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Speech Intelligibility and Marital Communication in Amyotrophic Lateral Sclerosis: An Exploratory Study

Karin Joubert[1], Juan Bornman[2], and Erna Alant[2]

Abstract

Amyotrophic lateral sclerosis (ALS), a rapidly progressive neuromuscular disease, has a devastating impact not only on individuals diagnosed with ALS but also their spouses. Speech intelligibility, often compromised as a result of dysarthria, affects the couple's ability to maintain effective, intimate communication. The purpose of this exploratory study was to determine the association between the deteriorating speech of persons with ALS (PALS) and couples' perceptions of marital communication. There were two participant groups: (a) persons with ALS (PALS) and (b) their spouses. Data were collected over a 12-month period through the administration of objective and subjective measures. A review of the findings suggested a positive relation between declining speech intelligibility and a couple's perception of marital communication. A holistic approach to communication intervention should be adopted for PALS, as communication as a means of facilitating and maintaining intimacy in the marital relationship is particularly pertinent to this population.

Keywords

amyotrophic lateral sclerosis, augmentative and alternative communication, communication, marital communication and speech intelligibility

The diagnosis of an acquired illness such as amyotrophic lateral sclerosis (ALS) during adulthood has a dramatic effect on the physical and psychosocial well-being of the individual (Rolland, 1999). ALS (also known as Lou Gehrig's disease or motor neuron disease [MND]) is a progressive neurological disease that usually results in severe physical disability involving all four limbs, speech, swallowing, and breathing (Young & McNicoll, 1998). The cause of ALS is unknown, but it occurs in 1.5 per 100,000 of the population worldwide, with the average age of onset at 65 years and a greater incidence in males (Freed, 2000). Persons with ALS (PALS) usually do not demonstrate any changes in cognitive abilities (Young & McNicoll, 1998), although evidence of a variety of cognitive and language difficulties (e.g., insight, concentration, ability to change topics) has been described (Strong, Grace, Orange, & Leeper, 1996). The disease is characterized by deficits in either the lower motor neurons or the upper motor neurons, but usually results from a combination of both (Freed, 2000). The progression of ALS across the functional modalities of speech, mobility, and ability to use upper limbs for activities of daily living has been documented by Riviere, Meininger, Zeisser, and Munsat (1998). In the early stage (State 1), there is a mild deficit in only one of three regions (speech, arms, legs) and the individual remain functionally independent in speech, upper extremities for daily living, and ambulation. As the disease progresses, the individual's ability to function independently is compromised until at the final stage (State 4), when the PALS has no functional use of at least two regions and moderate or no functional use of a third region.

The rapid decline of speech function as a result of dysarthria is common but not inevitable (Ball, Beukelman, & Pattee, 2004; Freed, 2000). The type of dysarthria that occurs depends on whether upper or lower motor neurons are affected. In the initial, mild stages, individuals with lower motor neuron involvement will present with flaccid dysarthria (breathy voice quality, hypernasality, and consonant imprecision), whereas those with upper motor involvement present with spastic dysarthria (strained-strangled-harsh voice quality, slow rate, hypernasality, and consonant imprecision; Wertz, 1985). However, as the disease progresses to involve both the upper and lower motor neurons, individuals will present with mixed dysarthria that will predominate throughout most of the disorder and inevitably result in reduced speech intelligibility (Ball et al., 2004; Freed, 2000). Freed (2000) reported that approximately 75% of PALS will

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reach a point where intelligible verbal communication is no longer possible.

As speech becomes less intelligible, PALS and their families need to acquire new communication strategies: PALS may move from communicating through speech to using augmentative and alternative communication (AAC) or eventually communicating through another person (Murphy, 2004). The considerable variability in the rate and patterns of progression across individuals, especially in the critical dimensions of speech, respiration, hand function, and mobility, dictate individual AAC needs (Yorkston, Strand, Miller, Hillel, & Smith, 1993). Several reports are available in the literature on the use of AAC by individuals with ALS (Beukelman, Fager, Ball, & Dietz, 2007; Fried-Oken et al., 2006; Murphy, 2004). The use of AAC by PALS has increased significantly over the past decade and is widely accepted by both PALS and their families (Beukelman, Ball, & Fager, 2008; Fried-Oken et al., 2006; Murphy, 2004). A combination of AAC strategies are typically used and range from low-technology strategies (e.g., topic and alphabet cues, gestures, sign language, facial expressions, eye gaze) to high-technology strategies, such as sophisticated computer systems with digitized speech (Beukelman et al., 2008; Fried-Oken et al., 2006; Murphy, 2004).

