Incomplete Locked-In Syndrome: Two Cases With Successful Communication Outcomes

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Two patients with diagnoses of locked-in syndrome (LiS) following basilar artery infarcts were admitted to the Rehabilitation Institute at Santa Barbara in 1987 and 1990. Both progressed from communication based on minimal eye movement to successful use of computerized communication devices. Details of the therapeutic intervention used are presented along with a consideration of cognitive issues as they relate to the syndrome's definition.

The term *locked-in syndrome* (LiS) was first used by Plum and Posner (1966) to describe a neurological condition in which consciousness may be preserved, but the patient is mute, and the only volitional motor activity is vertical eye movement and blinking. It differs from coma, persistent vegetative state, and akinetic mutism in that these conditions involve a lack of conscious interaction with the environment. Bauer, Gerstenbrand, and Rumpl (1979) divided the syndrome into three levels of severity, each of which presents with transient and chronic forms: (a) total, in which patients are immobile and unable to communicate but their EEGs reflect undisturbed cortical function; (b) classical, in which patients meet the criteria described by Plum and Posner; and (c) incomplete, in which the patients have limited voluntary motion in addition to eye movement.

Over 130 cases of LiS were summarized in two comprehensive literature reviews (Haig, Katz, & Sahgal, 1986; Patterson & Grabois, 1986). In these samples, vascular etiology was responsible for LiS in about 75% of the patients, and in the majority of these cases a brainstem infarct or hemorrhage had occurred. Basilar artery occlusion is often an etiologic factor (Hawkes, 1974; Keane, 1986; McCusker, Rudick, Honch, & Griggs, 1982). Other causes include brainstem encephalitis (Cherington, 1977), trauma (Bauer et al., 1979; Gauger, 1980), and central pontine myelinolysis (Stockard, Rossiter, Wiederholt, & Kobayashi, 1976). There is general agreement that a nonvascular etiology is likely to result in a more favorable outcome than a vascular etiology.

Reports of rehabilitation with LiS are limited, possibly because the patient mortality rate is high. Patterson and Grabois (1986) reported a mortality rate of 60%, with 87% of those patients dying within the first 4 months. The principal cause of death was respiratory complications (58%). As Haig et al. (1986) noted, these figures may be artificially high because the sample was composed primarily of post mortem reports. In the first systematic long-term study of LiS patients, Haig, Katz, and Sahgal (1987) reviewed the records of their facility over a 4-year period and identified 27 patients who had been admitted with a diagnosis of a brainstem stroke or LiS and had remained locked in for at least 1 year. The latter restriction served to exclude patients with transient forms of LiS. The 27 patients were between 1:2 and 12:8 (years:months) postonset when the follow-up information was obtained. Three of the patients had died, resulting in a mortality rate of 11%. About 40% of the patients could point, type, or trigger a switch, but none of them could voluntarily move an extremity against gravity. Over half of the patients received their nutrition primarily orally, and almost two thirds of the patients had returned to a home setting.

A variety of communication systems for LiS patients have been discussed in the literature. Simple yes/no eye blink systems have been used (Gallo & Fontanarosa, 1989; Kenny & Luke, 1989), as well as a more sophisticated eye blink-alphabet system (Frank, Harrer, & Ladurner, 1988). Morse code has been used with combinations of eye blinks and forehead movement (Gauger, 1980) and eye blinks and jaw movement (Feldman, 1971), and through a computer interface using chin movement (Tyson, 1990). Communication boards and electronic communication systems have been mentioned (Adams et al., 1986; DeGraaf & Rybnikar, 1986; Verhagen, Huygen, & Schulte, 1986). In the Haig et al. (1987) study, 14 of the 27 patients were using eye blinks or communication board systems, and 10 used electronic devices. Unfortunately, none of these studies details the process of developing the communication system.

When communication systems are discussed in the literature, the quality or content of the output is rarely addressed. Cappa, Pirovano, and Vignolo (1985) described a 31-year-old patient who was 12 years postonset from a probable vascular injury. He performed well on both naming and abstract language tasks using a modified typewriter, but his output was telegraphic in style and he rarely used the system voluntarily. In contrast, one of the patients described by Frank et al. (1988) was able to communicate complex thoughts and emotions despite the use of a rather laborious eye blink system.

