavior Bensing (1991). He notes these two types of systems reflect patients' need for cure and care when visiting a doctor: 'the

need to know and understand' (cure) and the 'the need to feel known and understood' (care). The Bales' Interaction Process Analysis, where the accent lies on information exchange, can be considered as a cure system Bensing (1991).

The Patient-Centered Method Henbest (1990:28) can be seen as an example of a more care oriented system. Many medical problems, however, cannot be solved by either instrumental or affective behavior Ong (1995). An interactional analysis system which attempts to capture both types of behavior, such as the Roter Interaction analysis system, seems most realistic Roter (1988). Besides the cure-care distinction, observation instruments differ from each other with regard to their clinical relevance (is the system specifically designed for analyzing communication in the medical setting); their observational strategy (coding from video-audio-tape, direct observation or literal transcripts), their reliability/validity, and channels of communicative behavior (applicable to verbal, non-verbal behavior or both).

### Specific Communicative Behaviors

Besides the different purposes of communication and ways of analyzing medical encounters, different communicative behaviors can be identified. Research of these behaviors is important because it is yet unclear if patients can discriminate between different physician behaviors, e.g. instrumental and affective communication. Roter (1987) shows that patients judge competence mainly by their doctor's technical behavior. In their study Blanchard et al, indicate that patients base their evaluation of the doctor's performance on the quality of the inter-personal skills (1986:694)..

Especially information-giving and information-seeking by doctors and patients has been a topic for research the past decade Ong et. al.(1995:906) Physician's contribution to the medical dialogue is 60% (average amount), patients contribute only 40% to the conversation Roter (1989). In an overview of the literature on doctor-patient communication, Roter et al, (1988) report that question-asking by physicians accounts for 23% of the interaction and is therefore the second most frequent kind of exchange for physicians. It usually takes place during history-taking. The questions asked are mostly closed-ended; a 'yes or 'no' answer is expected. A meta-analysis done by Roter et al (1998) revealed that in reviewing physician communication, information-giving is most frequent: 35.% of all interactions. Waitzkin (1984:2441) however, found that doctors spend very little time giving information to the patients- a little more than one minute in encounters lasting about twenty minutes.

#### Theoretical Perspectives

Next the sociological perspectives are presented. They commence with Talcott Parsons. A presentation of the sick role and the role of the physician within a social structure is set forth. Next the nature of roles and statues is explored. The theoretical explanations of these concepts are documented as defined by Blumer, Kuhn and Turner. Contemporary insights into these classic perspectives are put forth by Prigerson. She adds insight with her concept of socialization to the dying role.

To begin with, Parsons states that an increasing proportion of medical practice is now taking place in the context of organization (1951:436). He explains that to a large extent this is necessitated by the technological development of medicine itself, above all the need of technical facilities beyond the reach of the individual practitioner, and the fact

that treating the same case often involves the complex cooperation of several different kinds of physicians as well as of auxiliary personnel (Parsons 1951). In this arrangement the relation of the physician to the rest of the instrumental complex is greatly altered. The physician tends to be relieved of much responsibility and hence necessarily of freedom, in relation to his patients other than in his technical role, according to Parsons position. Cockerham points out that Parsons's concept of the sick role provided some basic guidelines for understanding doctor-patient interaction (1998:168). The physician has the dominant role, explains Cockerham since he or she is the one invested with medical knowledge and expertise, while the patient holds a subordinated position oriented toward accepting, rejecting, or negotiating the recommendation for treatment being offered (1998). There is a normative pattern of trust: the physician will be attentive to the needs of the patient and will act in the patient's interests in addition the patient has to cooperate and to do everything the doctor advises to become healthy as quickly as possible (Meeuwesen, Schaap and van der Staak 1991:1143).

Parsons theorizes there are four aspects of the institutionalized expectation system relative to the sick role (1951:436). The first two components consist of rights for the patient. First, is the exemption from normal social role responsibilities, which of course is relative to the nature and severity of the illness (Parson 1951). Although others may grant provisional validation (Wolinsky and Wolinsky 1981), it is the physician who has the final decision-making powers to legitimate the condition. Parsons adds it is noteworthy that like all institutionalized patterns the legitimation of being sick enough to avoid obligations can not only be the right of the sick person but an obligation put upon him (1951).

The second component of the sick role is that the person is not held responsible for his/her condition (Matcha 2000:167). In this sense also he is exempted from responsibility-he is in a condition that must “be taken care of” (Parsons 1951).

The third and fourth conditions of the sick role represent obligations of the patient according to Matcha (2000). Parsons puts it as the definition of the state of being ill as itself undesirable with its obligation to want to “get well” (1951). He explains “the first two elements of legitimation of the sick role thus are conditional in a highly important sense. It is a relative legitimation so long as he is in this unfortunate state which both he and alter hope he can get out of as expeditiously as possible” (Parsons 1951:427).

Finally, the fourth closely related element is the obligation-in proportion to the severity of the condition, of course-to seek *technically competent* help, namely, in the most usual case, that of a physician and to *cooperate* with him in the process of trying to get well. It is here, of course, that the role of the sick person as patient becomes articulated with that of the physician in a complementary role structure. (Parsons 1951:437).

Turner’s assumptions about the underlying processes of role-making include Mead’s definition of “taking the role of the other” or “role-taking”. Turner stresses the fact that actors emit gestures or cues-words, bodily countenance, voice inflections, dress, facial expressions, and other gestures-as they interact (Turner 1982:367). Accordingly:

Actors tend to act so as to alleviate role strain arising out of role contradiction, role conflict, and role inadequacy, and to heighten the gratifications of high role adequacy. Individuals in society tend to adopt as a framework for their own behavior and as a perspective for interpretation of the behavior of others a repertoire of role relationships. Individuals tend to form self-conceptions by selective identification of certain roles from their repertoires as more characteristically “themselves” than other roles. The self-



conception tends to stress those roles which supply the basis for effective adaptation to relevant alters. To the extent to which roles must be played in situations that contradict the self-conception, those roles will be assigned role distance and mechanisms for demonstrating lack of personal involvement will be employed.

