

Understanding Denial

Pamela Shockey Stephenson, RN, MSN, AOCN®, CS, CHPN

Purpose/Objectives: To explore the adaptive and maladaptive uses of denial while developing a clearer understanding of denial.

Data Sources: Nursing and psychological periodicals and textbooks.

Data Synthesis: Oncology nurses tend to have too broad a definition of denial because they overgeneralize similar patient responses and label them as denial. Because of the uncertainty as to its value, denial is viewed as a negative, fixed response to a crisis and can strain the nurse-patient relationship.

Conclusion: Denial is a fluid, interpersonal experience that can affect patients during many points of the cancer experience. By experiencing a clearer understanding of denial and recognizing its adaptive value, nurses can provide more effective patient care.

Implications for Nursing: Clinicians should not underestimate the value of the nurse-patient relationship when a patient is in denial. Patience, understanding, and self-awareness are crucial for providing a safe, trusting environment for patients who are experiencing denial.

Key Points . . .

- Denial, which often is viewed as a negative, fixed state, is actually a fluid, interpersonal process with adaptive and maladaptive qualities.
- Patients may use denial subconsciously when their physical health, important relationships, or sense of control is threatened.
- By understanding denial, clinicians will be able to identify windows of opportunity to discuss patients' situations while respecting patients' right to cope at their own pace.
- By understanding the interpersonal qualities of denial, clinicians will understand how their attitudes about denial affect the nurse-patient relationship and, ultimately, patients' abilities to confide in clinicians.

Many people diagnosed with cancer fear that it is a death sentence. The perceived threat to life brought about by a cancer diagnosis can lead to a denial response in some patients. Denial is a coping mechanism used in response to a psychological trauma and often is viewed by nurses as a maladaptive and undesirable by-product of crisis (Burgess, 1994). Clinicians have uncertainty about the role of denial in adaptation to cancer. Many believe that once a cancer diagnosis is made, a patient and family must acknowledge the illness immediately so they can make decisions related to treatment (Morley, 1997; Smith, 1993). This belief is reinforced by Kübler-Ross's (1969) stages of grief, which are viewed by many to be an accurate reflection of the dying process. Smith explained that because denial is regarded as the first stage of grief in Kübler-Ross's framework, it also is presumed to be the least mature. Clinicians often assume that moving through the stages of grief quickly is healthy; therefore, they tend to criticize those who linger in the denial stage (Ingebrigsten & Smith, 1997).

Denial sometimes is necessary for the preservation of well-being during crisis (Jones, 1999; Murray & Neilson, 1994). It is a coping mechanism that provides protection from stressors that are too overwhelming (Moyer & Levine, 1998). Denial buys an individual time to mobilize the resources needed to cope with the situation (Murray & Zentner, 1979) and, if used temporarily, can be a healthy coping mechanism (Kadlec-Fuller, 1997). Weisman (1972) explained that not only does the use of denial allow an individual to reject the threat to the physical self but also can safeguard important relationships that a patient believes are too fragile to withstand the truth of the diagnosis. This explains the transient nature of some cases of denial: Some patients perceive a need to employ a more rigorous measure of denial around some people than they do with others.

The struggle to maintain control is another reason patients use denial. The diagnosis of a devastating or terminal illness

can precipitate a loss of control over virtually every aspect of a person's existence. If the loss of control is perceived as unacceptable, a patient can take on a denial response subconsciously. By denying the precipitating event, control is restored and integrity maintained. Giving these individuals choices throughout their cancer experience may help to restore their sense of control, allowing them to view their illness honestly (Burgess, 1994). Considering the protective role of denial, individuals who use denial have the right to do so and should not be labeled negatively (Smith, 1993).

Denial may have adaptive value by protecting an individual from devastating, life-threatening information, or it can be maladaptive by preventing an individual from participating in informed consent, closing important relationships, and reconciling final affairs. Understanding denial can be a source of frustration for many healthcare professionals who have difficulty distinguishing between adaptive and maladaptive processes. This article will review the literature to explore the definition of denial. As nurses develop a clearer understanding of denial, they can better determine if and when intervention is necessary, thus enhancing patient care.

Dimensions of Denial

Salander and Windahl (1999) argued that denial lacks a clear conceptual definition, which prevents clinicians from sharing a

Pamela Shockey Stephenson, RN, MSN, AOCN®, CS, CHPN, is an oncology clinical nurse specialist in the Cancer CareCenter at Forum Health in Youngstown, OH. (Submitted July 2003. Accepted for publication September 4, 2003.)

