

# Determinants of Noncompliance of Speech-Language Pathology Recommendations Among Patients and Caregivers

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Lack of compliance with speech-language pathology (SLP) recommendations is a complex problem involving nursing staff, non-health care provider (NHP) caregivers, and patients, each having their own reasons for noncompliance. In some cases, SLP recommendations are met with open hostility (Colodny, 2005). Noncompliance with SLP recommendations is a serious and continuing problem within the profession.

## Health Care Professionals

Colodny (2001) identified three major reasons for nursing staff noncompliance in a skilled nursing facility setting: food preparation and feeding recommendations were perceived as bothersome by the staff, the staff lacked knowledge of appropriate procedures, and the nursing staff disagreed with the recommendations of the SLP. Registered nurses (RNs) tended to follow SLP recommendations less frequently than licensed practical nurses (LPNs) or certified nursing assistants (CNAs). The RNs reported that they regarded feeding patients with dysphagia as demeaning because they thought it should be conducted by health care staff with less training and education. Therefore, although they did not disagree with the SLP recommendations any more than other nursing staffers, they tended to regard feeding patients with recommended compensatory strategies as more onerous and time-consuming than other nursing staffers. They also indicated that they had less knowledge of feeding techniques than LPNs and CNAs. Lack of knowledge may be used as an excuse to avoid feeding patients with

dysphagia, so that they can do other required tasks, such as giving patients their medications, which, in the case of patients with dysphagia, can take a considerable amount of time.

Among CNAs, who shoulder most of the responsibility for feeding patients with dysphagia, the most common reason for not following SLP recommendations was disagreement with the recommendations (Colodny, 2001). CNAs generally have less formal education and training than RNs or LPNs, but have the most experience in feeding patients. Thus, they may perceive their experience as providing them with sufficient knowledge of feeding and swallowing to allow them to make judgments regarding the appropriateness of SLP feeding recommendations. This author has observed CNAs who have dismissed patients' signs and symptoms as an inconsequential part of the normal swallowing process.

## Non-Health Care Professional Caregivers

Although health care providers' noncompliance seems to be driven primarily by turf battles, non-health care professional (NHP) caregivers tend to choose to not follow SLP recommendations for a variety of reasons. The most common reason provided by NHP caregivers is to protect the quality of life of the patient (Colodny, in press). However, the term, "quality of life" covers a multitude of motivations. First, NHP caregiver noncompliance was correlated with income levels. Higher income level NHP caregivers tended to disregard SLP recommendations more than lower income level NHP caregivers because

of quality of life issues; additionally, they were more likely to disagree with the SLP. Also, noncompliance over quality-of-life issues correlated negatively with the number of visits to the patients by NHP caregivers and the closeness of the relationship to the patient of NHP caregivers. NHP caregivers who were less closely related to the patient followed SLP recommendations less frequently because of quality-of-life issues.

## Independent-Feeding Patients

Finally, the patients themselves may choose not to follow SLP recommendations. Because dysphagia often occurs as a secondary consequence of some other assault to the body, many patients are unaware of dysphagia as a sequela of stroke, chronic obstructive pulmonary disease (COPD), and Parkinson's disease (Kuhlemeier, 1994). Therefore, many patients with dysphagia, in an attempt to normalize their status, deny that they have a swallowing disorder (Colodny, 2005). Because of the threat of a swallowing disorder to the maintenance of the normalized self, many patients with dysphagia may engage in a variety of defense mechanisms designed to cope with their status. Chief among these defense mechanisms was denial, engaged in by half of noncompliant self-feeding patients.

Most patients manifested two forms of defense mechanisms. Many voiced dissatisfaction with the prepared foods; others claimed that they were willing to take the risk of developing possible dysphagia-related complications by eating regular foods; still others rationalized their noncompliance using excuses

such as, "I am too old to change." Other defense mechanisms included minimizing their symptoms, claiming to be compliant while in actuality they were not, projecting hostility toward the SLP, and blaming others for their noncompliance, such as, "My doctor didn't say I needed to eat modified foods."

