



**Interviewing at the End of Life: A Descriptive Formulation**

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<b>Part I:</b>	<b>Goals of Care Interviewing</b>
<b>Part II:</b>	<b>An Annotated Interview</b>
<b>Part III:</b>	<b>Descriptive Psychology Formulation of the Goals of Care Interview</b>

***“...dying is no longer something that happens to you but something you do.”***

*Margaret Pabst-Battin in Physician Assisted Suicide: Safe, Legal, Rare? 1998.<sup>1</sup>*

***“If the situation calls for a person to do something he can’t do he will do something he can do...if he does anything at all.”*** Peter O. Ossorio

**Abstract**

It is axiomatic that we stand and exist in some particular and unique place in order to behave in one way or another. We act in one way or another intending the world to be one way or another. This is so even when confronted by a chronic or terminal illness both which challenge one’s very ability to physically stand or to psychologically retain one’s social place, let alone behave as one was accustomed to when healthy. Hospice, palliative care and other health care professionals are called upon to help individuals at this difficult time when their statuses, eligibilities and abilities are changing and challenged, often for the worse. This paper describes an interview developed by the author to provide a framework for patients and families to make medical treatment and personal decisions consistent with individual and family values

The purpose of the paper and the structured interview is to provide an accurate, complete and useful description of such interviewing so that it can be understood, learned and performed by health care professionals as they work with patient’s and families in distress. Relevant descriptive concepts are reviewed as they provide the conceptual background and stage for understanding end of life world reconstruction as well as the achievement and significance of the interviewer’s behavior, questions and facilitated discussions with families. When successfully performed the interview provides patients and families useful concepts to guide medical decisions, treatments and end of life planning.

## **Part I: Goals of Care Interviewing**

### **Background**

Hospice programs were created through Congressional legislative action in the late 1980s to address the significant struggles, dilemmas, physical and psychological suffering that patients and their families experience in facing an uncertain future. They provide individuals and families an opportunity to find their own way at the end of life. This is accomplished by providing support, education, and treatments consistent with individual and family wishes and values. There is a strong emphasis on respecting autonomy and maintaining control over treatment options and medical decision-making.

One of the most difficult transitions for individuals and families occurs at the time of hospice referral. Physicians occupy the unenviable position of medical status assigners who confirm an individual and family's worst fears. They initiate conversations euphemistically referred to in end of life training as "how to communicate bad news". What may not be appreciated is that an individual person sitting across from a physician is being assigned a new status: that of a chronic or terminally ill patient foreshadowing the end of his or her life. Although it is true for everyone that death comes sooner or later, it becomes real when one has to act upon the information provided by the physician. Such status assignments may also initiate an intense and distressing period of "thinking the unthinkable" where the future becomes uncertain and limited. Accompanying the high level of distress that an individual experiences with "thinking the thinkable", a patient may question his or her eligibility to make appropriate medical and personal decisions. This is heightened by the initial phases of the diagnostic and treatment journey, often fraught with extended periods of personally invasive and intrusive diagnostic evaluations, lab work, illness staging, and further laboratory testing. The usual outcome often requires choices to be made among various treatment options, some relatively benign others with life threatening side effects of their own.

During this period of time patients and families are overloaded with new and unfamiliar medical information with little sense of its significance for them personally or how it can be integrated into their future planning. Patients and families who struggle with a transition from more typical and ordinary goals of care (cure, desiring aggressive treatments and maintaining their pre-diagnosis quality of life), to a comfort focus can be helped by a skillfully conducted goals of care interview. Such interviewing creates mutually created and agreed upon goals of care and a plan of care to achieve them.

## **Goals of Care**

*Goals of care* in hospice and palliative care programs is an important *concept of care* which guides medical and personal decision-making at the end of life. The concept makes explicit what is implicit in the physician/healthcare professional-patient/family relationship: medical treatments are chosen by the patient and family that are consistent with the patient's wishes, values, and life projects. This central focus on patient self-determination and autonomy, although present in all patient-physician relationships to one degree or another takes on a unique significance at the end of life and with any life-limiting illness. The typical medical goals of care which are to heal or ameliorate symptoms through curative treatments or management of chronic disease are no longer viable options. A referral to hospice care and hospice programs often occurs when the patient and family goals of care both medically and personally are so challenged and may not be clear. A skillfully conducted goals of care interview addresses this stressful transition in treatment goals and the need to face an uncertain and limited future.

## **Clinical Interviews: Constructing a Shared World of End of Life Possibilities**

Clinical interviews are very powerful tools in mutually creating a shared view of the patient's and family's current psychological and physical reality. They also inform the clinician, the patient and family members about important family and professional caring values and goals in facing an uncertain future. As the clinician, patient and family members assemble for such encounters, a unique, albeit time limited, and ad hoc healthcare-patient-family community is created where information is shared, difficult issues are discussed, and values can be clarified. Conflicts among family members or patients and clinicians can also be addressed. When successful, such interviews outline a plan of care to achieve the patient and family's desired goals and steps are taken to implement it in a timely fashion. The stakes are often quite high as time is limited and if conflicts aren't resolved they can have a multigenerational legacy of continuing ill-will and mutual recriminations.