Prigerson adds to this an explanation of the process of socialization to dying. She examines the effects that select components of socialization have upon the odds that the patient will assume the dying role (i.e., his/her acknowledgement of death and receipt of exclusively palliative treatments) or the sick role (i.e., his/her non-death acknowledgement and receipt of curative treatments) (1992:378).

## CHAPTER III

### QUALITATIVE RESEARCH

The word qualitative implies an emphasis on processes and meanings that are not rigorously examined, or measured (if measured at all), in terms of quantity, amount, intensity, or frequency (Denzin 1998:8). Within the medical setting qualitative research can investigate practitioners' and patients' attitudes, beliefs, and preferences, and the whole question of how evidence is turned into practice according to Green and Britten (1998). As stipulated by Denzin qualitative researchers seek answers to questions that stress how social experience is created and given meaning (1998). Furthermore Denzin adds that there is an emphasis on value-laden inquiry. The value of qualitative methods lies in their ability to pursue systematically the kinds of research questions that are not easily answerable by experimental methods. (Green and Britten 1998:1230). Friedson states that clinical experience, based on personal observation, reflection, and judgment, is also needed to translate scientific results into treatment of individual patients (1970). Katon and Kleinman viewed encounters between doctors and their patients as the bringing together of often conflicting explanatory systems about health and illness, which required negotiation to achieve good outcomes.

Qualitative research design begins with a question. Of course, qualitative researchers design a study with real individuals in mind, and with the intent of living in

that social setting over time. They study a social setting to understand the meaning of the participants' lives in the participants' own terms (Denzin 1978:38). The researcher often relies on triangulation, or the use of several kinds of methods or data. Among those identified by Denzin (1978) are these basic types of triangulation:

1. data triangulation: the use of a variety of data sources in a study
2. methodological triangulation; the use of multiple methods to study a single problem

The qualitative research exemplified in the case study usually brings us closer to real human beings and everyday life (Feagin et al 1991:23). Case studies using qualitative methods are most valuable when the question being posed requires an investigation of a real life intervention in detail, where the focus is on how and why the intervention succeeds or fails, where the general context will influence the outcome and where researchers asking the questions will have no control over events (Keen and Packwood:1995:444)

The following four case studies exemplify these theoretical principles. These four individuals all resided in the Rio Grande Valley. They had large families. Three of them were Catholic, the other Protestant. They each understood English but their preferred Spanish for all their conversational use.

#### Case History: Lupita's Fall

In attempting to go the bathroom in the middle of the night, Lupita fell near her bed. Her husband attempted to help her but could not raise her up onto the bed. Lupita, a 78 year old suffered a stroke in the fall of 1990. Her husband, Cando was too overwhelmed to dial for emergency services. They lived on the outskirts of town where the houses are not close to each other. His voice, too weak to carry across the couple of

acres that separated him from his neighbors, seemed to him like that of a child. His sense of helplessness at this point seemed greater than that of his great-grandchildren. He got his neighbors attention by flashing his car lights onto their bedroom window. She arrived at a local emergency room by ambulance.

Their first-born, Tom, was as devoted an adult child as could be found. The majority of the time he would have his first cup of coffee at Cando and Lupita's. During his mother's later years he was the one to attend to her calls late at night. Lupita was prone to hypochondria. Tom was there to calm her over the phone. If that was not enough, more than several times during the past year he had taken her to the hospital emergency room. So when this call came from the neighbors, Tom was not particularly shaken. However, seeing her in the emergency room, he was quick to realize this was the real one. In the morning he dutifully called his out-of-town sisters and brother.

Indeed, Lupita had suffered a major stroke. The prognosis revealed a gulf-ball size blood clot in her right frontal lobe. Immediate surgery to evacuate the blood clot, did not guarantee recovery. She could very well remain in a 'vegetative' state. However, she was not brain dead.

Cando regressed further into his sense of helplessness. Lupita had been in charge of all household decisions. He'd been the breadwinner. She'd taken care of all family matters. To Cando it was only natural that the whole family come to a decision. Tom was resolute in his decision to let her be. She'd lived a long and full life. She was getting on in years. She'd always been a religious mother. Guided by her faith, certainly she would want to go when God called. The out of town siblings felt differently.

So Lupita had surgery. She was incapacitated, so much so that the children questioned their decision to have her go through heroic measures. She could not speak, could not eat unassisted, could not walk, could not get in or out of bed unassisted. Her lively spirit was gone. Gone was her praying voice, according to one of the daughters.

Three years later Lupita told her son to save up some money because she wanted to go on a trip. By this time Lupita had been through extensive rehabilitation. Although living at a nursing home, she was capable of a full 72 hour leave. She enjoyed going to her home. She visited relatives in their homes. She attended Sunday church service. With help she did all this. Her son commented that her long term memory was clearer than her short term memory. The out-of-state daughters relished in coming down to visit her. They created new memories with their mom. They exclaimed their gratitude for this second chance.

In due course, Lupita again mentioned she wanted to go on a trip. She stipulated she wanted to go say her farewells to her out-of-state daughter. She wanted to honor her sons-in-law under their roofs with her final goodbyes. The family laughed a nervous laugh. Yet the primary care taker set about making arrangements with the nursing home director.