A critical aspect of the differential diagnosis of LiS is intact cognitive status. Typically, initial claims of intact cognitive functioning center on a normal EEG or test results using a yes/no system based on eye movements. In the literature, extensive cognitive testing has been reported for only three patients. One patient who was 12 years postonset showed no deficits in verbal or visual-spatial tasks but scored 26/36 on the Coloured Progressive Matrices (Raven, 1962), indicating a mild impairment in nonverbal problem solving (Cappa & Vignolo, 1982). Mapou (1988) described two patients who suffered brainstem infarcts and who were 4 and 13 months postonset. They demonstrated attentional deficits that affected memory and organizational skills.

Two patients with LiS have been admitted to The Rehabilitation Institute at Santa Barbara (RISB) over the past 4 years. The case histories presented below describe the rehabilitation of these patients, with a focus on the techniques used to assess and develop their communication skills. The first patient, B.T., was a patient of the authors during his acute rehabilitation stay. Information on the second patient, G.F., was obtained from medical records and interviews with the patient and her treatment team.

Case 1

Medical Background

B.T., a 39-year-old male, was a truck driver with 10.5 years of education. He had had pericarditis in his 20s. About a week prior to his admission to an acute facility, he reportedly had tingling on the left side of his body, but a CT scan did not show any neurological changes. Just prior to admission he was found nonresponsive, having suffered a brainstem stroke. A series of CT scans indicated a large area of ischemia involving the right cerebellum and extending into the brainstem on the right side, consistent with acute thrombosis of the basilar artery. An EEG about 10 days later indicated normal brainwave patterns. He remained functionally tetraplegic.

B.T. had both a tracheostomy and a gastrostomy on admission to the acute facility. The tracheostomy tube was plugged for the first time about 2 months later and was removed when he was 6 months postonset. A modified barium swallow study was conducted 4 months postonset following extensive prefeeding exercises. Poor oral movement and both aspiration and penetration were observed. A conservative prefeeding program was initiated, and a second videofluoroscopic evaluation was conducted 4 months later. It showed minimal change, and B.T continued to take all nutrition through the gastrostomy tube at the time of his discharge from RISB.

Communication and Cognition

B.T. developed a yes/no response based on eye widening for *yes* and eyes closed for *no* while still in the acute hospital setting. He was able to answer basic questions, but his yes/no responses varied significantly with interest and fatigue. Attempts to use a communication board were not successful. When he was transferred to RISB 4 weeks postonset, the staff found the yes/no system difficult to interpret.

He began to show volitional movement of the large toe on his right foot at 3 weeks postonset. Attempts to use this movement for communication began 3 weeks later. A soft touch-pad switch was attached to a cloth and placed by his toe. This proved only moderately successful because of two factors. First, it was awkward to place the switch properly for his toe to have sufficient range to activate it. Second, although he could touch the switch on command over 80% of the time, he had difficulty limiting himself motorically to only one response at a time. The latter precluded the use of the switch for a yes/no system.

Subsequently, the switch was attached to a standard alphabet scanner on an Adaptive Communication Systems (ACS) SpeechPac system. We anticipated that a combination of motoric, cognitive, and visual problems would make the system too difficult for B.T. to operate effectively, but we thought that the morale of the patient and his wife would benefit from the attempt. On a couple of occasions he did produce a few short words, including a reference to his favorite beverage.

Visual fields were tested 8 weeks postonset with the assistance of the occupational therapist. B.T. was consistent in his responses on the toe switch to questions involving either the appearance or the disappearance of an object from his visual field. It was clear that he could not see in the lower quadrants bilaterally, a fact that was consistent with his tendency to keep his eyes pointed downward. This information was useful in the positioning of augmentative communication devices.

At 9 weeks postonset, movement began to appear in the right hand, and the soft switch was tried at that location. B.T. now had little difficulty limiting himself to single, discrete responses. The switch was then connected to the SpeechPac. The standard scanner was reconfigured in stages from a yes/no choice to 8, 16, and then 21 letters. This met with varying success that was not consistently related to the increase in complexity. For example, he could spell highly routine words, such as his name, or specific targets the authors supplied, such as "sand." When he was asked to generate words on his own, his output was misspelled to the extent that the target could not be guessed. The errors may have been the result of reduced scanning range, scanning speed, or processing speed, or a combination of these factors.

At the same time, two new procedures for yes/no responses were tried. The first involved one and three hand squeezes for *yes* and *no*, respectively. This proved to be more accurate than his eye blinks and was readily accepted by the staff. About 3 weeks later, author McGann built a hand-held buzzer box that used a soft momentary switch attached to a battery-operated noise generator. A Velcro strap was attached to the box to keep it positioned properly in the patient's hand. This mechanism also became reliable quickly, and it largely replaced the hand-squeeze system.