Speech intelligibility is defined as the extent to which a spoken utterance is understood by the listener (Yunusova, Weismer, Kent, & Rusche, 2005). The effect of listener familiarity on intelligibility judgments indicated better performances for familiar as opposed to unfamiliar listeners (DePaul & Kent, 2000). Speech intelligibility is a significant factor in determining whether an individual is an effective communicator (Ball et al., 2004; DePaul & Kent, 2000). Communication situations are not universal but instead occur in specific contexts characterized by interpretations, circumstances, and personal purposes (Burleson & Denton, 1997; Tönsing, Alant, & Lloyd, 2005). In a study comparing speech intelligbility and communication effectiveness across 10 social situations, Ball et al. (2004) found that for PALS with even a slight decrease in speech intelligibility, some social situations (e.g., a noisy environment, speaking for a long period of time) became difficult. However, even intimate communication situations with familiar communication partners became more difficult when speech intelligibility scores were less than 70%.

Various studies have confirmed that the main purpose of communication for all persons with communication disorders and their spouses is to nurture their personal relationships and maintain social closeness (Locke, 1998; Murphy, 2004). It is widely recognized that clear and accurate communication between spouses is considered essential in maintaining relationships and is an expected element in marital roles (Beach & Arias, 1983; Kahn, 1970). Frustration as a result of communication breakdowns and limited verbal communication, especially in the later stages of disease progression, has reportedly influenced the level of intimacy experienced by couples (Rolland, 1999). Bob Williams's (2000) quotation, "The silence of speechlessness is never golden" (p. 255), aptly describes reported perceptions of widening gaps in relationship and decreased closeness as a result of impaired speech intelligibility.

The impact of physical and psychosocial problems on marital relationships where one spouse has ALS has been investigated. Although it has been established that "communication plays a central role in marriage" (Burleson & Denton, 1997, p. 884), little research is available on the association between deteriorating speech in ALS and marital communication.

As there is a paucity of information on how this decline in the speech intelligibility of the PALS affects marital communication, the primary aim of this study was to determine whether there is an association between the deteriorating speech of PALS and couples' perceptions of marital communication. The current study, which was part of a larger research project, was exploratory and had two goals: (a) to describe the communication abilities and speech intelligibility patterns of PALS and (b) to determine the perception of marital communication indicated by couples across the disease progression.

Method

Research Design

A nonexperimental correlational design was employed for this study. This design was selected as appropriate to examine the extent to which differences in one variable are related to differences in one or more other variables of the cohort at intervals over time (Maxwell & Satake, 2006). In this study, the relationship between the deteriorating speech of PALS and couples' perceptions of marital communication was examined at three visits at 6-month intervals over a 12-month period using a variety of objective and subjective measures.

Participants

Participant Group 1: PALS. Four individuals with a neurologist-confirmed diagnosis of ALS were included in this group. Using a nonprobability, purposive sampling strategy (Maxwell & Satake, 2006), PALS were recruited with the assistance from the Motor Neuron Disease Association of South Africa and met the following selection criteria: (a) had been in an established, intimate relationship for at least 12 months prior to the onset of ALS; (b) had no reported speech-language, hearing, or visual impairments other than those resulting from the ALS; and (c) spoke either English or Afrikaans as their mother tongue. This group comprised three men and one woman and was representative of the broader ALS population because men are typically more affected than women (Mitsumoto, 1997). The average age of the participants was 54.8 years (range = 42–68; SD = 5.7 years) and as ALS peaks

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Table 1. Descriptive Information for All Participants

Characteristic	Couple 1	Couple 2	Couple 3	Couple 4
Spouse				
Age (years)	48	60	40	70
Gender	Female	Female	Female	Male
Years married	30	32	14	45
PALS				
Age (years)	52	59	42	68
Gender	Male	Male	Male	Female
Time post symptoms (in years)	5.7	5.9	5.1	2.1
Time post diagnosis (in years)	4.1	5.6	4.3	0.6

PALS = person with amyotrophic lateral sclerosis.

in the fifth and sixth decade of life, the sample was consistent with reports in the literature (Chiò et al., 2004).