It so happened that Lupita's out-of-state visit fell during her saint's day, December 12., day of the Virgin of Gaudalupe. Her daughters took her to their Catholic church. The ceremony began with the traditional processional. The hymns were sung in Spanish accompanied by a mariachi band. Lupita glowed in the company of her daughters and in-laws. Upon leaving to return home she was very clear in stating that this was her final farewell. She blessed her daughters. Lupita had another stroke exactly

a month later. Honoring her wishes, the sons decided not to have any extraordinary medical measures. She was not to be in pain.

During this hospital stay, the primary caregiver brought Lupita's sole surviving sister. They prayed, asked for forgiveness, and said goodbye. However, before leaving, Lupita's sister asked for a sign of understanding. As she held Lupita's hand she asked her to squeeze their hands if she had heard and understood. Surprisingly so, Lupita gave an assertive squeeze. Lupita died at the hospital early the next day. She was 81. Given our cultural proclivity to deny death and employ heroic means to sustain life (Kasterbaum and Aisenberg 1976), many patients considered "terminal" by the medical profession (i.e., having a life-expectancy of six months or less) are expected to be discouraged from perceiving themselves as dying and encouraged to fight for life. Lupita had verbalized her wishes that if she were to suffer a subsequent life-threatening episode, she would not wish for heroic measures. She had exercised her will and a proxy, her son, carried out her advance directive.

Patients who acknowledge that their death is imminent and who receive exclusively palliative rather than curative care are defined here as persons who have been socialized to the dying role (Prigerson:1992 380). This case study points out Prigerson psychosocial analysis of modeling the patients' therapy as a function of their death acknowledgement and the characteristics of their formal (i.e., physicians) as well as informal (e.g., family member, friend) caregivers. The role enacted by Lupita after her first stroke is one characterized by Turner, R H as "the process of role verification" (in Turner J, 1982:368). Lupita had a supportive family willing to engage and respond to her new cues. Turner states that if cues are consistent with previously emitted ones then the

actor will continue to adjust responses in accordance with the imputed role of the other (1982). This points what Turner notes as “the process of role verification,” (1992:368).

#### Case Study: Paulita’s Reclusion

Paulita had lived a healthy life to about age 65. At that time she suffered severe gastrointestinal disorders culminating in a colostomy. A very proper and private person, Paulita became most reclusive. She saw immediate family only after her husband had screened them. Paulita insisted on her privacy. To appear disabled was to appear without dignity. She was certainly loved by her extended family for she was quick witted with a snappy comeback. Her conversations never hinted on the maudlin. According to her stepson, her extended family came to understand the privacy she needed.

Paulita overcame this condition. Unfortunately at about the same time, she suffered a fall in the garden. She hit her forehead on a sharp stepping stone. The injury resulted in a detached retina. Paulita only had peripheral vision. Her sight became worse with time. Again she insisted on solitude. She felt embarrassed at not recognizing people in the room. How could she hold a conversation with someone she could not see? Paulita was in her mid seventies at this point. Never one to go to church, she nonetheless asked for forgiveness for her sins. She wished for the end to come for how could she expect to be cared for hand and foot?

With time she grew used to her condition and returned to witty ways. She was able to discern cars and their occupants as they approached her driveway. She hinted at being psychic for being able to describe someone’s clothing. Those who were allowed close to her acclaimed how good humored she was.

Paulita next suffered a heart attack. Her primary caregiver described how adamantly she refused any type of operation. She did not want to suffer any more. Her time had come. It was God's will. According to the primary caregiver, the attending physician was ready to initiate the requisite procedures for by-pass surgery. Paulita had not signed a living-will. She was able to vocally communicate her wishes. Within a day of being admitted to the emergency room, Paulita passed away. She did not suffer at the end. She very calmly said goodbye to her husband and nephew. Adult socialization has been defined as the process by which an adult develops the sense of identity and behavioral patterns associated with role occupancy (Becker et al. 1961) Paulita had been treated in the hospital by a physician who was her nephew. He understood her wishes for palliative care and carried them out. According to Prigerson it is assumed that knowing the roles to which a person has been socialized provides critical insight into this person's self-perceptions and decision-making processes (1992:379).

### Third Case: Cando's Depression

Cando was one to relegate authority to his wife. In all major decisions he always was one to include the family in the decision-making process rather than act unilaterally. Lupita was his wife and she could no longer make decisions for him.. Cando died after having spent eleven days with a ventilator. His oldest son was informed by the attending physician of the impending reality. Cando had not made end-of-life directives or communicated his wishes in any way. So it fell on his first born to make the decision.

Prigerson points out that "despite the fact that the legal system has consistently upheld the patient's right to the self-determination of treatment and states have enacted 'right to die' legislation, a substantial number of patients do not appear to exert control



over the type of treatment they ultimately receive (1992:378). Cando portrays what Prigerson describes as a patient who has been socialized to the sick role. Her definition of the sick role is those “individuals who refuse to acknowledge that they are dying and who opt for curative treatments in the terminal phases of their illness” (Prigerson: 380). Cando’s lack of communication compounds his socialization role toward dying. Of the four case studies he spent the most time in intensive care. As his illness progressed he was dependent on the medical profession to act for him.

This unilateral approach is justified by research indicating that older and critically ill individuals are more prone to accept the subordinate, dependent role of the patient and less likely to challenge their physician’s authority than are younger patients (Haug 1979; Waymack and Taler 1988). Terminally ill elderly patients, in particular, have been shown to want to abdicate the responsibility for determining their own medical care (Ende et al. 1989).

