



**Navigating a World of Multiple Perspectives in End of life Care
How to conduct a care conference**

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The national drama surrounding Terry Schiavo brought home the difficult and often tragic choices family members have to make regarding medical care at the end of life. Photographs, videos and details of her day-to-day existence in a persistent vegetative state were relentlessly televised and reported. Such images evoked a “face in the wall” for us as a nation and provoked important questions for everyone to ponder. Who and what is a person in a persistent vegetative state? Who should decide the fate of a person who can no longer speak for him or herself-- a husband or a parent? How do we reconcile disparate views of the good for what is essentially a private family matter? What is the role of the state in safeguarding a vulnerable person?

The answer to these questions is never easy or routine. In my work as a hospice medical director and a geriatric psychiatrist I have found that descriptive psychology concepts have provided useful navigational tools and maps for both families and health care professionals to end of life care decision-making. In my presentation I reviewed how I use these concepts to help families find their answers to “what is the right thing to do”. I turned first to describing the players and venues in this dramaturgical pattern. I then discussed some of the work I do with families and with health care professionals using descriptive concepts. Finally, I presented a descriptive psychology informed strategy to conduct a care conference and solve a problem regarding the decision to insert a feeding tube in a hospice patient with vascular dementia who could no longer swallow or eat.

Venues of Care and End of Life Decision-Making: What is the right thing to do?

The question of the right thing to do, and who is the appropriate decision maker, describes a daily reality confronted by spouses, adult children, friends and surrogate decision-makers, in their homes, in nursing homes and in hospitals. A unique aspect of such decision-making is that it occurs simultaneously in private and public spaces. The context includes not only the persons present in each venue, but also the communities that each represents. Care in each of these venues is not unlike the distributive problem solving that occurs in any organization where multiple sub-communities come together to create a product (e.g. software development). For example in any care setting there may be three shifts of nursing staff, multiple physicians and consultants, social workers, chaplains, nutritionists, speech therapists, physical and occupational therapists. Each professional also represents their community perspectives, norms, decision-making principles, language, and social practices, which can include any or all of the following: medical, psychological, social, cultural, legal, ethical and religious. As one might imagine there can be many ways so many persons and so many

perspectives can create confusion if not outright conflict if the goals of care are not clear, not well and frequently communicated, or they violate someone's deeply held personal or professional values.

The reader with a descriptive psychology background might see from this description of persons, families, professional communities and end of life decision-making an opportunity for descriptive concepts to be of some help. The help is not just to the participants but also in guiding this presenter who regularly meets with families to help make decisions about feeding tubes and goals of care. The next sections describe the descriptive concepts as I outlined them in my talk and how I apply them to end of life decision-making as well as how to use them in conducting a care conference.

Talking with family members of a cognitively impaired patient without decisional capacity

The focus in the Schiavo case was removal of a feeding tube. A number of concepts from descriptive can help sort out "what are we doing, when we do that" in this case either inserting or removing a feeding tube, or for that matter the significance in using any technology or treatment. When a patient with dementia or impaired decisional capacity can no longer swallow, does not take in enough nutrition to sustain life, or simply refuses to eat, families and health care professionals are confronted with a dilemma: what is the right thing to do for this person? In order to answer this question descriptive concepts help construct a narrative to facilitate an answer to this difficult question. The guiding concepts sequentially involve the definition of a person, the intentional action calculus, and the community paradigm.

1. Person concept: a person is an individual who paradigmatically is a history of deliberative action in a dramaturgical pattern. This leads to asking the family member or surrogate decision maker about their spouse or parent: what were they like before their illness, what did they do and what was important to them, and what did they value. What relationships were important to them? What type of activities and groups did they participate in?
2. Intentional Action leads to the next set of questions: If your spouse, mom or dad were fully present and lucid what would they want at this point? Would they want to continue to live this way? Is this a meaningful life for them? Would they want to be treated at this point and if so, in what way?
3. Significance and Re-description: For someone who is in a persistent vegetative state or who has end stage dementia I also raise another question regarding what we are doing by providing or continuing certain types of treatments. I find a way to educate and suggest a different appraisal of "what we might be doing by inserting a feeding tube, starting an antibiotic, performing cardiopulmonary resuscitation, or any other life sustaining or prolonging treatment. "In thinking about the future there may be a point where treatments may actually prolong suffering and prolong the dying process rather than return someone to a previous higher level of functioning or to a meaningful quality of life." I also use a particular locution to reinforce the concept of a person: "As persons we have a biological and biographical life which at end of life may become primarily a biological life."