Digital Object Identifier: 10.1188/04.ONF.985-988

common understanding. In fact, they believed that clinicians hold too broad a conceptual definition of denial by overgeneralizing similar coping mechanisms and calling them denial. For example, many coping processes are mislabeled as denial when they are more accurately described as “disavowal” or “avoidance.” Denial is described as the “psychotic’s repudiation of reality” (p. 269), whereas disavowal occurs when the crisis is not refuted but rather its significance is altered by distortion, rationalization, or positive reframing (Salander & Windahl). This means that although denial ignores the very existence of a crisis, disavowal distorts its significance or minimizes its importance. Finally, avoidance is making the conscious choice not to acknowledge distressing information. Choosing not to investigate symptoms that are concerning is an example of avoidance (Salander & Windahl).

Healthcare providers tend to label any inconsistent or noncompliant patient behavior as denial (Rousseau, 2000); however, only the complete rejection of the crisis is identified as pure denial. In an effort to reduce the risk of using the term denial inappropriately, Salander and Windahl (1999) recommended using accurate descriptions of denial-like behaviors, such as denial, disavowal, or avoidance, according to the degree of repudiation.

Denial can have adaptive or maladaptive qualities. If denial does not interfere with treatment compliance or quality of life, it is considered adaptive. On the other hand, if either of these is compromised, denial becomes maladaptive. Maladaptive denial at the end of life can interfere with an individual’s need to resolve legal affairs or repair broken relationships. This can be detrimental to surviving family members who must live with unresolved conflict or legalities as a result of the inability to achieve closure.

Cancer prevention efforts have been affected negatively as individuals expose themselves to carcinogens despite being educated about their risks. The use of tobacco or alcohol and overexposure to sun are examples of this. Others understand the importance of an early diagnosis of cancer yet do not take advantage of screening services because they believe that cancer cannot afflict them. Both scenarios illustrate how denial-like behaviors can allow individuals to pretend that cancer cannot happen to them (Kreitler, 1999). Weisman (1979) outlined three orders of denial to describe how it can be experienced at different stages of the cancer trajectory.

Weisman (1979) described first-order denial as denying the illness itself, even after the diagnosis has been disclosed. This is similar to Salander and Windahl’s (1999) description of true denial. Second-order denial refers to the lack of association between symptoms and diagnosis. One example is when medical attention is voluntarily postponed by an individual experiencing serious symptoms. This delay has been quantified as lasting more than three months (Kunkel, Woods, Rodgers, & Myers, 1997). In hindsight, patients may express remorse at waiting to seek medical attention but admit that they never would have believed that this could happen to them. Finally, third-order denial disregards that the illness could be serious enough to be life-threatening. According to Weisman (1979), patients can employ more than one order of denial or vacillate among them. Understanding the prime characteristics of denial will help clinicians to distinguish between the adaptive and maladaptive uses of denial and determine when appropriate interventions are warranted.

Denial as a Fluid, Interpersonal Process

Denial is not a fixed event from which patients cannot be released but rather is dynamic, with fluid qualities that fluctuate with experience and time (Copp & Field, 2002; Ross, Peteet, Medeiros, Walsh-Burke, & Rieker, 1992). Patients often experience periods when the possibility that things might be worse than they thought becomes apparent (Morley, 1997). Kübler-Ross (1981) referred to these as “windows of opportunity,” a time when the resilience of denial may appear temporarily weakened. This allows individuals to consider the reality of their situations. These opportunities often present themselves during the quiet, early-morning hours when sleep is difficult and few distractions disrupt their thoughts. Weisman (1979) described this awareness as “middle knowledge,” or the experience of simultaneously realizing and not realizing the crisis. For as long as it may last, patients in middle knowledge may display windows of opportunity, being somewhat prepared to examine their vulnerability in the midst of crisis.

Denial is also an interpersonal process. Personal opinions about denial can greatly affect the way an individual thought to be in denial is regarded by others, including nurses. Nurses often consider themselves open minded to the process of denial but can experience ambivalence when conflict arises between their own coping style and patients’ denial and produces tension. This principle of consistency states, “When inconsistency occurs, a person feels tense or uncomfortable until the differences can be resolved” (Murray & Neilson, 1994, p. 34). A nurse who feels compelled that a patient should confront his or her denial first must consider for whom the intervention is intended. Is it to provide psychological relief to the patient or nurse? As long as the nurse fails to recognize denial as a fluid, interpersonal process, an opportunity exists for interventions to be selected that benefit the nurse. Consequently, the patient may feel discouraged from coping with a life crisis in his or her own way. This conflict will tarnish the nurse-patient relationship and jeopardize its effectiveness.

