



**Hospice Volunteers of Uncertain Status:
Descriptive Psychology meets the Ethics of Caring Relationships**

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Presented at the 29th Annual Conference of
The Society for Descriptive Psychology
Golden, Colorado
2007

Relationship and Status

*“It is been perfectly clear to most people most of the time that human behavior is a function of the person’s relationships and of the person’s place in the scheme of things”. Peter G. Ossorio, *The Behavior of Persons*, pg 230*

1. The relationship formula

If: A has a given relationship, R to P

Then: The behavior of A with respect to P will be an expression of R

2. The relationship change formula

If: A has a given relationship, R, to P

And: The behavior of A with respect to P violates R, and the behavior of A with respect to P is an expression of another relationship, R1, which is incompatible with R

Then: The relationship changes from being R toward being R1.

Descriptive Psychology, as we know, has far reaching applications. Over the past several years in my work as a hospice medical director it has come to my aid with the usual suspects: organizational community issues such as health care teams, leadership, and collaboration. In the past two years as I have been pursuing a masters degree in bioethics, I have had occasions to apply descriptive psychology concepts and bioethics concepts to some of issues that occur in within the doctor-patient relationship. Today’s presentation is one such integration of descriptive and bioethics regarding relationships and relationship violations.

Today’s presentation was provoked by a dilemma presented to me from Hospice of the Lakes volunteer coordinator. Before I discuss the dilemma I want to give you some background on hospice volunteers. All hospice programs have a volunteer component. In order to be a Medicare Hospice in

good standing, 5% of all patient care hours must be provided by hospice volunteers. Prior to seeing patients the volunteers must complete a volunteer training program. There is a short section in the training that covers “boundary issues” with patients. Something about the term “boundary issue” has always caused me some cognitive discomfort. It seemed better applied to geography than relationships. So, when the following dilemma was presented to me, I found myself waiting to pounce on the “boundary issue” by attempting a re-description of the problem. Here is the dilemma. As you listen think about the following issues:

1. what problems are created by volunteers of uncertain statuses?
2. what advice would you give to the Volunteer Coordinator?

Brenda a hospice volunteer was assigned to JS, a 79 year old patient with severe, recurrent depression, parkinson’s disease and dementia. Despite monthly ECT his depression was unremitting, he was losing weight, and he was referred to hospice. ECT was discontinued. Brenda was quite challenged by the patient’s situation as well as what she could do for the patient. The patient was described as a frail, elderly gentleman, who lay in bed, curled up in a fetal position. He did not say anything to Brenda during the visits and did not appear to acknowledge her presence. Undeterred by professional categories, therapeutic nihilism, or other ways we categorize patients, she decided to try some different ways of engaging the patient. When she visited she decided to read various items from the newspaper or comment on seasonal events taking place in Minnesota. Over a period of weeks to months he began to respond to her visits. He sometimes would speak a few words to her in response to questions or items that she would recount. Eventually she asked him if he would like to go outside the facility. She would then take him on short outings in his wheel chair. During this period of time he became more alert, more interactive, began eating, gaining weight, and therefore no longer met eligibility criteria for hospice. He was discharged from hospice, or as we say, he graduated.

The hospice volunteer was quite concerned that if she stopped seeing the patient, then he would relapse. She made a decision to continue seeing the patient and told the hospice volunteer coordinator that she was going to continue seeing the patient even though he was no longer in hospice. So, let’s take a few minutes in small group to discuss the following:

1. what problems are created by volunteers of uncertain statuses?
2. what advice would you give to the Volunteer Coordinator?
3. how can descriptive psychology concepts re-describe “boundary issues”

Getting the concept right

Initially the Volunteer Coordinator presented the problem to me as a boundary issue. She told me that she thought the volunteer would have to take a leave from the volunteer program if she continued to see the former hospice patient. She wanted my advice on what to do as she considered this volunteer a very mature, thoughtful and reflective person who clearly believed she was doing the right thing for the patient. I responded to her by saying, “let me think about this”. I also said I didn’t like the term boundary issue as I didn’t quite know what it meant and also believed that the concept was poorly defined. I did think that the concept was more appropriately defined as a relationship violation, but that begged the question regarding of what kind of relationship I was thinking about nto mention what type of relationship violation had or would occur.

Here is where the bioethics was helpful. The bioethics literature over the past 60 years has been akin to liberation theology for patients reflecting on the nature of the patient-physician relationship. Although I will refer to the patient-physician relationship, this is a stand in for patient-clinician relationship as well a paradigm for professional health caring relationships. Autonomy within the research setting and the patient – physician relationship has been a central focus against the bogey man of medical paternalism. There are two important perspectives on professional caring relationships that I want to briefly present as ways of understanding what type of relationship violation can occur in such relationships and how this can help us understand volunteers of uncertain statuses.

Beauchamp and Childers are well known in the field of bioethics for their Principlism approach to the doctor-patient relationship and bioethics. Most of the ethical dilemmas addressed who gets to decide what is permissible or impermissible for the patient or the physician regarding decisions having to do with the well being of the patient at the beginning or end of life. Most of you will recognize the four principles although perhaps not exactly in these terms:

- Autonomy – respect for persons
- Beneficence – the good or best interests of the person
- Non-maleficence – do no harm (benefits – burdens analysis)
- Justice – fairness, equity, non-discrimination

Although not exactly a paradigm case of a professional caring relationship, these four choice principles for guiding one's actions certainly would be a good start. In addition to Beauchamp and Childers work, Emanuel and Emanuel describe the nature of doctor-patient relationship in somewhat different terms:

- Paternalism
- Informative
- Interpretive
- Deliberative model.