#### Fourth Case Study: Rodolfo’s Broken Heart

Rodolfo never complained of illness. He had lived a healthy and quiet life. Blessed with a large family, that and work was his life. His first wife passed away when he was around sixty-five. Happily he remarried a life-long friend from his early youth and lived with his second wife until he was 94. After his second wife passed away, Rodolfo became very lonely. The principal care-giver reluctantly moved him into a nursing home so as to be close by. At this time Rodolfo manifested extensive colon cancer. He was very clear about not wanting surgery or chemotherapy. When interviewed, his principal care-giver said that Rodolfo died of a broken heart. He said

others in his family would not have followed his Dad's wishes and would have forced curative rather than palliative treatment.

This case points out Prigerson's tenant that knowing the roles to which a person has been socialized provides critical insight into this person's self-perceptions and decision-making processes (1992 379). Rodolfo was articulate about his wishes. He chose a family member who was receptive to listening to him.

These case studies are the second part of the methodology. They were conducted before the questionnaire was constructed. These case studies are the guiding bases for some of the items in the questionnaire. The third method of the study is participant observation. There are four observations conducted on site. These observations were sanctioned by the Institutional Review Committee of the research facility. The committee required adherence to specific guidelines. Neither note-taking, nor tape-recording were allowed. Neither the patient nor family members were allowed to be interviewed.

## CHAPTER IV

### PARTICIPATANT OBSERVATION

Participant observation is defined by Denzin (1994) as observation carried out when the researcher is playing an established participant role in the scene studied. A fourfold typology is presented by Gold and Junker as cited in Denzin: complete observer, observer as participant, participant as observer, and complete participant (1994:249). The following dimensions of variation are stated:

- a). whether the researcher is known to be a researcher by all those being studied, or only by some, or by none
- b). how much, and what, is known about the research by whom
- c). what sorts of activities are and are not engaged in by the researcher in the field, and how this locate her or him in relation to the various conceptions of category and group membership used by participants
- d). what the orientation of the researcher is; how completely he or she consciously adopts the orientation of insider or outsider.

Qualitative research may seem unscientific and anecdotal to many medical scientists. However, as the critics of evidence based medicine are quick to point out, medicine itself is more than the application of scientific rules. Clinical experience, based on personal observation, reflection, and judgment, is also needed to translate scientific results into treatment of individual patients. Personal experience is often characterised as being anecdotal, ungeneralisable, and a poor basis for making scientific decisions. However, it is often a more powerful persuader than scientific publication in changing clinical practice, as illustrated by the occasional series, "A patient who changed my practice" in the BMJ. Green and Britten (1998:1231.)

The following observations were obtained during a two-week period at the research site. The protocol for the level of participation and dimension variations as described above was established by the facility's Institutional Review Committee. Again, these guidelines provide that the researcher may not take notes, or use a tape-recorder during the observation period. Questions or conversations with the patient or family members were not permitted. A copy of these recommendations is in the appendix. Whereas physicians had an option to be observed, as indicated, all the observations were conducted solely as the representative from Guests Relations administered these advance directives. She is an RN with a Ph.D. in Education.

In each of the occasions below, the hospital administrator introduced the researcher. She made clear to describe the researcher's role. The administrator obtained verbal permission for the presence of the researcher from the family members and when possible from the patient.

#### First Participant Observation: She's Not Dying?

This was a 55 year old women with asthma complications. She was in the Intensive Care Unit. The patient was alert and communicative. She was aware of the purpose of the procedure. The dialogue about advance directives was in Spanish. Two daughters were present. They asked their mother to state what she wanted if the moment came when she could no longer speak for herself. The patient responded that she didn't want to die all "tubed-up", "no quiero morir toda entubada".

The hospital administrator used vocabulary and phrases understandable by the patient. An example of this was the 'culturally' appropriate use of the term 'Do Not

Resuscitate', "no quire ser resucitada". In addition, the representative from Guest Relations also was empathic. She related her own asthma episode and the anxiety associated with that particular breathing pain. When it was clarified and understood what was being signed, one of the daughters asked, "This doesn't mean she's going to die?" It was explained that this was only a procedure to assure that in case of incompetency the patient's wishes for medical procedures would be followed. The complete conversation lasted four minutes.

Subsequent to the signing of the DNR order, the Guest Relations representative set about the administrative details of entering the information in due course.

As the patient was fully alert the process went smoothly. The family members were naturally anxious but equally receptive to hearing about their mother's future care. The patient was adamant about not wanting heroic measures. Noteworthy is the hospital representative's bilingual abilities. The advance directives are a complicated matter, yet the administrator is able to explain the procedures most adequately. This explanation was in culturally appropriate Spanish.

These daughters were most receptive to hearing their mother speak forth. As socialization agents, the daughters wanted their mother to speak about her future treatment options. Prigerson directs that certain processes of socialization are expected to influence the type of treatment received by the terminally ill patient (1992). If the socialization agents enable the patient to participate in the making of his/her treatment plans (i.e., they have a democratic decision-making style), the patient should have a high probability of receiving the type of treatment s/he most desires (Prigerson 1992). The daughters exercise a democratic decision-making style. At this level they encourage their

mother to speak about what she wants in the future. This patient's future wishes are acknowledged by her signature on the DNR order.

#### Second Participant Observation: Daughter's Self-needs

The second 'round' in the medical facility was with an eighty-five year old woman. The patient was not fully aware. She was unable to speak. The family, a rather large gathering of about fifteen, was allowed to come in to visit three at a time. Because of the patient's advanced stage of illness and her airborne infection each visiting member was required to wear a gown and mask.