Patients who sense nurses’ discomfort might avoid talking about their illness for fear of causing nurses anxiety. This mechanism can be labeled as denial. Patients may seem to be protecting themselves from an uncomfortable situation when, in fact, they are protecting someone else. This process has been referred to as the “conspiracy of silence,” eluding to patients’ fear of abandonment by family, friends, and staff if the illness is discussed openly (Kübler-Ross, 1981). This inadvertent collusion on the part of clinicians unintentionally encourages denial-like behaviors by displaying discomfort through mannerisms and body language (Rousseau, 2000). Patient awareness of clinicians’ discomfort and the inability to distinguish the cause as the denial behavior and not the disease itself may convince patients that people are avoiding them already, further facilitating isolation and silence. As clinicians become more uncomfortable with patients’ denial response, patients, in turn, become more convinced that they must not discuss their condition with clinicians. This cycle can perpetuate itself, leaving all parties involved feeling uncomfortable and frustrated with one another.

Clinical Implications

Nurses who view denial as a fluid, interpersonal process will recognize the need to reassess denial frequently and eliminate the need to view it as either good or bad. Attaching the label of

denial haphazardly to a patient can insinuate inadequate coping (Moules, 1998). Clinicians must avoid placing the burden of coping correctly on patients by labeling them as being in denial and, therefore, implying that they should act more appropriately by facing their illness (Smith, 1993). If denial is viewed as a complex and changing phenomenon, clinicians can respect patients' desires to move slowly (Moules). Therefore, nurses must be sensitive to the amount of information patients are prepared to handle at any one time (Gates & Nishimoto, 1997) while working within windows of opportunity.

Kübler-Ross (1981) claimed that the fluidity of denial is most evident in the early-morning hours when surroundings are quiet and distractions minimal. In this environment, denial may weaken temporarily. Unfortunately, clinicians often are unavailable during the early morning hours to take advantage of these opportunities with patients. Being cognizant of these windows of opportunity allows nurses to be available to patients during such times. Spending a few moments at the bedside with a patient who is unable to sleep can allow the process of denial to evolve. Approaching the subject of denial and illness with the patient, however, must be done with extreme sensitivity and care.

Because denial can be an interpersonal process, nurses must be aware of the role they play in patients' denial processes. Development of nurses' self-awareness has been cited as an important step toward dealing with denial effectively (Morley, 1997). The process of self-awareness is critical to the nurse-patient relationship so nurses may avoid participating in what Kübler-Ross (1981) called a conspiracy of silence. Nurses also must be able to reflect on their own feelings, ensuring that the need to confront patient denial is in the best interest of patients and not themselves (Burgess, 1994).

Similarly, if family members (particularly spouses) are in denial, patients may not feel comfortable speaking openly about the illness in their spouses' presence. In this case, nurses should provide a confidential, safe environment for patients to reveal concerns and ask questions. On the other hand, family members can push their loved ones into facing reality too quickly. Educating family members about the need to respect patients' wishes to move slowly can encourage patience and relieve tension among family members.

Patients should not be labeled as using denial simply because they do not choose to follow recommended treatment options. Clinicians' views of optimal treatment may not coincide with patients' wishes (Burgess, 1994). Patients have the right to choose their course of treatment (or choose no treatment at all). Clinicians also must be cautious not to assume that patients who suddenly refuse to talk about their illness are demonstrating denial. Occasionally, people experiencing a devastating illness require time away from the crisis. The choice not to discuss their situation may not reflect denial but rather may be evidence of the need to take temporary respite from their situation.

Case Study

The following case study examines the differences between adaptive and maladaptive uses of denial.

"Martin" is a 55-year-old, divorced, self-employed computer consultant. He presented to his physician with vague complaints of "I just don't feel well." He also complained of generalized fatigue and weight loss. Upon entering the examination room, Martin's physician immediately noticed an unpleasant odor and

conducted a thorough examination, which revealed an eroding, apparent carcinoma of the rectum. Martin's sphincter muscle had been destroyed by advanced disease. As a result, Martin was incontinent of liquid stool and would pad his underclothing with tissues or toilet paper in an attempt to absorb this drainage.