In this model the authors attempt to capture the dynamic nature and nuances of this complex relationship. Clinicians are asked at times what they would recommend because of the complexity of the situation, the information asymmetry between the patient and clinician, etc, and in such cases a “weak paternalism” can be very appropriate, e.g. stent vs no stent for CAD. At other times a consumer model may be more appropriate where the clinician gives the facts and that is all that is necessary, e.g. laser surgery for near-sightedness. The interpretive or counseling model is useful in clarifying the patients concerns and values, whereas the deliberative model is a more dynamic interpersonal engagement where the clinician and patient reflect together on the health related values and the patient's moral, psychological, and interpersonal well-being.

A more complete description of the role of the volunteer

Hospice Volunteers: Roles, Responsibilities and Supervision

Volunteers who develop a relationship with Hospice patients take on a status/role of a volunteer in Hospice of the Lakes that amounts to a professionally defined caring relationship. Volunteers are guided by the ethics of caring relationships, and their involvement with the patient is defined by the HOL care plan and supervised by the team members including the social worker, the nurse case manager and the hospice volunteer coordinator. The ways of interacting, the types of activities that

unfold are guided by what is permissible and not permissible behavior in professional caring relationships.

Volunteers of uncertain Status

Volunteers motivated by a human desire to provide comfort to vulnerable populations are an important hospice and societal asset. As society ages more and more persons are volunteering to help vulnerable persons of all ages. It is critical that we honor and use this valuable, important, and caring resource. It is also critical that we understand the “rules of the game” in a way that protects the vulnerable patients beings served by volunteers. One area for a shared understanding of the “rules” to be clarified is the uncertain status of volunteers when a patient they have been seeing is no longer part of hospice. The following considerations are a first attempt to provide a way of approaching volunteers who do continue or maintain a relationship outside of the hospice program.

Volunteer Relationships outside of Hospice

When a hospice patient is not recertified for hospice because they no longer meet hospice criteria (e.g. graduated) or for any other reason, a volunteer may decide to continue or maintain the relationship with the patient. The most common and compelling reason to maintain such a relationship occurs when and where an important (to the patient) relationship has formed that would likely set the patient back if terminated—and where the volunteer experiences an ethical responsibility to maintain “continuity of volunteering”.

This raises a number of concerns as well as opportunities to think through when such a continuing volunteer-patient relationship is in the best interest of the patient or when the volunteer-patient relationship turns into something else that may not be an appropriate relationship to form and maintain.. Here are some of the considerations:

1. Defining the relationship: What term best describes the impending relationship post hospice affiliation?
 - a. Is the hospice-volunteer relationship to change if the volunteer continues to see the patient post hospice?
 - b. Does the volunteer continue to adhere to the professional definitions of the hospice volunteer-patient relationship even though independent or a “free lance” volunteer?
 - c. Does the previous volunteer-patient relationship shift to being something else where the patient and volunteer can participate as persons and not as patient and as volunteer?
 - d. If so, what term best describes this new relationship? Is the volunteer a friend? A life coach? A sounding board? A patient advocate? A “big brother or sister?”
2. Establishing an appropriately sustainable expectation: Has the volunteer thought through how the relationship will change and what type of commitment he or she is making to the patient?
 - a. Is the volunteer aware of why they are doing what they are doing, e.g. can they have a reasonable account of their motivations, their concerns about the patient?
 - b. Are there any red flags? → Does the rationale for maintaining the relationship outside of hospice pass the sniff test, e.g. how would this look if it became a story on the front page of the Star Tribune? Examples of red flags: financial coaching, counseling beyond scope of volunteer training and explicit role, relationship being hidden from family, residential institution, or caregivers.

- c. Has the volunteer thought through their ability to make a sustainable commitment? How could the volunteer appropriately terminate such a relationship. And in what way? And who else would know about it?
 - d. Are there family members who are aware of the relationship and has their view been taken into account?
3. Transfer of volunteer status to another institution:
- A. What is the context (venue – home, nursing home, assisted-living, etc) and larger community in which the patient lives and what is permissible and what is not permissible in such settings? Is there an explicit transfer of the volunteer from HOL to this institution an option and is there a process to accomplish the transfer?
 - a. Nursing homes do have volunteer programs such that the hospice volunteer could become a volunteer in the nursing home program and have the appropriate status/role and supervision by the nursing home social worker or nurses
 - b. Has the volunteer informed the community in which the patient lives of the change in status from hospice volunteer to free lance or independent volunteer? If not, why not, and when will they do this?
 - c. Senior high rises, apartments and other independent living circumstances raise similar issues of who will ensure the safety of the resident/patient or provide supervision for the volunteer if it is necessary? Could family, friends, neighbors have a role in such supervision or at a minimum be informed and agree that continuing or maintaining the volunteer patient relationship is in the best interest of the patient.
 - B. How will the volunteer be evaluated or accredited as having met the criteria to assume a new volunteer role/status with the patient?
 - d. Should there be a formal letter from hospice to the nursing home or other patient residence?
 - e. Who meets and reviews the change in role/status → volunteer coordinator with review by program managers (medical director, nursing supervisors?)
 - f. Should volunteers continue seeing patients in hospice while also seeing patients outside of hospice? This could be confusing to nursing home staff if wearing two hats simultaneously as NH volunteer and Hospice volunteer.

First pass at a “best practices recommendation”:

1. Defining the relationship—appropriate or not
2. Establishing a sustainable expectation
3. Transfer of volunteer status (supervision) to another institution