Educating Health Care professionals on End of Life Decision-making

In preparing professionals for conversations and caring of patients and families the "Face in the Wall" device is a useful way to capture the experience of patients and families, especially at the end of life. In various health professional education settings the exercise is done as an interactive exercise. Everyone in the room is instructed to focus on a wall, imagine a face appeared and slowly recedes. After roughly 30 to 60 seconds the participants are instructed to share their experience with someone

close to them. A facilitated call out from each group defines the reactions, thoughts, and feelings to “thinking the unthinkable”. I then reviewed some of Ray Bergner’s elegant work on how “words change worlds” and ask them to imagine hearing their physician say to them “you have alzheimer’s disease” or you have cancer and you have 6 months or less to live.” The discussion then focuses on the experience of many patients, family members and friends who are have undergone profound changes in their personal worlds and often find themselves without tools to navigate their changed world. I then ask the health professionals to think about what is their role with patients in their changed world and assign them the status of guides as they are quite familiar with the territory ahead.

In addition to the face in the wall device, I also discussed a table in the form of a grid titled: Navigating a world of multiple perspectives, which is a short hand way to represent the many communities that come together in various care venues. The columns of the grid sequentially are: Players, Medical, Psychosocial-Cultural, Ethical, Legal, Religious, Public Policy/Political. All but the first column represent the perspectives of each community and all of the decision-making principles, social practices and locutions that characterize the community. The first column, players, represents all of the participants in the various care settings and include the patient, family, professional care givers (nurses, home health aids, etc), medical professionals, and at end of life hospice professionals. The grid is primarily an accounting device to remind professionals and family members of the complexity of making decisions about what to do. (Figure 1).

Figure 1: GOALS OF CARE: Living in a World of Multiple Perspectives

A person is an individual whose life history is, paradigmatically, a history of deliberative action who participates in the social practices of his community.

Consider the following perspectives and people involved in setting Goals of Care

Feeding Tubes: What are we doing by doing that?

Players	Medical	PsychoSocial Cultural	Ethical	Legal	Religious	Public Policy Politics
Person						
Family						
Caregivers						
Primary Health Care Team						
Government						

I presented a case to the audience and asked them to assume that they were to be the facilitators of a care conference. Care conferences occur daily in hospitals and nursing homes where family members, professional staff and hospice personnel meet to discuss goals of care. This usually occurs when there is a difficult decision to make and the patient's condition will continue to decline depending on the treatments chosen or not chosen. The audience was asked to refer to the navigational grid to determine who should be at the care conference, how to conduct the care conference, and to solve a difficult clinical problem regarding the use of a feeding tube. The problem simply put was that the 85 year old impaired patient's two daughters, both of whom had durable power of attorney for health care decision-making, could not agree upon whether to insert a feeding tube. The patient was no longer able to swallow and was declining. One daughter believed that the patient's prior advance directives were clear which stated that she did not want a feeding tube. The other daughter recognized that her mother was declining and believed that her mother would suffer more by not having a feeding tube, e.g. would experience hunger and be uncomfortable because of dehydration.

The discussion revealed many important considerations from each of the relevant perspectives and specific decision-making principles and social practices from each community. The topics and issues included: medical benefits and burdens of feeding tubes, family legacy of not coming to a consensus on how to proceed, advance directives and informed consent regarding respecting patient's choices, the complex interactions among medical professionals and nursing staffs, and the need at the care conference to come to some resolution on how to proceed. The importance of the facilitator role was highlighted and the strategy the facilitator can use to bring the various parties and perspectives into clear relief and resolution. Those steps include: clarifying the goals and desired outcome of the care conference, creating a shared world view of the current situation by allowing everyone to speak and to be heard, educating everyone regarding the current medical status of the patient as well as the benefits and burdens of a feeding tube, and honoring everyone's attempts at doing what is in the best interests of the patient. In the specific case where the two decision-makers could not come to an agreement, the facilitator did propose a time limited intervention which involved the insertion of a naso-gastric tube to evaluate if it would provide some comfort for the patient, e.g. address "hunger". This is a non-surgical, immediately reversible intervention. The two daughters agreed to the trial. The patient pulled out the tube after 12 hours. The daughters were then in agreement to proceed with the comfort focus. The patient died a few days later with good symptom control.