A consultation meeting was set-up outside the intensive care unit. This family was Hispanic. The entire conversation was conducted in English. There were three daughters and a niece in the 'consultation'. The process was most litigious. A contentious daughter was most upset about prior delays in obtaining an aspirin for her mother. The hospital representative was cordial throughout the hour-long process. The confrontational daughter refused to sign the DNR order. She ceded her signatory position to her oldest sister. Whereas there was no question about their mother's terminal medical stage, these family members did not ask about the mother's life signs. The daughters seemed more concerned with their own process rather than with their mother's comfort.

This dispute exemplifies Prigerson's hypothesis on the process of socialization to dying. When the socialization agents state that the primary goal of terminal treatment should be the prolongation of life as long as medically possible (even if the patient suffers from aversive side-effects) ...the patient should be less likely to acknowledge that s/he is terminally ill (1992). She further adds that if the patient's identity is formed through interactions with physicians and caregivers who hold these views, then the

patient should be substantially less inclined to acknowledge that s/he is dying because s/he is cared for by individuals who advocate treatments aimed at keeping him/her alive (Prigerson 1992). These family members had made it clear they wanted life-prolonging measures for their mother.

That these daughters extended their mothers state of obvious deterioration to exert themselves on the hospital representatives over delivery of an aspirin clearly shows a skewed perspective. Although this eighty-five year old mother could not speak, she was visibly in pain. The socialization process pointed to medical procedures that prolong life.

### Third Hospital Observation: No Artificial Life

For the third participant observation in the hospital intensive care unit, the situation was classic. The patient was afraid of dying in a technological maze. She as much stated so. The family members agreed. This family was addressed in Spanish. Again, the hospital administrator used culturally appropriate language. She addressed the family in short concise sentences. In explaining the DNR order she restated the concept using the phrase “no quiere vida artificial...”. Literally this means the patient does not wish artificial life. Everyone nodded in accord.

As cited by Prigerson, Callahan writes that the greater fear of the elderly is “a death marked by technological oppressiveness, wrapped in a cocoon of tubes and machines” (1992). This encounter exemplifies the intersection of democratic decision-making and the socialization to the dying role. Patients who acknowledge that their death is imminent and who receive exclusively palliative rather than curative care are defined here as persons who have been socialized to the dying role (Prigerson 1992:380).

#### Fourth Participant Observation: Community Presence

In the following opportunity to observe, the patient had just deceased. Although this was not the moment of study, it none the less serves as a point of clarification. The patient and family had been advised about end-of-life directives. The large family gathering was representative of a wide age spread. There were teenagers to senior-most family members.

Noteworthy was the entrance and presence of a non-family member. She walked in with an authoritative gait. First she approached the body of the deceased and blessed herself. She then prayed over the body. Everyone joined in prayer. She raised her hands upwards and everyone raised their hands upward. She then announced that the rosary arrangements had been detailed. After that she went about the room extending her condolences to each and every person in the room. After this the mood in the room changed. It was as if the matter was no longer a family affair. It was now in the community.

This serves as a point of clarification. This study is about the process of dying. It is not about the moment after. That is a separate and distinct category.



## CHAPTER V

### ADMINISTRATION OF THE SURVEY

The study proposes to ascertain the degree of influence of communication styles of physicians in decision-making of advance directives at the end-of-life. Forty-nine questionnaires were completed. These were obtained in two ways. One was through general distribution among the medical staff. The other method was an exchange of Continuing Medical Education Units for questionnaires completed. The sampled population is small and any generalizations are limited to this group of physicians. It must be stressed that the generality of the results of this study will have to be demonstrated in further research.

#### Questionnaire Construction

The construction of the questionnaire items is guided both by the literature review and insight gained through the qualitative elements of the case studies. These four case studies are located within a family setting. Dialogues over a long period of time with extended members of these families provided a glimpse into how different individuals present their wishes. These wishes were discussed long before death was near. Some of these individuals presented their insights with humor. On the other hand, one individual could not confront his finality. As these elders talked about their death, those around them reacted differently. Some only teared-up. Others seemed to listen with their hearts.

As these senior members encountered the medical setting, none of them had prepared advance directives. They all relied on their family to speak their wishes. It should be stated that these deaths occurred within two years between 1993 and 1995. The PSDA was still new at that time.

Some family members took careful consideration of these elders' wishes. An example of this is Lupita's wishes not to be hooked up to extra heroic measures after her first stroke. This characterizes a democratic communication style in decision-making. The opposite was related by another primary care-giver. When asked if his brother would have carried out his father's wishes, this proxy replied no. He explained further that the brother was one not to listen.

Explaining these wishes before the medical doctor became part of presenting these elders' social history. Their wishes became part of their reality. By fulfilling their families' wishes, the primary care-givers validated the trust placed upon them. This trustworthiness had been tested over time by the older generation. They knew whom to turn to within their family.

Critical analysis of these social texts lent insight as to what to look for in the literature in constructing items for the questionnaire. Awareness of the ethnic lived experiences helped to explicate local cultural knowledge and to map it within this literature review.

#### Characteristics of Sampled Population

Table 1 contains the personal characteristics and educational profile of the medical doctors sampled.

Table 1  
 Characteristics of Sampled Population  
 Participants (n = 49)

Sex	%	n
Male	83	41
Female	17	8

Age	%	n
25-39 years	26	13
40-55 years	42	21
56 and over	24	12

Education	%	n
Med School-in-State	51	25
Med School-out-State	22	11
Med School-out-U.S	20	10
Residency-in-State	51	25
Residency-out-State	45	22
Residency-out-U.S	2	1
Missing cases	2	1

The median years in medical practice was 17 years with twelve of these years in the Valley.