Around this time, the first attempt to administer a standardized test to B.T. was made. For the Reading Comprehension Battery for Aphasia (LaPointe & Horner, 1979), B.T. responded by sounding the buzzer when the examiner pointed to the desired target. He was able to match words and sentences to pictures (Subtests I-III and VI) with 70% accuracy.

Morse code was first attempted 4 months postonset and quickly met with success. A large chart with the code was placed in the therapy office and another by the patient's bed for reference. B.T. had difficulty producing dots and dashes of consistent length, which made translation of the code through a computer system such as the SpeechPac problematic. However, his awareness of the system was striking, and he demonstrated some attempts at problem solving. For example, in producing an *a* (dot-dash), if the dot was longer than usual, he would make the dash twice as long as that dot.

A breakthrough occurred about a week later when, for the first time since his injury, the patient used Morse code and expressed an idea on his own without prompts or a closed response set. His first four comments were "help," "no one listens," "eyes," and, more specifically, "cant see." Each phrase took him approximately 2–3 min to produce. The "spelling" errors that had occurred with the SpeechPac were not evident. It should be noted with regard to the code that none of those listening to it memorized the system, relying instead on code reference sheets.

By 22 weeks postonset, B.T.'s hand movement had improved sufficiently to allow the addition of a second switch on the buzzer box near the ring finger. One switch was connected to a high-pitched buzzer, and the other used the original low-pitched sound. This allowed differentiation of "dot" and "dash" on the basis of pitch rather than duration of sound. B.T. is currently using this system when he is away from other augmentative devices.

An additional box was built that used the same two switch positions connected to two line outputs. These lines were connected to the SpeechPac, with one line dedicated to "dot" and the other to "dash." This removed the problem of the inconsistency of the length of each dot or dash. Within a week, B.T. produced a complete, seven-word sentence.

Shortly thereafter, B.T. began using a prototype device that allowed him to use the same switch box to control a cursor scanning a large-print alphabet display on a television monitor. The large print, in combination with nonprescription reading glasses, enabled B.T. to see the message he was generating on the screen. Within a week of the introduction of this device, he produced messages at a faster rate and with fewer errors than he had with Morse code.

With the new system, B.T.'s messages increased in length and diversity. For example, he reminded his wife to "check the butane tank" that provided heating for their house. He was most successful with a scan rate of about 1 s per line of 6 letters, and his output rate averaged about 3.5 letters per min. The apparent discrepancy between scanning speed and word production was due to his insistence on correcting errors as they occurred, even when the content of the message was clear.

About 8 months after his injury, four standardized tests were administered by author McGann and the staff neuropsychologist. B.T. scored 53/60 on the Boston Naming Test (Kaplan, Goodglass, & Weintraub, 1983). On the Standard Progressive Matrices (Raven, 1958), he scored 30/60, a score that reflected deficits in sequencing and integrating parts of a complex geometric pattern into a whole structure. Although somewhat reflective of impairment of the ability to predict and organize visual-spatial information, this result also reflected compromise in the ability to solve problems at the nonverbal level. This observation was reinforced shortly thereafter when the staff neuropsychologist administered the Category Test (Halstead, 1947) of the Halstead-Reitan Battery. B.T. made 83 errors on this test, for which 51 is generally considered consistent with brain impairment. This low score reflects compromise in cognitive flexibility, the ability to inhibit incorrect responses, shift cognitive sets, and move from concrete to more abstract problem solving. He obtained a raw score of 145 on the Peabody Picture Vocabulary Test–Revised (Dunn & Dunn, 1981), for a percentile level of 18 (low average).

One year after his injury, B.T. is able to reach and grasp objects with his right hand and, with a mobile arm support, to touch his chin. He can lift his head and his right leg against gravity. Trace movement is beginning to appear in his left hand. He is able to phonate consistently when he laughs or cries, and he is beginning to phonate volitionally. For his communication needs, he is using a laptop computer that has a voice synthesizer, permits Morse code, and utilizes scanning with word prediction through a single or dual switch input. He has been home for 1 month and is participating in outpatient treatment with a goal of improving his use of the computer system for advanced communication and intellectual stimulation.