Given such high stakes, such interviews should be thoughtfully crafted and implemented. Every question or interviewer action should be able to answer the following question: "What am I doing by doing that (asking the question in a specific way with a specific locution)" and "what do I intend to achieve by asking this question at this time?" Such interviews should be crafted to expand the patient and family's concepts of what is and what isn't possible. Individuals and families may have little or no experience with or understanding of the commonly used concepts in hospice and palliative care such as "comfort care", "end of life care", "goals of care" and "palliative care".

In addition to articulating and enriching “concepts of end of life care” the clinician and interview should be prepared to directly address the “moral malaise” and ethical dilemmas that can occur when family members attempt to honor their ill family member by “doing the right thing”, especially when patients are too sick or unable to speak for themselves. Common moral and ethical dilemmas at the end of life frequently include the following:

- “Won’t I be killing my mom if we don’t treat the infection?”
- “How can I withhold treatment; won’t my dad suffer?”
- “If we don’t put in a feeding tube won’t my mom die of starvation?”
- “Don’t we have to make sure mom eats three meals a day?”
- “Doesn’t the Church say that we have to do everything possible?”

### **Goals of Care Interview Considerations**

There is no one right way to conduct such an interview. The following outline is a particular sequence that has evolved after trial and error with many patients and families. It is not prescriptive only descriptive and provides suggestions to guide any goals of care interview approach.

#### *Establishing a professional caring relationship*

Much of what unfolds on entering a hospice program occurs among strangers. Hospice medical directors, nurses, social workers, home health aids, chaplains, music therapists, massage therapists, volunteers and other members of the care team literally surround the patient in his or her home, nursing home or at hospital bedside. Given what may be experienced as an intrusion of outsiders at a critical and stressful time in family life, it is important to establish a strong, professional caring relationship at every encounter, and more so when meeting with patients and families to develop a plan of care to achieve their goals of care.

To create a successful professional caring relationship the clinician needs to create the type of relationship he or she intends to develop with the patient and family. It may seem obvious, but still worth repeating and describing the type of professional relationship that is desired. It is a relationship where the patient or any family member experiences the clinician as an interested, caring, competent, professional who values and respects each member of the family. The effective clinician creates an atmosphere where open dialogue encourages every family member to ask any and all questions of concern as well as a one that considers the best interests of each member of the family including the patient. Additionally, a relationship is created where the clinician is able to expand and enrich each family member’s concept of what is possible to achieve in the face of stressful and disease limiting choices—providing hopes for what can happen rather than focusing on what can’t happen in the time

that remains. The relationship that is thus created also has an educational purpose so that the patient and family know what choices are medically, legally and ethically permissible, or impermissible. The successfully created relationship is thus characterized by respectful, interchanges where the patient and family's wishes are voiced and lead to a plan of care that will achieve their goals while at the same time be consistent with what is professional and clinically viable and possible.

### *Structuring the Meeting*

Many of the initial hospice team meetings with patients and family members occur at a time of high stress and uncertainty. Successful meeting formats can directly address the initial crises, ameliorate and contain the stress by efficiently and effectively clarifying the goals for being in hospice and what can be accomplished. A goals of care meeting is intentionally designed to explore and document everyone's goals--for the patient and family a plan of care and caring that will help guide them in the days, weeks and months ahead; for the hospice care professionals an understanding of the specific needs, wishes and goals of the family and how best to employ their expertise to achieve them.

The meeting format, agenda and structure should be made clear at the beginning of the meeting once everyone is together. The following is a rough outline of how the meeting could be structured and the issues/topics that should be addressed:

- Introductions
- Setting the Agenda and purpose of the meeting
- Addressing burning or other important questions
- Eliciting patient biography/autobiography, personality, values, wishes and goals
- Eliciting and providing updated clinical information,
- Answering questions, educating patient and family on what is possible/permissible, not possible/not permissible,
- Honoring everyone's efforts at confronting and solving difficult problems in the best interest of the patient and each other
- Summarizing understandings and confirming goals and next steps.

### *Introductions*

Although obvious, it is always worth repeating that everyone in the room should be introduced including how each person is related to the patient or what role the specific clinician plays as part of the care team. If the patient is no longer making his/her own decisions, it is important to determine who is the legally designated decision-maker as well as who are the other key family or other persons

who are involved in the care of the patient who should also be consulted in the decision-making process, e.g. family members who are out of town.