## Challenges of Compliance

Compliance with the swallowing and feeding recommendations of the SLP is difficult. First, it requires education, training, and an extra commitment of time, patience, and energy. It also requires that an individual assume responsibility for feeding the patient according to recommendations. Health care staff is not only responsible for feeding patients, but they are also supposed to remind self-feeding patients, many of whom resist compliance, to use recommended feeding strategies. As noted above, the assignation of responsibility can create tension among health care providers. In addition, NHP caregivers may abrogate their responsibilities for any number of reasons.

Swallowing and feeding recommendations by the SLP might be perceived negatively by those who must take responsibility for the feeding of patients with dysphagia, especially the patients themselves. Not only does it require a greater commitment to feeding, but it also signals a reduction of pleasure in the eating process. The sensuality and taste of modified foods may be reduced compared to regular food. The use of compensatory strategies, such as a chin tuck or a head turn, makes the feeding process arduous and may be embarrassing. Mealtime is usually a time in which people talk and socialize. Normally, food is a pleasurable adjunct to social interaction. When the focus becomes a chore of ingesting food without dysphagia-related consequences, the social aspects of mealtime di-

minish. This is a tremendous loss and is not easily forgone.

In order for patients to accept the sacrifice of mealtime pleasures, they have to redefine themselves as at risk for the sequela of dysphagia. The presence of a disability means that the patient has to accept the stigma of no longer being normal (Goffman, 1974). It requires that patients with dysphagia and their significant others acquiesce to the change in the patient's identity. When identities change, social relationships change. A person who was independent may subsequently have to rely on others for the satisfaction of their needs. Feelings of vulnerability and fear of mortality increase. Psychological responses to assaults to the body resulting in dysphagia may lead to depression, denial, feelings of hopelessness, helplessness, loss, and the mourning of that loss (Antonovsky, 1979; Pearlin & Yu, 2000). Even when there is hope of substantial recovery in swallowing function through intervention, patients may experience these feelings.

When the fact that the potential of sequela of noncompliance to SLP swallowing and feeding recommendations is not immediately visible, patients and NHP caregivers have a strong incentive to take the short-term view and deny the consequences (Colodny, 2005). Because the sacrifice is high and the consequences may be delayed, it is not surprising that noncompliance with SLP recommendations is a serious and ongoing problem. From the patient's perspective, it is a wonder that there is compliance at all.

## Understanding the Patient

As noted above, compliance requires not just a considerable effort, but a change in how patients view themselves and how family members perceive them. If SLPs provide the appropriate technical informa-

tion but do not cultivate a social/emotional/psychological basis for compliance, then the SLP will be right back where he or she started, with the patients achieving no benefits from swallowing intervention.

In an earlier paper (Colodny, 2005), I advocated SLPs taking a step back and a step forward. SLPs need to step back and view noncompliance not as an attack on them, but as a reaction to a stressful situation. Especially in the case of patients and their NHP caregivers, the issue of compliance centers on a necessary alteration in the self concept of the patient and in the perception of significant others toward the patient. SLPs are making recommendations that alter significant portions of the patients' lifestyle that indicate physical, psychological, and social losses. Therefore, after stepping back to focus on the patient, rather than on the feelings of rejection by the SLP, the SLP must take a step forward and put him/herself in the position of the patient to understand what is being asked and how it affects their life and psychological well-being.

Understanding is a cognitive dimension; empathy is emotional. The SLP needs to connect with the patient on an emotional level. The SLP must not only feel the patient's pain, but understand where it is coming from and why it is so painful. Although SLPs are experts in swallowing disorders, they must know how to help people who are in pain and help them cope with their loss. Carl Rogers, in his discussion of client centered therapy, advocated that the clinician adopt an attitude of "unconditional positive regard" (Rogers, 1965). By that he meant that the therapist must genuinely treat the patient as worthy and capable whether or not his or her behavior is perceived as such. The SLP must accept the premise that in some cases noncompliance represents a rational choice. Satisfaction comes in the knowledge that we did our best to provide the pa-

tient and NHP caregiver the information they needed to come to their own decisions about the foods they ingest and how they ingest them.