Further assessment revealed that Martin had experienced progressive bowel changes over several months. Only recently, though, had he experienced fecal incontinence. Martin admitted to knowing "something was wrong" but explained that, because he was self-employed and had no healthcare benefits, he "did not have the resources to get help." He assumed that high stress levels related to child custody issues and the challenges of his job were responsible for this chronic diarrhea. "Besides," he said, "It's embarrassing to have accidents like a child." Fecal incontinence forced him to remain socially isolated at home. Recently, Martin began to experience rectal pain that he was managing with warm showers and an old narcotic prescription.

He was admitted to the hospital, and a referral was made to a medical oncologist. Biopsy and staging workup confirmed a diagnosis of poorly differentiated adenocarcinoma of the rectum with multiple lesions in the liver. Martin consented to receive palliative external beam radiation therapy with concomitant 5-fluorouracil. Martin refused a surgical debridement of the rectal area, fearing that it would lead to a colostomy.

The medical and radiation oncologists engaged in in-depth discussions with Martin to explain the seriousness of his disease and his poor prognosis. Despite multiple conversations, Martin acknowledged only the primary cancer of the rectum and continued to deny evidence of metastatic disease. He would become angry with staff members who attempted to discuss it with him. He was compliant with the radiation and chemotherapy protocols and often alluded to achieving a complete remission. This was completely contradictory to the palliative goal that was explained to him by his physicians on several occasions.

Discussion

Martin's case is evidence of the complexity and fluidity of denial. Throughout his course of illness, Martin fluctuated among several orders and categories of denial. His inability to associate the severity of his symptoms with a serious medical condition is indicative of second-order denial. Although Martin's symptoms progressed, he continually minimized their importance. His resourcefulness in taking measures to manage incontinence demonstrated that he did not repudiate the symptoms entirely but rather minimized their significance, indicating disavowal. He acknowledged that something was wrong but delayed medical attention because of time constraints and embarrassment. He claimed that he did not seek help because he "did not have the resources." At first, this appears to refer to the resources of time and insurance benefits; however, he actually may have referred to limited coping skills and support as the resources he was lacking.

This use of denial was maladaptive because it prevented him from seeking medical advice sooner. This may have allowed the rectal carcinoma to be diagnosed earlier, improving his prognosis. After diagnosis, Martin's coping techniques could be adaptive or maladaptive. On one hand, he did accept radiation and chemotherapy to combat his disease, and, although his refusal to accept surgical intervention seemed to reflect maladaptive denial by interfering with treatment compliance, his decision simply may have reflected his right to self-determination of health care. Martin may have had very good reasons

for not choosing the surgical recommendations. Perhaps he was unwilling to accept the disfigurement of a colostomy or was unconvinced that a radical surgical intervention would offer more success than the radiation and chemotherapy alternatives. Regardless of his reasoning, Martin had the right to choose which recommendations were compatible with his view of quality of life. Clinicians must not assume that Martin's treatment decisions are more evidence of denial without thoroughly investigating his motives.

Overall, Martin adhered to medical treatment even though he did not acknowledge his metastatic disease. His anger toward staff members who spoke of metastatic disease illustrated the use of third-order denial as a means to minimize that his illness could be life threatening. This denial was not interfering with treatment compliance, but it was cushioning the seriousness of his reality. Acknowledging his metastatic disease could jeopardize his hope. Although his inability to face the metastatic disease appears to not be in his best interest, it does not change his course of treatment and clinicians may choose to pardon Martin's denial of metastasis while continuing to watch for windows of opportunity.

If Martin is labeled negatively as being in denial, everyone involved could feel uneasy. Clinicians could experience uneasiness by not knowing how to approach Martin about his illness. Martin could misinterpret this uneasiness as being related directly to his incontinence and disease. As Martin's embarrassment leads to more isolation and anxiety, a cycle could develop that causes strain on the nurse-patient relationship. Martin would have difficulty developing the necessary trusting relationship with his nurse to discuss his condition openly. As a result, he might be less inclined to process his experience with others as open windows of opportunity, forcing him continue to keep his fears and concerns private. Martin appears to be a private, somewhat isolated man. Members of the healthcare team may be his best source of emotional support throughout his illness. Without a trusting nurse-patient relationship, Martin may feel too alone to process the extent of his illness.

A diagnosis of cancer can be isolating when friends and family feel uncomfortable in the presence of someone with cancer. Patients who sense others' discomfort may fear abandonment and subconsciously use denial to protect these relationships. Being reliant on medical teams for treatment also can leave patients feeling vulnerable. Rousseau (2000) explained that vulnerability can provide fertile ground for denial because feelings of vulnerability can be linked closely to a loss of control. Clinicians and loved ones should reassure patients that they will not abandon them. Explaining that their disease is best managed through teamwork and that they are important members of a multifaceted team helps them to regain a sense of control not only over how their illness is managed but also, ultimately, their life.

