

"I'M FINE! FINE! FINE!"

Dealing with Maladaptive Denial

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The woman who sat before me, hunched in her chair with her hand supporting her chin to keep her head from drooping, looked to be at least in her late seventies. I knew from talking to some of the Sisters with whom she lived that she was two decades younger. I had come for a consultation at the request of this Sister's local community whose members were seriously concerned, not only with the marked deterioration they observed in her, but in what they described as her "constant refusal to admit that anything is wrong."

The Sister who called to ask me to come to their convent described Sister as a person who had managed a chronic illness for many years and who up to the last several years had managed "fairly well around her limitations." She noted that in the past year the members of the community had become "very worried" about what she described as ever worsening symptoms incurring ever more real limitations in what she could manage, yet, a constant insistence that she was "as good as ever."

In her description of problems, Sister noted that the constant retort to anyone's inquiry about her health or welfare was, "I'm fine! Fine! Fine! And, how are you doing?" From the narrative, I could hear a number of emotions reflected in Sister's words, ranging from care and concern to frustration and even anger. "We just don't know what to do to help Sister, and at this point, we don't know what to do to support ourselves in dealing with Sister. It is a bad situation that is becoming worse by the day."

After an hour talking with Sister myself, much of what she said and did not say verified the caller's concerns and report. It was obvious looking at Sister that her illness had reached a point at which what once may have been supportable disabling had become major debilitation. My observation noted that walking,

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moving, even sitting in an upright position for any length of time was very difficult for her. We had walked down a corridor together, a distance of some thirty feet, and when she reached the small parlor for our meeting, she was breathing hard and had to rest several minutes before she could speak. In the course of our conversation, she lost track of what we had been saying several times and changed points in her narrative repeatedly. She recounted three different versions of the event that had precipitated her most recent hospitalization, with time, place and conditions remarkably altered. When I raised what I heard as contradictions, Sister became at first confused and then highly defensive. She insisted that she could return to work, (a job in a hospital that entailed considerable walking and required clear cognitive focus), that she should be allowed to drive (a prohibition put on her by her fellow Sisters after they discovered her inability to park the car in the convent lot), and that she “be left alone to handle” her own medical appointments (a responsibility overseen by one of the Sisters after she had missed several).

Sister is not the first individual I have seen who has exhibited these and similar symptoms, although she is perhaps the most extreme case I have engaged still living at a house for those in active ministry. She had, quite consistent with her symptoms, refused to enter, even for a time, the congregation’s infirmary. Why would she? She was “Fine! Fine! Fine!” What Sister was, in fact, was deep in the state of denial.

WHAT IS DENIAL?

Denial, which lacks a clear conceptual definition, is typically categorized as one of the primitive or primary defense mechanisms, rooted in the early world of the infant, in a time of preverbal, prelogical and magical thinking. First construed by Anna Freud as a normal archaic process in the initial

developmental stages of the child, she also noted that “the mature ego does not continue to make extensive use of denial because it conflicts with the capacity to recognize and test reality” (*Columbia Encyclopedia*, 2009, p. 1). The operational word here is “extensive.” Most persons can and do employ some form of denial at stressful, even catastrophic times in their lives, especially in life-threatening situations. In these occasions, the defense can function as “necessary for the preservation of well-being . . . as a protection from stressors that are too overwhelming . . . to buy time to mobilize the resources needed to cope . . . to safeguard important relationships . . . too fragile to withstand the truth” (Stephenson, 2003, p. 985). The defense of denial in these cases is often observed at the beginning of the crisis (as in Elisabeth Kubler-Ross’s stages) or at the end of a terminal struggle.

In its simplest form, denial means that when a person is faced with a fact that is too uncomfortable to accept he or she rejects it instead, insisting that it is not true despite what realities he or she may have to eliminate or ignore in order to protect against facing them. Operating in a largely unconscious way, there really is no “simple” form of denial with its many manifestations ranging from minimizing to what borders on manic states. In terms of physical illness, much research, reactivity, response and recognition has occurred over the past couple decades as to the protective, and perhaps even life-sustaining, effects of some forms of denial. Warning that the role of the physician faced with patient denial is to avoid “collision with it,” Zhang (2002) notes that outcome research on the use of denial, especially with persons with terminal cancer, “has produced mixed results” (p. 2). She concludes that while “some empirical studies suggest denial may serve a useful purpose early on, it may become maladaptive if sustained over prolonged periods of time” (p. 2). Rabinowitz and

Peirson (2006) give some markers to the state of denial that would qualify it as maladaptive. They include when it “interferes with one or more necessary actions” in dealing with the illness . . . decreasing the chance of accepting intervention that might lead to remission, cure or longer life” as well as engaging in behaviors that put the person or others at risk when performed (p. 71). Stephenson (2004) cautions that families and friends may be not only victims of denial but even perpetrators of it when they either accept unquestioningly the refrains of “Fine,” or when their own need to protect against the “worst case” fosters denial in the one suffering.

The state of the Sister whose profile opened this article is one of maladaptive denial. What makes it such and how individuals faced with dealing with different degrees of it compose the remainder of this discussion.

COMPONENTS OF MALADAPTIVE DENIAL

In working with those dealing with maladaptive denial, understanding components of it can be helpful. Operationally defining it has become an ongoing process. Coming mainly out of the work of in-patient facilities and the psychiatrists and other health workers who encounter severe stages of the defense operating among their patients, work toward a operational definition has been slow in coming. Most persistently seen on hospital wards as a complete denial of illness and refusal of

all treatment, researchers have proposed and pushed for (without much apparent success) some form of inclusion of this in the *Diagnostic and Statistical Handbook of Mental Illness* as early as 1990 (Stearns, Spitzer & Muskin), again in 1998 (Muskin, Feldhammer, Gelfand & Strauss) toward the DSM-IV-TR edition, and as recently as 2007 for the DSM-V publication (Fava, Fabri, Sirri & Wise).