In addition to understanding and empathy, SLPs, as well as other health care professionals, need to be aware of the potentially asymmetrical power relationship they may have with their patients. First, their patients are experiencing a serious decline in their own personal power. What was once taken for granted, swallowing, is now a problem that needs addressing. They have suffered a loss of status and have taken up the sick role, in which they are dependent on others for their well-being. In a society in which chief values are independence and self-sufficiency (Albert & Kluckhohn, 1959), the decline into a state of dependency constitutes a serious psychological blow. Such a loss incurs the same mourning process as the loss of a significant other that involves denial, anger, bargaining, depression, and acceptance (Kübler-Ross, 1997).

### ***Communicating With Patient and NHP Caregivers***

Patients with dysphagia are confronted by a professional who has a knowledge base that is esoteric and, most likely, unknown to them. Therefore, they must learn about their condition from the SLP, which may emphasize the power asymmetry of the relationship. Patients are mourning the loss of their physical powers, whether temporary or not, and are confronted with learning about a disabling condition of which they had little or no knowledge; it is not at all surprising that they might react to their own loss of power and dependency through denial and anger. It is incumbent upon the SLP to recognize and understand that the patient may be less focused on compensatory measures than on his/her losses. It is through the communi-

cation process that the SLP can begin to ameliorate the pain of the patient and change the focus to the swallowing and feeding recommendations to cope with dysphagia.

The consultation process provides the SLP with the opportunity to change the patient's and the NHP caregiver's focus from the past to the future. Instead of mourning the loss of physical capabilities, which is a necessary step, the patient and NHP caregivers need to be redirected toward positive coping with the changes in the patients' swallowing function. This reorientation occurs through a collaborative process in which the SLP, the patient, and the NHP caregivers exchange information. The diagnostic process, including the clinical examination of swallowing (CES) and possible instrumental examination, focuses on the technical aspects of swallowing. This process can be alienating because the SLP is probing and searching in order to determine the patient's swallowing status. SLPs can humanize this examination by empathizing with the patients' sense of loss and indicating that they understand that what they are doing may not be pleasant, but is necessary to determine their swallowing status. Oftentimes, SLPs can make patients feel at ease through small acts of consideration.

Hobden (2006) has articulated a model of concordance within consultations in which she advocates the inclusion of patient perspectives in the consultation process. Once a diagnosis is made, the SLP must consult with the patient and, if necessary, the patient's NHP caregiver. According to the concordance model, the outcome of the consultation is a shared awareness among all participants. The health professional's role, the patient's role, and the marker of success are all defined. Simply put, the concordance model is one in which all participants have a common understanding. Role expectations are out-

lined and all participants are satisfied with this process.

Several researchers have conducted studies on communication concordance between patients and physicians (Aita, McIlvain, Backer, McVea, & Crabtree, 2004; Bekelja Wanzer, Booth-Butterfield, & Gruber, 2004; Epstein et al., 2005; Walker, Arnold, Miller-Day, & Webb, 2001). Findings have indicated that patient-centered communication enhances patient care. Effective communication should be patient-centered, in which patients' perspectives should be considered, their participation encouraged, and their emotions, needs, values, and preferences included in the interaction. Miscommunication between patients and doctors was found to be a consequence of patients' lack of participation in the communication process and ineffective physician communicative styles (Britten, Stevenson, Barry, Barber, & Bradley, 2000; Veder, Krafchick, Kovach, & Galluzzi, 2002). Professionals who offer supportive and partnership-building communication allow for greater patient participation and, subsequently, improved health care (Street, Jr., Gordon, Ward, Krupat, & Kravitz, 2005).