Subspecialties are divided in the following manner:

Table 2  
 Medical Practice Subspecialties

Anesthesiology	3
Cardiology	
Cardiovascular	
Neurology	3
Oncology	
Radiology	
Family Medicine	17
Internal Medicine	
Orthodontics	
Ophthalmology	9
Pediatrics	
Psychiatry	
Surgery	5
Neurosurgery	
Urology	
Other	8
Missing Cases	4

### Medical Practice Characteristics

Thirteen respondents are sole practitioners; 33 are in practice with someone else. Forty-four percent of the respondents reported an average patient load of 270. Twenty-two percent of the sampled respondents reported having someone in their practice trained to administer advance directives. Thirty-six percent do not have any one trained to administer advance directives. Eighty percent of the sampled population has not had special training to administer advance directives.

### Socialization Attributes of Sample Population

Thirty-seven percent of the respondents speak very little Spanish or not at all; twelve percent speak Spanish almost always.

Forty-nine of the sampled population socializes with Hispanics moderately or not at all. Sixteen percent almost always socialize with Hispanics.

Fifty-one percent have moderately or very little friendships with Hispanics. Eleven percent have friends of Hispanic origin.

### Analysis

First, the sampled population data was analyzed for basic frequencies. Next a Factor Analysis was ordered without specifying factor solutions. From this preliminary analysis a scale was constructed using the following fifteen variables:

19. A Less stressed patient is better qualified to make end of life directive
20. A Medicaid patient is very capable in making end of life directive
21. A Medicare patient, on the average is very capable in making end of life directive
22. A private insurance patient, on the average is very capable in making end of life directive
23. A private pay patient, on the average, is very capable in making end of life directive
24. The patient has a right to ensure that relevant information is disclosed
25. The patient's active participation is desired (in making end of life directive)

26. Patients should respect physician's expertise
27. The physician controls communication flow between the two parties
28. The physician makes all important decisions
29. The physician should provide some explanation to the patient
30. The patient must be a central player for medical the encounter to be successful
31. In today's medical setting more input is required of the patient
32. Patient should not interrupt end of life decision conversations
33. RN should initiate end of life decisions conversation

This scale yielded an alpha coefficient of .837. The reliability of the scale is strong. It has a Std. Dev.= 8.76, mean = 36.8 with n = 43.

Five items from the above scale were clustered. They were analyzed for reliability to determine the extent to which these five items are related to each other and thereby obtain an overall index of their internal consistency. These are questionnaire items:

24. The patient's active participation is desired.
25. The patient has a right to ensure that relevant information is disclosed.
29. The physician should provide some explanation to the patient.
30. The patient must be a central player for the medical encounter to be successful
31. In today's medical setting more input is required of the patient.

Cronbach's Alpha model of reliability was used. It is a model of internal consistency, based on the average inter-item correlation. An alpha coefficient of .6969 was obtained. This specifies a moderate correlation among the items.

Next these five variables were then collapsed into one item. This variable was named "egalitarian communication". It became an independent variable in a regression analysis to determine to what extent egalitarian attributes of communication predict the dependent variables. The dependent variables selected were questionnaire items:

7. Patients who do make end of life directives are older
8. Patients who do make end of life directives are less healthy than those with out end of life directives

9. Most of my patients who have heard of durable power of attorney understand the purpose of this document.
10. Physicians should initiate conversation about end of life directives
11. In an end of life directive conversation with a patient, physicians should discuss situations in which most patients receive only palliative care.

The out come of how “egalitarian communication” style at decision-making impacts the above variables is as follows:

7. Patients who do make end-of-life directives are older: R square = .067.
8. Patients who do make end-of-life directives are less healthy R square = .011.
9. Most of my patients who have heard of durable power of attorney understand the purpose of this document R square = .000
10. Physicians should initiate conversations about end-of-life R square = .022
11. In an end-of-life directive conversation with a patient, physicians should discuss situations in which most patients receive only palliative care R square = .022

These findings are not significant. It may be that other factors influence the decisions.

In a similar manner, the following four items were clustered to comprise one variable labeled “authoritative communication”. These four items are:

26. Patients should respect the physician’s expertise
27. The physician controls communication flow between the two parties
28. The physician makes all-important decision
32. Patients should not interrupt a physician in mid-sentence

Cornbach’s Alpha model of reliability was used. This is a model of internal consistency, based on the average inter-item correlation. An alpha coefficient of .4278 was obtained. This specifies a less than moderate correlation among the items.

As above, these four variables were then collapsed into one item. This variable was named “authoritarian communication”. It became an independent variable in a linear regression analysis to determine to what extent authoritarian attributes of communication

predict the dependent variables. The dependent variables selected were questionnaire items:

7. Patients who do make end of life directives are older
8. Patients who do make end of life directives are less healthy than those with out end of life directives
9. Most of my patients who have heard of durable power of attorney understand the purpose of this document.
10. Physicians should initiate conversation about end of life directives
11. In an end of life directive conversation with a patient, physicians should discuss situations in which most patients receive only palliative care.

The outcome of how “authoritarian communication” style at decision-making impacts the above variables is as follows:

7. Patients who do make end of life directives are older: R square = .073
8. Patients who do make end of life directives are less healthy than those with out end of life directives: R square = .066
9. Most of my patients who have heard of durable power of attorney understand the purpose of this document: R square = .119
10. Physicians should initiate conversation about end of life directives: R square = .130
11. In an end of life directive conversation with a patient, physicians should discuss situations in which most patients receive only palliative care. R square = .134.

These findings are not significant. It may be that other factors influence the decisions.

Eighty-nine percent of the respondents agree that a patient should respect the physician’s expertise. Sixty-seven percent agree that the physician controls the communication flow.