### *Setting the Agenda and Purpose of the Meeting*

After introductions are completed the clinician facilitating the meeting should briefly state the purpose of the meeting, sketch out the agenda and verify that everyone attending shares the same understanding and the desired outcome, e.g, clarifying the focus on comfort rather than hospitalizations, possible blood transfusion in order to attend a grandchild's wedding, etc. Patients, family members and care givers often have important questions regarding diagnosis, prognosis, treatments, options, hospice benefits, coverage issues, care concerns, medication concerns, as well as family planning for the near term future. Letting everyone know up front that the meeting will begin with eliciting their concerns and questions is often a critical step in both communicating interest and concern for them as well as defining the clinical relationship as patient-family focused. It also has a powerful impact, accrediting each person in the meeting as partners who will share in developing solutions for their most important concerns.

### *Eliciting Questions of all participants*

There is a tendency to start goals of care meetings discussing treatment choices or discussion of hospice philosophy and treatment approaches. Doing so prematurely can often lead to frustrations on the part of the family and the hospice care professionals as there may not be a shared understanding of the patient's previously expressed wishes and values; yet to surface family conflicts; not to mention the lack of understanding of what hospice can or can't do. Most importantly the family and the care team do not have a shared, mutually created understanding and shared world to place the treatment options in a personally meaningful context.

One of the more effective uses of time as well as ensuring a successful meeting is to elicit questions and concerns from the patient and family members at the beginning of the meeting. This allows the clinician facilitating the meeting and care team members to understand and quickly focus on the important concerns from the patient and family perspective and not waste time on providing irrelevant information or making erroneous assumptions on what is important to cover. It is useful to make a mental and/or written list of the questions while at the same time informing everyone that the questions will be addressed later on in the meeting. It is important to avoid answering the questions until later in the interview. This is particularly important when the patient can't meaningfully participate in the meeting or other discussions as in situations where the patient has dementia, is

aphasic or is too ill to participate.

### *Eliciting patient biography/autobiography, personality, values, wishes and goals*

When a patient can't speak or participate in the meeting, spending time having the family members describe the patient's life and personal world prior to the illness is critical. The clinician facilitator should spend some time eliciting a brief overview of the patient's life and work history as well as a description of the patient's personality and values. If advance directives have been filled out and a health care agent is present this too should be part of the discussion. Having a good sense of the patient's previous level of function, values and wishes can then be brought into the discussion when focusing on specific treatment options, e.g. "if he or she were fully present what would his or her choice be?"

Having described the patient in the fullness of life can be especially helpful when families are in conflict about what is the right thing to do. When at a particular choice point regarding comfort or more vigorous treatments, trying to decide what would the patient want regarding medical hydration and nutrition, feeding tubes, blood transfusions, lab work and diagnostic testing, or antibiotics, the emphasis can be placed on the previously expressed values, wishes and way of living. Not infrequently families in a disagreement about a particular treatment or goal can resolve their differences when the decision is put into the framework of "what would mom or dad want if they were fully present?" When asked in this context the family's response often is "mom never wanted to be in a nursing home" or "dad never would want to continue living this way." As families press against the reality of the patient's continuing decline and terminal illness the goals of treatments often shift from maintaining quality of life or seeking another remission to avoiding prolonged suffering and dying by continuing aggressive treatment interventions, emergency room visits or hospitalizations which no longer restore the person to a reasonable level of functioning or quality of life.

### *Eliciting and providing updated clinical information*

It is not unusual for patients and family members to have discussed the patient's condition with dozens of health professionals including family physicians, specialists, nurses, nutritionists, physical and occupational therapists, speech therapists as well as many members of the hospice program. In addition to the health care professional community, the patient's family and friends may also have perspectives on the patient's clinical status and medical conditions. Creating a shared understanding of the patient's current clinical status and medical conditions can be a daunting enterprise due to clinical information that may be constantly evolving and potentially misinformation because so many people

are involved. The goals of care interview should take the time to review the pertinent current medical information and clinical status as viewed by the patient, family members and hospice team members. The concept of “cross sectional observations” can be helpful for everyone recognizing that it often requires piecing together everyone’s observations to get a more accurate clinical picture of “how the patient is doing” and what the likely prognosis will be.

When discussing the clinical status and medical condition is also an opportunity to educate the patient and family about the terminal illness, concerns regarding symptom management and how the illness will unfold. Families may have concerns which they have not been comfortable in asking that range from worries about the hereditary aspects of the illness and their risk factors to basic questions about how a person dies from lung cancer, emphysema, heart failure or dementia. Not infrequently everyone will want assurance that suffering and pain can be effectively addressed.