Three participants' MND classification was *severe* across all three visits, with one of them moving to *terminal* at the last visit. The remaining participant was classified as *moderate* at the initial visit and rapidly moved to *terminal* at the last visit. The primary mode of communication for all the participants at the initial visit was speech, although obvious speech abnormalities were present that necessitated behavior modifications, such as frequent repetition of messages. Only one participant made use of a high-technology AAC device at the initial visit but reportedly abandoned use due to a decline in functional abilities. During the follow-up visits, communication was expanded to include facial expression, eye gaze, vocalizations, and low-technology AAC (e.g., alphabet board). One participant was nonvocal at the last visit, and she utilized writing as her primary mode of communication. For the duration of the research project, none of the participants reported receiving any speech therapy intervention.

Participant Group 2: Spouses. This group comprised the four spouses (three women and one man) of the PALS in Participant Group 1, and none reported any communication, vision, or hearing difficulties that affected their activities of daily living. All four were either English or Afrikaans first-language speakers. The average age of the spouse group was 54.5 years (range = 40–70; *SD* = 3.2 years). See Table 1 for detailed information regarding each couple.

All participants were married for more than a decade, with an average of 30.3 years (range = 14–45; *SD* = 12.7 years). The average time since the onset of the ALS symptoms was 4.7 years (range = 2.1–5.9) and the average time since diagnosis was 3.7 years (range = 0.6–5.6).

Materials

To meet the requirements posed by the research aims, the following internationally accepted measures were utilized: the *Amyotrophic Lateral Sclerosis Severity Scale* (ALSSS; Hillel et al., 1989), *Classification of MND* (Riviere et al., 1998), *Sentence Intelligibility Test* (SIT; Yorkston, Beukelman, & Tice, 1996), *Modified Communicative Effectiveness Index* (CETI-M; Yorkston, Beukelman, Strand, & Bell, 1999), and the *Primary Communication Inventory* (PCI; Navran, 1967).

ALSSS. This ordinal scale was used to obtain information regarding the level of severity in four categories: speech, swallowing, lower extremity abilities, and upper extremity abilities. Each of the four subscales provides a choice of 10 scores based on progressive decline in function (Ball, Willis, Beukelman, & Pattee, 2001; Hillel et al., 1989; Yorkston, Strand, & Miller, 1997). The first author, a speech-language pathologist with 20 years of clinical experience, rated participants at each visit by interviewing the PALS and spouse. For the purpose of this article, only the results from the speech scale were used to describe speech abilities. The 10-point scale of function consists of general categories of normal speech processes (scores of 9 and 10), detectable speech disturbance (scores of 7 or 8), need for behavioral modifications (scores of 5 or 6), need for use of augmentative communication (scores 3 or 4), and loss of useful speech (scores of 1 or 2). In a study conducted by Ball et al. (2001) the ALSSS Speech Scale was identified as a valid and reliable assessment tool.

Classification of MND. This classification system was developed to describe the severity of ALS across the functional modalities of speech, mobility, and the ability to use upper limbs for activities of daily living (Riviere et al., 1998). Classification ranges from one to four states: State 1 (mild), State 2 (moderate), State 3 (severe), and State 4 (terminal). At each visit, the first author identified the current classification through observation and ALSSS rating.

SIT. The SIT, a widely used standardized clinical transcription test, was used to objectively measure speech intelligibility of the participants. A series of 11 randomly generated unrelated sentences were read by participants at each visit. Sentences varied in length of 5 to 15 words. Standard administration and measurement procedures were employed. The recorded responses were transcribed by the first author using

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broad transcription techniques, and analysis resulted in the percentage intelligibility rate and speaking rate in words per minute (wpm). In the standardization procedures for the SIT, Ball et al. (2001) reported no significant interrater differences for intelligibility over time.