When the diagnosis and recommendations are understood, the roles delineated, and the outcomes are specified, participants in the consultation process have a concrete understanding of what has happened, what will be done, and what outcomes are likely. The process of building concordance is also the process of building trust. Communication is not unidirectional from expert to lay person, but rather, a discussion and negotiation of various aspects of the healing process. The issue transcends positive regard for the patient. The SLP needs to listen carefully to the patient and consider nonverbal communicative signs. The SLP needs to attend not only to the content of the patient's speech, but also to their tone of voice, body language, facial expres-

sions, and so forth. In addition, the SLP should take into consideration contextual influences on communication. For example, awareness on the privacy of the setting, the influence of others—such as family members—on the interaction, and time allotted to the discussion must be factored into the exchange.

The process is inclusive and brings the patient and NHP caregivers into the consultation as active participants. Rather than being told what to do, they are provided with the necessary information to make their own judgments. Because they are active participants, judgments made will be more likely to be carried out. If patients and NHP caregivers come to their own decisions about compliance or non-compliance, their behavior will be more predictable, because it will be based upon their own informed decisions. They will be less likely to say one thing and do another. They will be less likely to feign compliance, because the decision is theirs rather than one that was imposed by a professional authority.

### **Providing Support**

An important component of any compliance plan is to provide support for recommended behaviors. Human beings are social animals; they influence and are influenced by others around them. If SLPs want to increase compliant behavior, they need to help create a system of social support that reinforces healthful behaviors. The establishment of the support system involves a two-pronged approach: helping nursing staff, family, and friends to organize themselves as a patient support system and encouraging patients and NHP caregivers to participate in self-help groups (Colodny, 2005). Although such functions may fall under the jurisdictions of social work and mental health professionals, SLPs should be aware of the need to develop support systems for patients with dysphagia and be able to refer to the appropriate services.

Organizing a social support system for a patient can be dealt with under the education function provided by SLPs. When discussing patient care, SLPs can provide NHP caregivers information on providing support. This can be done in a variety of ways using various media, including scheduled informational meetings, brochures, videos and guest speakers. In addition, the SLP, in collaboration with social work and mental health professionals, may be able to suggest support groups for the patient and NHP caregivers or organize dysphagia support groups on the premises of health-care facilities. It is beyond the scope of this paper to provide specifics about social support; however, it is important that SLPs be aware of the necessity for social support and be able to help patients and NHP caregivers maintain an optimal environment for supporting alternative behaviors required to ensure the best quality of care for patients with dysphagia.

### **Conclusion**

Compliance with SLP recommendations has been an ongoing problem among nursing staff, NHP caregivers, and the patients themselves. Several alternatives have been proposed to increase compliance. These include acknowledging and regarding the patients' perspectives on their disorder, engaging in patient centered communication, and providing a supportive environment for compliance. One might ask, "If nursing staff is noncompliant, how can it be possible to encourage compliance among NHP caregivers and patients?" The answer seems to lie in the development of a culture of compliance in which nursing staff, NHP caregivers, and patients mutually reinforce compliant behaviors.

A major component of the culture of compliance is education. However, a culture is a living thing. The educational component must be accompanied by a normative envi-

ronment in which compliance is reinforced in everyday interactions. When nursing staff witness compliant behaviors on the part of NHP caregivers, they should be complemented. When noncompliant behavior is exhibited, nursing staff and the SLP should inquire whether a NHP caregiver or patient needs assistance or information. Openness should be encouraged so that when there are questions about compliance, people feel free to inquire about proper procedures. A non-threatening environment that encourages compliance leads to a higher level of information exchange and concordance among participants in the culture.

There will always be noncompliance. However, patients' and NHP caregivers' informed decisions need to be respected. The more that noncompliance is a consequence of informed decision-making rather than ignorance, lassitude, resistance, or hidden agendas, the more healthful the environment. Patients may develop dysphagia-related complications. However, it is our hope that the plan of care will be a consequence of knowledgeable decision-making. Whatever happens, it is important that the SLP provides the best quality of care based upon evidence-based practice.

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