In a significantly hands-on view of it as an oncology nurse would have, Pamela Stephenson (2004) suggests regarding denial not as a fixed diagnosis or event, but “a dynamic with fluid qualities that fluctuate with experience and time” (p. 986). As such, the Sister in the profile is behaving neither well or badly, making choices neither appropriately nor inappropriately in terms of her illness, but doing what her innermost and, yes, in many ways infantile, self is demanding for what she deep down feels is her survival. Like a trapped animal, lashing out with claws, or perhaps, more compassionately, a terrified child who feels abandoned and alone, she is, even in a distorted way, doing what she needs to do to preserve what is core to herself.

Several key facts emerge when a person can regard the *process* of denial (not diagnosis of it) as fluid and protective. The first is that the person, whether in a certifiable state of delusion or befuddled state of distortion, can move to other less self-destructive emotional places. But, since the defense is largely unconscious, it requires outside help. If Sister is defending

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herself against something, the conclusion must be that she is beset with fear. A major help to her is to find the source of her fear and help her alleviate it as much as possible. While ideally this could be done best through the professional help of a therapist or counselor, until she is able to accept such intervention, great good could be done by the caring individuals who want to help her. Being able to talk to a non-judgmental person (perhaps a friend in the community, a mentor, someone she highly regards and trusts) could allow Sister to unburden herself of the immediate terrors she faces. In family situations, those most able to handle the diagnosis and its implications are the most likely ones to support. Some might be totally irrational, such as “If I go to the infirmary, I will be shut up there and never allowed to return.” Others might be more rational and even highly probable, as in “I may never be able to drive again.” Even separating the real from unreal lessens the catastrophizing in Sister’s mind. Providing some occasions of relief and/or success can also help for at least temporary symptom relief. Going out for some R and R time—to a movie, an arboretum, a drive along a country road—can offer respite. Giving Sister small duties she can accomplish with a sense of “job well done,” even with another’s assistance, can boost her morale.

A second major fact to be recognized is that denial is an interpersonal process. Stephenson (2004) argues that “personal opinions about denial can greatly affect the way an individual thought to be in denial is regarded by others” (p. 986). Tension, discomfort, frustration and eventually anger mount when persons—family members, friends, associates, medical personnel included—insist that the denial is a manufactured state, like facetiousness or malingering, that can be overcome if the person just “puts her

fist in her face and shakes it.” When those around the person have all the answers for how the individual in denial should, must, can handle her illness, this removes all possibility of autonomy and self-coping from the person suffering. It also complicates and eventually disintegrates any personal connections.

This final event can produce a kind of mutuality of denial. Elisabeth Kubler-Ross describes this as a “conspiracy of silence,” meaning that the person who is suffering may, in an attempt to protect or shield those to whom he or she is close, avoids talking about or even demonstrating evidence of the illness (in Stephenson, 2004, p. 986). Often, the evasion and denial escalate as the discomfort sensed on the part of others increases. At the same time, open confrontation by someone not skilled in such intervention can also be harmful and push the person deeper into denial.

WHAT CAN A NON-SPECIALIST DO?

How then can others intervene in ways that are helpful? The first part comes in open, compassionate communication. In an editorial addressed from an internationally renowned physician to his peers, Dr. M. E. Sabbioni (1999) draws on the “gold standard” of ethical practice, emphasizing the patient’s right to informed consent. He underscores that informing about illness with all its ramifications must be “a lengthy process” in normal situations (p. 11). When maladaptive denial is complicating the process of acceptance, the health communicator must insure that the denier “has the resources to deal with negative emotions . . . have an environment, adequately supporting . . . and that the relationship between them is stable enough to address the denial” (p. 11). Here are steps the lay person, in Sister’s case her local community and other support persons, can take (adapted from Zhang, 2002, pp. 2-3):

1. They insure that Sister understands the real facts about her condition in as gentle and genuinely caring a way as possible. This includes things that Sister can do that might help her to feel better and more involved in the management of her illness. If she refuses such “professional” helps as psychiatrists, counselors, etc., help might be found from such other more acceptable sources as nutritionists, alternative medicines (massage, relaxation means, water therapy, etc.), spiritual counselors or directors.

2. They can make themselves available, first in non-threatening, pleasant, leisurely conversations. When a degree of trust has been established, they can make themselves open to more personal issues, including those of Sister’s behavior.

3. They should carefully choose their battles. Some degree of the denial may be necessary for Sister’s stress management at the point she has reached in her illness. If the denial is not interfering with major decisions about life or adversely affecting others, it need not be confronted at the time.

4. They need to remove themselves from value judgments about Sister’s decisions and actions. Instead of regarding these as good/bad, inappropriate/appropriate, sick/healthy, it is more helpful to wonder “Is this helping Sister deal with her overwhelming emotions? How else can we help with these?”

5. Sister’s fears encompass a multitude of worries, both typical and idiosyncratic, but underlying all is the terror of being abandoned in her illness. Whatever the other Sisters can do to reassure her that this will not happen can alleviate many of the fears.

6. Finally, the old adage about only giving what one has is a ground rule in helping someone deal with such a complicated issue as maladaptive denial. Therefore, any and all involved in the process need to have their own supports—spiritual, communal, relational. Each and all need to insure that they are handling their own issues and getting their own help.

RECOMMENDED READING

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