CETI-M. This index was adapted by Yorkston et al. (1999) for the evaluation of the communication effectiveness of PALS. The CETI-M uses a visual analogue for 10 contextual situations on a Likert scale of 1 (*not at all effective*) to 7 (*very effective*). The PALS and their spouses completed the CETI-M separately to determine perceived communication effectiveness in the same situations. The first author assisted PALS to complete the CETI-M by marking the response form in accordance with their verbal or gestured responses because the participants were unable to hold and manage a pen. This provided a measure of personalized evidence on communication performance and social limitation of the PALS communication (Ball et al., 2004). For this article, only the rating "Having a conversation with a familiar person in a quiet environment" is reported because it is most pertinent to marital communication.

PCI. The PCI, a 25-item instrument, was completed separately by both members of the couple at all three visits. The first author assisted the PALS by marking the response form with their responses. The PCI was designed to assess marital communication, and the overall score appears to be a reliable indicator of the soundness of communication between two members of a couple (Navran, 1967). To determine the reliability of PCI for this study, the first author conducted a pilot factor analysis by administering the scale to 51 couples (n = 102). One factor, Communication, was identified with an eigenvalue that was 7.56 for all items. Reliability was measured through use of Cronbach's alpha, which was .89 for the entire sample, indicating very high reliability. The PCI was therefore found to be appropriate for use in this study to provide valuable information on individuals' perception of marital communication.

Procedures

Ethical considerations. Various ethical considerations were implemented throughout the research study. The researcher obtained ethical clearance from the University of Pretoria's Research Ethics Committee before this research study was conducted. Written informed consent was obtained from the MND Association and all participants using established and approved methods. All participants in the study were fully informed of the nature of the study and were assured of anonymity and confidentiality. Each participant was required to sign a consent form, providing proof of his or her willingness to partake in the study, and had the right to withdraw from the study at any time without any negative consequences.

Data collection. Once participants were identified, appointments were made by the first author to visit them at their homes. At the initial session the baseline information was recorded and two subsequent visits scheduled at 6-month intervals. All sessions were audiorecorded using a SANYO ICR-B180NX stereo digital voice recorder for later transcription. There was no contact or intervention with the participants between data collection visits.

Reliability. Basic considerations were taken into account during data collection. The recorded SIT responses were transcribed by the first author using broad transcription techniques. The second rater, a speech-language pathologist unfamiliar with the participants and stimuli sentences, transcribed 25% of the SIT recordings. Interrater agreement for the SIT transcriptions was 95%. The SIT analysis was conducted by the first author using standard procedures (Yorkston et al., 1996). Interrater agreement was also determined for the ALSSS, Classification of MND, CETI-M, and PCI by the first author and a second rater, a registered nurse with 30 years of clinical experience in the field of MND. She accompanied the first author on 20% of the visits, where she first determined the disease state according to the MND classification and then used clinical observation to rate the functional speech impairment of the participants with ALS using the ALSSS Speech Scale. She further independently completed the CETI-M and PCI while the first author conducted the interviews with the PALS. Across all these measurements the interrater agreement was 100%.

Results and Discussion

The purpose of this study was to describe the deteriorating speech of PALS and the couples' perception of marital communication across the disease progression. The first aim addressed the description of communication abilities and speech intelligibility patterns across the disease progression and the second aim addressed couples' perception of marital communication.

Speech Intelligibility

Three measures were utilized to describe the communication abilities and speech intelligibility of each PALS participant: ALSSS, SIT, and CETI-M.

PALS 1, 2, and 3 were classified as severe at the initial and second visits. While PALS 1 moved to terminal at the last visit, PALS 2 and 3 remained in the severe classification. PALS 4 was classified as moderate at the initial visit and rapidly moved to terminal at the last visit (see Table 2).