Case 2

Medical Background

G.F., a 32-year-old female, was a bank teller with 12 years of education. She suffered an apparent whiplash while on a commercial water slide. No other sequelae were noted immediately, although later she complained of severe chronic headaches. Following a sudden loss of consciousness about a week later, she entered an acute care facility. An initial CT scan suggested cerebral edema, but a cerebroangiogram revealed a basilar artery occlusion. Three weeks after her admission, G.F.'s attending physician indicated, on the basis of consistent eye blinks, that G.F. had intact cortical functioning. An MRI 1 month after admission suggested some low density within the mid- to upper pons, but no evidence of hemorrhage.

Like B.T., this patient had both tracheostomy and gastrostomy tubes placed on admission to the acute facility. The tracheostomy was plugged 3 months later at RISB. A modified barium swallow study was done 3.5 months postonset. The results of the study indicated moderate dysphagia characterized by poor control of the bolus, a swallow delay of 3–30 s, reduced initiation of a cough, and poor head control. Swallowing training, including thermal stimulation and oral-motor exercises, was initiated, and within a month G.F. was able to eat almost an entire meal with assistance. When she was discharged, she was taking all nutrition orally in a pureed consistency with supplemental fluids through a gastrostomy tube, and her cough had recovered to a functional status.

Communication and Cognition

At 12 weeks postonset, G.F. was extremely labile, but she was achieving fair success with shaking her head "no." When she was transferred to RISB at approximately 3 months postonset, she was exhibiting weak, delayed movement of the upper extremities, and she began to show some neck rotation on command. A yes/no system based on one eye blink for *yes* and a slight head nod for *no* was initiated but was found to be inconsistent.

Visual testing conducted 4 months postonset revealed that, although no lateral visual field loss was noted, G.F. had some visual acuity and perceptual problems, and she was fitted with glasses. This enabled her to read words and phrases, but she was easily distracted by visual stimuli.

Around the time of the visual testing, a number of communication system options were explored. An alphabet board using eye blinks was found to be ineffective. A headpointer system, the Sentient Systems EyeTyper, which makes use of subtle head movements and an infrared signal to indicate the target letter or phrase, was also tried but proved to be unsuitable because G.F. was unable to control extraneous head movements. However, when G.F. began to show some active motion of her left thumb and third finger, this motion was used to operate a soft pad switch in conjunction with the alphabet scanning system on the ACS SpeechPac. The production rate was very slow, and maintaining proper positioning of the soft switch was difficult.

Almost immediately after introduction to the SpeechPac system, G.F. produced three phrases about her situation. Within a month, she was using the system frequently to express complex ideas. It was noted that she was still having some difficulties with memory, attention, word retrieval, and perseveration. Furthermore, no system had been developed by which she could alert the staff when she desired to use the SpeechPac.

Shortly before G.F.'s discharge from RISB, the staff neuropsychologist conducted psychometric testing. On the Peabody Picture Vocabulary Test–Revised (Dunn & Dunn, 1981), she had a raw score of 146 and a percentile rank of 16 (low average). On the Peabody Individual Achievement Test mathematics subtest (Dunn & Markwardt, 1970), she had a raw score of 53 and a percentile rank of 25. G.F. was able to complete only five subtests of the Category Test (Halstead, 1947) before she became fatigued. Her responses, like B.T.'s, reflected mild to moderate difficulty with flexibility in thinking and in generating alternative problem-solving strategies.

At the time of her discharge, 7.5 months postonset, G.F. remained functionally quadriplegic. She was able to protrude her tongue, but voicing remained infrequent and nonvolitional. Her attention skills had improved. She was still reporting word-finding difficulties, and prompting was required for specific details in her communications. She was unable to perform some simple reasoning tasks. Because of logistic and financial issues, she was not available for formal outpatient speech-language treatment.

Three years after her injury, G.F. still resides at home with her family. Her husband cares for her with the help of a part-time caretaker. She takes all of her nutrition orally and is on a pureed diet. Although she is unable to phonate volitionally, she communicates effectively with the SpeechPac. Her production rate is approximately 15 letters per min.

Discussion

Locked-in syndrome patients are unique within the realm of rehabilitation because of the high degree of focus on communication. The emphasis should begin in the acute care setting, where communication can assist with the differential diagnosis of these patients by confirming a functional yes/no system. Attention to communication needs should continue through the acute rehabilitation process and into the outpatient setting.

A coordinated interdisciplinary team approach to communication is essential to the management of the patient. The most obvious role for the speech-language pathologist is to identify a practical system for communication early on and to continually reevaluate the system in light of the patient's physical and cognitive progress. Working closely with the nurses can maximize the use of the communication system to determine the patient's needs and reduce patient isolation. The speech-language pathologist might also assist other members of the treatment team in areas such as visual and cognitive testing. Finally, the speech-language pathologist may evaluate and remediate dysphagia.