Fifty-one percent of the respondents disagree that a physician makes all-important decisions. Thirty-four percent agree that patients should not interrupt a physician in mid-sentence, with sixty-five percent disagree or highly disagree.

Ninety-six percent of the respondents agree that in today's medical setting more input is required of the patient. Sixty-three percent of the respondents speak Spanish moderately, very little (11% don't speak Spanish at all). Forty-nine percent of the respondents have moderate or not at all socialization with Hispanics. Fifty-one percent of the respondents have 'moderate or very little' friends of Hispanic origins.

Whereas ninety-four percent of the questionnaire respondents agree that physicians should initiate conversations about advance directives, during the participant observation phase only the Guest Relations coordinator was present. In a \$28 million, eight-year study with over 9,000 patients, of how physicians handle the wishes of terminally ill patients (Connors 1995), nurses were placed in five teaching hospitals to facilitate communication between physicians and patients gravely ill. The study hoped that the pain of such patients, who account for 40 percent of all hospital deaths, would be diminished and that their wishes concerning the withdrawal of care would be heeded. But the project reported failure. Unfortunately, this effort to enhance decision-making at the individual patient-clinician level did not improve the experience of seriously ill and dying patients (Prichard, et al 1242). A physician who participated in the study reported that he was not surprised by the results because "the drive of the system is to provide life-extending versus comfort care" (Devires and Subedi 1998 74). The lack of physician participation in the observation phase of this study is noteworthy. This study echoes the conclusion of the SUPPORT study by Prichard, we must focus on adjusting the levels of resources and developing the patterns of practice that reliably meet the needs of dying patients (1998 1240).



The case studies validate the process of socialization toward the dying role. Three out of four, Lupita, Paulita, and Rodolfo, identified with behavioral patterns associated with the dying role. Their expressed beliefs of having lived a long life, not wanting heroic measures, not wanting to suffer excessively, exemplify a preference for palliative treatment rather curative treatment. They were adamant that those near them listen and follow through with their wishes. They chose pain alleviation over life-prolongation. Because the patients exhibited a dominant and assertive communication style, the caregivers were *'given their marching orders'* and fulfilled their loved ones wishes. The attending physician in Paulita's case was a relative. He did not challenge the decision. He thus exhibited a democratic communication style in decision-making. In the case of Lupita and Rodolfo the attending physicians also adhered to the family's wishes.

The fourth case study, Cando, was not one to express himself to such an extent. He was much more a private person. He kept his feelings to himself. Equally when he did speak, his family did as told. In this way his communication style about decision-making was authoritative. Cando spent some eleven days in the hospital before his death. He was intubated with a cuffed endotracheal tube. His family did not know what to do. The process ran its course and the physician spoke with the oldest son. The family gathered and Cando to see Cando pass away. Because of unspoken instructions, Cando death was different than the other three cases. His hospital stay was much longer and subsequently more expensive.

The case studies occurred before the questionnaire instrument was constructed. These case studies are a guiding influence in constructing the elements of the questionnaire. From these case studies one gains insight into the socialization process of

role taking in communicating about end-of-life wishes. From the patient point of view a dominant communication is necessary to fulfill his/her wishes. The socialization process involves care-givers who are receptive to a palliative rather than a curative procedure at end-of-life.

The participant observation methods bring out demographic characteristics of the area. Whereas 87.3% of the population is Hispanic, sixty-three percent of the medical physician respondents speak Spanish moderately or very little and 11 percent don't speak Spanish at all. Furthermore none of the physicians volunteered to be observed as they broached the topic of advance directives with their terminally ill patients.

#### Policy Recommendations

Policy recommendations call for a training program in advance directives for medical doctors. As noted in the findings, eighty percent of the medical doctors questioned do not have training to administer advance directives. The findings also point out that only twenty-two percent of the respondents have someone in their staff trained to administer these advance directives.

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APPENDIX A  
QUESTIONNAIRE



## Communication Styles End of Life Directive Questionnaire

Please provide the following information:

- a. Are you ...? Male \_\_\_\_\_ Female \_\_\_\_\_
- b. Medical school education: City \_\_\_\_\_ State \_\_\_\_\_ Country \_\_\_\_\_
- c. Residency City \_\_\_\_\_ State \_\_\_\_\_ Country \_\_\_\_\_
- d. Number of years in medical practice \_\_\_\_\_
- e. Number of years in medical practice in South Texas \_\_\_\_\_
- f. Field of practice: Anesthesiology \_\_\_\_\_ Oncology \_\_\_\_\_ Public health \_\_\_\_\_  
 Cardiology \_\_\_\_\_ Ophthalmology \_\_\_\_\_ Surgery \_\_\_\_\_  
 Cardiovascular \_\_\_\_\_ Orthopedics \_\_\_\_\_ Neurosurgery \_\_\_\_\_  
 Dermatology \_\_\_\_\_ Physical medicine \_\_\_\_\_ Surgery-other specialty \_\_\_\_\_  
 Family medicine \_\_\_\_\_ Psychiatry \_\_\_\_\_ Urology \_\_\_\_\_  
 Internal medicine \_\_\_\_\_ Radiology \_\_\_\_\_ Other \_\_\_\_\_  
 Neurology \_\_\_\_\_ Pediatrics \_\_\_\_\_ Obstetrics and gynecology \_\_\_\_\_

Select the choice that best approximates your situation.

- |   | 100-75%                  | 74-50%                   | 49-25%                   | 24-0%                    |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. Percent of patients I consult who speak only Spanish.....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Percent of patients I consult who speak Spanish and English.....   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Percent of patients I consult who are informed about end of life directive.....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Percent of patients I consult who have executed an end of life directive.....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Percent of time, unfamiliarity with advance directives is cited as reason for not having an end of life directive..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Percent of time, procrastination is cited as reason for not having an end of life directive.....                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please rate the following items by checking your best choice.