Depending on the particular patient and family it may be important to educate everyone about medication choices. Taking vitamins, cholesterol lowering medications, weekly measures of clotting times (INR), weekly or monthly blood stimulating drugs, or other treatments have become ingrained and reassuring routines for patients. It can be a difficult transition for them to realize that they are no longer necessary, nor will they help at this stage of their illness. The clinician interviewer can emphasize the voluntariness of stopping and discontinuing unnecessary medications, treatments, lab tests as well as informing the patient and family of the hospice guidelines for medication coverage. This is particularly important as the patient’s medical condition and status declines and when swallowing medications and aspiration are likely to occur.

*Answering questions, educating patient and family on what is possible/permissible, not possible/not permissible*

It is at this juncture that the clinical interviewer should summarize his or her understanding of the concerns, problems, treatment options, choices and patient/family specific personal goals. When the patient and family acknowledge that the interviewer has a clear and accurate understanding, he or she can provide focused, tailored responses to everyone’s questions and concerns. At this point in the interview a shared framework has been created to determine if a particular treatment will be helpful or not in achieving the patient’s or family’s desired outcome.

Many patients and families want to know what can be done so that they will not suffer at the end of life. Less frequently patients or family member wish to hasten the dying process or even request assistance in dying. Some end of life scenarios are further complicated by family members who are in conflict with each other concerning what to do for a family member who has dementia or

otherwise can no longer participate in decision-making. Occasionally some family members may wish aggressive treatments to be initiated that are viewed by medical care professionals as futile care that will increase the patient's suffering and prolong the dying process. Any of these situations are important opportunities to educate patients and families about palliative care as well as medical-legal-ethical aspects of decision-making. Having developed a good understanding of the patient's wishes through the shared narrative and biography when the patient can't speak for him or herself, may allow conflicts among family members or conflicts between the medical care professionals and family to be resolved. Reference to "what the patient would have wanted consistent with his/her values, personality, wishes and way of living" can be the way forward.

### *Strategies for responding to conflicts: Choosing Move I or Move II*

The clinical interviewer should be prepared for the inevitable conflicts that can occur among family members or between medical professionals, patients and families. Not infrequently the hospice care team will have information about the conflicts regarding treatment that are occurring among the patient and family members. In other situations early on in the interview such conflicts will emerge. Over time the clinician interviewer can try various interviewing strategies to address such conflicts. Descriptive Psychology provides a useful and simple way of categorizing conflicts that can guide the interviewers approach in the session. Conflicts are either solvable within the framework of the ongoing discussion or they are unsolvable and require a different approach to achieve resolution. Conflicts that are solvable can be addressed by a "Move I". Conflicts that are not solvable require a "Move II".

Move I is to engage the conflict within the framework that is presented by the patient and family. Typical move I situations have to do with straightforward issues such as a continued treatment that typically isn't covered in hospice such as frequent blood transfusions, requests for care giving that is the family's responsibility. The conflict is resolved more or less because of the Medicare ground rules for the type of care that is provided in hospice. A reasonable solution might be to continue the treatments which are then charged to the patient and family or they are reimbursed with other insurance.

Move II conflict situations are more complex and frequently have no "right", correct or single solution. Often they represent differing values and judgments made by the patient and family member. Discussing the situation within the given framework cannot lead to an agreed upon solution because the family members or patient have different concepts, values, or goals that are not shared. It is in these situations that the interviewer may need to take a detour around the current conflict and return to

the situation by creating a new framework that all participants can embrace. These latter conflicts often occur when the patient can't speak for him or herself. This is why the interview focuses on the patient's values, wishes, previous written advance directives, conversations or other ways the discussion shifts to "what the patient would have wanted", not what the individual family members believe is the "right thing to do" from their own perspective.

*Closing the interview: Plan of Care Next Steps and Honoring everyone's efforts: Trying to do the right thing*

If the goals of care are clear and conflicts are resolved then the clinical interviewer can summarize the shared plan of care plan of care to achieve the desired goals. This summary should be specific with an understanding of the steps the hospice care team will implement in the coming days and weeks ahead. It is a good time to ask the patient and family members one more time if this achieves their goals and meets their expectation. Patients and families can also be reassured in closing that nothing is set in stone and that the goals of care and plan of care are routinely reviewed every two weeks or more frequently if necessary.

If agreement on the goals of care has not been accomplished during the meeting for whatever reason, it is important to acknowledge that everyone has "done their best to do the right thing." It is important to summarize points of agreement as well as the continuing issues of concern to make sure that all participants have an accurate understanding of each other's views, perspectives and concerns. A follow-up meeting should be scheduled while an interim plan of care that addresses the areas of agreement continues to be in place. The interviewer should also normalize the difficulties in arriving at an agreed upon goals and plan of care. Most families have had little experience, desire, or skills in negotiating with each other end of life goals and the responsibility is often experienced as overwhelming, fractious, and aversive. Honoring their best intentions in doing the right thing may in itself move the framework of the conflict from "who is right" to "what is in the best interest of the patient/family member."