The psychological challenges to LiS patients and the staff working with them are particularly acute. It should be noted that both B.T. and G.F. maintained a remarkable degree of self-motivation. This may have been due to their premorbid personalities, their participation in early intervention, and/or the vital support provided by their spouses and the staff. On the other hand, as B.T. and G.F. improved, their efforts to establish control over the environment sometimes manifested itself in oppositional behavior. For example, they occasionally refused to participate in a given therapy. This increase in control should be recognized as a positive long-term development in spite of the short-term disruption it may cause.

A major issue for the family of the LiS patient is acceptance of the profound degree and long-term nature of the injury. This acceptance begins with education and support from the treatment team and, in particular, from the physiatrist and the psychology and social service departments. The isolation felt by the family also needs to be addressed. Locked-in syndrome patients present a unique combination of motoric and communication problems that made the spouses of B.T. and G.F. feel particularly isolated even in a rehabilitation hospital setting. Both these patients and their spouses indicated that they benefited substantially from having the opportunity to meet each other and share their experiences.

Having the time to adjust emotionally can help the family members in deciding whether to assume the burden and commitment involved in taking an LiS patient home. Once that decision has been made, family members should be integrated into the daily care and treatment of the patient as early as possible. Training may deepen the family member's understanding of the challenges of home placement and of those faced by the nursing staff and treatment team in the hospital setting. It also can improve the family member's ability to give direction to the healthcare providers who will assist with the care in the home.

The goals and desires of the LiS patient must also be taken into consideration. A system must be designed to move beyond basic communication to enable the patient to initiate interactions and communicate his or her own thoughts. For example, a yes/no system can be adapted to identify row, column, or group on an alphabet board. Eye movement can also be used with standard coding systems such as Morse code or with systems tailored to the patient's specific movement limitations (Frank et al., 1988). One concern is that the patient will reduce communication so that passive yes/no responses will suffice to meet his or her needs (Adams et al., 1986; Cappa et al., 1985). Helping the patient to succeed in communicating complex thoughts, even if slowly, can help reduce this concern.

For the patient with incomplete LiS, the options for mode of output are considerably greater than for those with classical LiS. These patients generally have enough movement to activate a switch, which can be used independently or integrated with a computerized device. In addition to low-technology solutions, sophisticated, portable systems with voice synthesizers are now a reality. At the same time, the technology must be adapted to each patient's unique skills. For example, B.T. had remarkable problems operating the SpeechPac, resulting in the conclusion that he had poor spelling skills. In fact, the errors may have reflected problems in tracking the scanner, limitations in his field of vision, slow reaction time, and/or difficulties with shifting focus from scanning to activation of the switch.

The ethics of identifying the LiS patient's goals focus on two factors ("Who Speaks for the Patient," 1985). The first factor is the limitation inherent in a yes/no response system, which precludes elaboration and initiation of topics. The flexibility that can be built into low- and high-technology systems has made this aspect of the impairment less problematic and has improved the ability of most patients to initiate discussions of their concerns. The second factor is that many ethical issues relating to the patient's goals are too complex to be phrased adequately through yes/no questions. In fact, the problem may not be the limitation of the yes/no system but rather the limitations of the patient's cognition.

Although one of the characteristics included in the differential diagnosis of LiS is intact cognition, the published literature lacks data on formal cognitive testing with these patients. Testing with B.T. and G.F., combined with the results for the patients described in Mapou's (1988) paper, indicates a pervasive decrease in cognitive functioning, particularly in the area of executive functioning. These results may reflect a global impairment secondary to the neurological event, i.e., anoxic encephalopathy. Comprehensive cognitive evaluation, incorporating the patient's limitations in terms of vision, response mode, and fatigue, can help to clarify the patient's ability to handle complex decision making.

Conclusion

For these patients, comprehensive and intensive intervention helped promote a pattern of steady, though admittedly slow, progress. They were fortunate in having insurance programs that permitted the long stay necessary to achieve these gains. This enabled them to avoid placement in a long-term-care facility, which, in the long run, would have been more expensive. The support and education the spouses received may have helped them to decide on a home placement for the patients. To ensure that other LiS patients will receive this level of care, further research needs to be published regarding cognition, effectiveness of communication systems, and long-term outcomes.

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