Conclusion

Nurses working with patients facing a cancer diagnosis must understand the fluidity and interpersonal characteristics of denial. The first steps toward managing denial are to (a) identify that it exists by recognizing the characteristics and motivations of denial, (b) determine whether it is adaptive or maladaptive, and (c) if it is maladaptive, choose gentle, appropriate interventions while taking advantage of windows of opportunity.

Patients experiencing a devastating illness require positive relationships and support from their healthcare providers to muster the strength to cope with their illness. Determining whether patients are in denial to protect themselves, their relationships, or their sense of control will guide clinicians toward appropriate interventions. This attentiveness to patient needs will not only enhance patient care but also strengthen the valuable nurse-patient relationship.

Author Contact: Pamela Shockey Stephenson, RN, MSN, AOCN®, CS, CHPN, can be reached at pstephenson@forumhealth.org, with copy to editor at rose_mary@earthlink.net.

References

- Burgess, D. (1994). Denial and terminal illness. *American Journal of Hospice and Palliative Care*, 11(2), 46–48.
- Copp, G., & Field, D. (2002). Open awareness and dying: The use of denial and acceptance as coping strategies by hospice patients. *NT Research*, 7, 118–128.
- Gates, R.A., & Nishimoto, P.W. (1997). Communicating, caring, and coping. In R.A. Gates & R.M. Fink (Eds.), *Oncology nursing secrets* (pp. 428–436). Philadelphia: Hanley and Belfus.
- Ingebrigsten, P., & Smith, M.W. (1997). Family issues. In R.A. Gates & R.M. Fink (Eds.), *Oncology nursing secrets* (pp. 459–462). Philadelphia: Hanley and Belfus.
- Jones, A. (1999). 'Listen, listen trust your own strange voice' (psychoanalytically informed conversations with a woman suffering serious illness). *Journal of Advanced Nursing*, 29, 826–831.
- Kadlec-Fuller, J. (1997). Helpful hints. In R.A. Gates & R.M. Fink (Eds.), *Oncology nursing secrets* (pp. 453–458). Philadelphia: Hanley and Belfus.
- Kreitler, S. (1999). Denial in patients with cancer. *Cancer Investigation*, 1, 514–534.
- Kübler-Ross, E. (1969). *On death and dying*. New York: MacMillan.
- Kübler-Ross, E. (1981). *Living with death and dying*. New York: Touchstone.
- Kunkel, E.J., Woods, C.M., Rodgers, C., & Myers, R.E. (1997). Consultations for 'maladaptive denial of illness' in patients with cancer: Psychiatric disorders that result in noncompliance. *Psycho-Oncology*, 6, 139–149.
- Morley, C. (1997). The use of denial by patients with cancer. *Professional Nurse*, 12, 380–381.
- Moules, N.J. (1998). Legitimizing grief: Challenging beliefs that constrain. *Journal of Family Nursing*, 4, 142–166.
- Moyer, A., & Levine, E.G. (1998). Clarification of the conceptualization and measurement of denial in psychosocial oncology research. *Annals of Behavioral Medicine*, 20, 149–160.
- Murray, M., & Neilson, L. (1994). Denial: Coping or cop-out? *Canadian Nurse*, 90(2), 33–35.
- Murray, R.B., & Zentner, J.P. (1979). *Nursing assessment and health promotion through the life span* (2nd ed.). Upper Saddle River, NJ: Prentice-Hall.
- Ross, D.M., Peteet, J.R., Medeiros, C., Walsh-Burke, K., & Rieker, P. (1992). Difference between nurses' and physicians' approach to denial in oncology. *Cancer Nursing*, 15, 422–428.
- Rousseau, P. (2000). The art of oncology: When the tumor is not the target. Death denial. *Journal of Clinical Oncology*, 18, 3998–3999.
- Salander, P., & Windahl, G. (1999). Does 'denial' really cover our everyday experiences in clinical oncology? A critical view from a psychoanalytic perspective on the use of 'denial.' *British Journal of Medical Psychology*, 72(Pt. 2), 267–279.
- Smith, D.C. (1993). The terminally ill patient's right to be in denial. *Omega*, 27, 115–121.
- Weisman, A.D. (1972). *On death and denying: A psychiatric study of terminality*. New York: Behavioral Publications.
- Weisman, A.D. (1979). *Coping with cancer*. San Francisco: McGraw-Hill.