Please do not leave any items unanswered.

- |  | Highly Agree             | Somewhat Agree           | Agree                    | Disagree                 | Highly Disagree          |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 7. Patients who do make end of life directives are older.....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Patients who do make end of life directives are less healthy than those without end of life directives.....   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Most of my patients who have heard of the durable power of attorney understand the purpose of this document.....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Physicians should initiate conversation about end of life directives.....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. In an end of life directive conversation with a patient, physicians should discuss situations in which most patients receive only palliative care..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Select one choice, please.

Please do not leave any item unanswered.

- |   | Highly Agree             | Somewhat Agree           | Agree                    | Disagree                 | Highly Disagree          |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 12. Patients who only speak Spanish should be addressed by the next of kin about end of life directives.....                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Male patients who only speak Spanish should be addressed about end of life directives by a son.....                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Male patients who only speak Spanish should be addressed about end of life directives by a daughter.....                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Female patients who only speak Spanish should be addressed about end of life directives by a son.....                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Female patients who only speak Spanish should be addressed about end of life directives by a daughter.....                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Patients who understand English are better qualified to make end of life directives than patients who don't understand English..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Select one choice, please.

Please do not leave any item unanswered.

	Highly Agree	Somewhat Agree	Agree	Disagree	Highly Disagree
18. A family member is always better qualified to make end of life directives.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. A less stressed patient is better qualified to make end of life directives than an overstressed patient.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. A Medicaid patient, on the average, is very capable in making end of life directives.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. A Medicare patient, on the average, is very capable in making end of life directives.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. A private insurance patient, on the average, is very capable in making end of life directives.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. A private pay patient, on the average, is very capable in making end of life directives.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Select one choice, please.

Please do not leave any item unanswered.

	Highly Agree	Somewhat Agree	Agree	Disagree	Highly Disagree
24. The patient has a right to ensure that relevant information is disclosed.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. The patient's active participation is desired.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Patients should respect the physician's expertise.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. The physician controls communication flow between the two.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. The physician makes all important decisions.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. The physician should provide some explanation to the patient.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. The patient must be a central player for the medical encounter to be successful.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. In today's medical setting more input is required of the patient.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Patients should not interrupt a physician in mid-sentence.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Social workers should initiate end of life decisions conversations.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Registered Nurses should initiate end of life decisions talks.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please provide the following information:

35. Are you the sole practitioner in your practice Yes \_\_\_\_ No \_\_\_\_

36. How many physicians are in you practice \_\_\_\_

37. On the average, what is your monthly patient load \_\_\_\_

38. Is there someone in your practice trained in administering end of life directives? Yes \_\_\_\_ No \_\_\_\_

Please fill in one for each selection:

	Not at All	Very Little Not very Much	Moderately	Much/ Very Often	Almost Always/ Extremely Often
g. I speak Spanish					
h. I socialize with Hispanics					
i. My friends are of Hispanic origins					
j. I speak only English					
k. I speak a second language					

l. Other language(s) I speak are \_\_\_\_\_

**APPENDIX B**  
**INFORMED CONSENT**

Consent Form  
End-of-Life Directives and Communication Styles Questionnaire

UTPA Sociology Master's Program  
Social and Behavioral Sciences Building, SBS #229  
1201 West University Drive  
Edinburg, Texas 78540  
956-381-2138

Name: \_\_\_\_\_

ID # \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Armando G. Dominguez of the Master's Thesis Program of the Sociology Department at The University of Texas-Pan American, Edinburg is conducting a study about end-of-life issues and communication styles at this medical institution. The questionnaire addresses issues of advance directives, do not resuscitate orders, durable power of attorney, and communication styles in a medical setting.

We are asking you to participate in this study. The study consists of filling out a questionnaire. The questionnaire takes about fifteen minutes to complete. In addition you will be asked to participate in a presentation by Mr. Dominguez and Chaplin Timothy Mathews on end of life issues. For the lecture and the completion of the questionnaire you will be awarded Continuation Education Units as set by the hospital.

All the information will be kept strictly confidential. A number assigned to you by Mr. Dominguez will identify you. Your name will never be associated with the study.

The decision to participate is yours. If you decide to participate and later change your mind, for whatever reason, you can stop responding to the questionnaire at any point. Please note that you can withdraw from the study at any time, but you must complete the questionnaire to receive the CEUs.

If you have any questions, please call Mr. Dominguez at 381-2138.

I, the undersigned, accept to participate in this study conducted by the Master Thesis's Program of the Sociology Department at The University of Texas-Pan American. All the information in this letter has been explained to me and I understand it.

\_\_\_\_\_  
Subject

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date

**\*\*This research has been approved by the Institutional Review Board –Human Subjects In Research. For research related problems or questions regarding this questionnaire subject's rights, contact the Human Subject's Committee: 381-2287, Dr. Bahram Faraji.**

## VITA

Armando G. Dominguez, BA, University of Texas-Pan American, 1995. Co-author, Work Trajectories as Predictors of Mental and Physical Health Among Middle Aged and Older Foreign and Native Born Mexican Americans, presented at the Fourteenth World Congress of Sociology, Montreal Canada, 1998. Co-author, Mexican-American Drinking Attitudes in the Lower Rio Grande Valley, presented at the Seventy-ninth Annual Meeting of the Southwestern Social Science Association, San Antonio, Texas, 1999. Co-author, Mental Health and Disability Status of the Diabetic Older Mexican American, presented at the Fifty-second Annual Scientific Meeting of the Gerontological Society of America, San Francisco, 1999.

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