At the initial visit, the mean percentage of speech intelligibility (as measured by the SIT) for all participants was 73% (range = 42%–98%; SD = 27.0), which decreased to 53.8% (range = 45%–81%; SD = 18.5) at the second visit and continued to decrease to an average of 37.5% (range = 0%–73%;

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Table 2. MND Classification, ALSSS (Speech Scale), and SIT Results Across All Visits

	MND Classification			ALSSS (Speech Scale)			SIT (%)		
PALS	Visit 1	Visit 2	Visit 3	Visit 1	Visit 2	Visit 3	Visit 1	Visit 2	Visit 3
1	3	3	4	5	4	3	42	49	38
2	3	3	3	5	5	5	93	81	73
3	3	3	3	4	4	4	59	40	39
4	2	3	4	7	3	1	98	45	0
							M = 73.00	*M* = 53.75	*M* = 37.50

PALS = person with amyotrophic lateral sclerosis; MND = motor neuron disease; ALSSS = *Amyotrophic Lateral Sclerosis Severity Scale* (Hillel et al., 1989); SIT = *Sentence Intelligibility Test*.

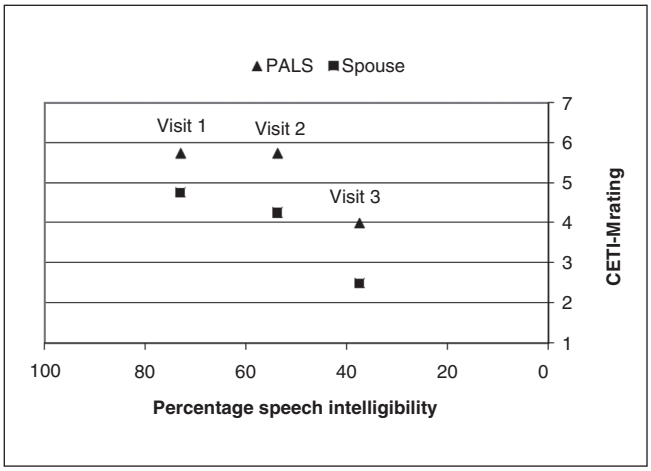


Figure 1. Speech intelligibility and communication effectiveness: mean scores per participant group across visits.
PALS = persons with amyotrophic lateral sclerosis; CETI-M = *Modified Communicative Effectiveness Index*.

SD = 29.8) at the last visit. Between the first and last visits, PALS 1 showed a 4% decrease, and PALS 2 and 3 a 20% decrease. The most dramatic decrease in speech intelligibility was recorded for PALS 4, who moved from 98% at the first visit to 0% at the last visit (see Table 2). PALS 2 and 3 were classified as severe across all visits, but their speech intelligibility decreased only 20%. In contrast, PALS 4 showed a rapid progression of ALS, with a concurrent loss of speech intelligibility. Notably, PALS 4 was the oldest participant and the only one recently diagnosed with ALS.

Communication effectiveness ratings (CETI-M) were completed by both the PALS (self-perceived) and spouse (listener-perceived) at each visit. It was evident that the mean communication effectiveness ratings of the PALS were consistently higher than those of the spouse group (see Figure 1). The decrease in speech intelligibility was consistent with the decrease in communication effectiveness as rated by both participant groups. Figure 1 offers a graphic version of the mean scores across visits, demonstrating a positive relationship between communication effectiveness and speech intelligibility for the PALS and spouses, respectively.

These results are consistent with reports in the literature that have indicated that (a) the progression of speech symptoms varies greatly among individuals with ALS (Beukelman & Mirenda, 1998), (b) approximately 75% of PALS will experience difficulties with intelligible verbal communication during the final stages of the disease (Beukelman & Mirenda, 1998; Freed, 2000), and (c) most communication situations become more difficult when intelligibility is less than 70% (Ball et al., 2004). Due to compromised speech intelligibility and the fact that PALS must often expend great effort to communicate, verbal communication is often kept to the minimum (Murphy, 2004). This was supported by the findings of the current study in which all the PALS facilitated communication through the use of low-technology AAC, which included facial expression, partner-assisted yes/no questions, direct optical selection alphabet boards, and in the case of PALS 4, writing.

Marital Communication

The second aim, to describe the perception of marital communication across the disease progression as indicated by the couples, was addressed by administering the PCI at each visit. Higher scores are indicative of better or more positively viewed communication, with a possible range of 25 to 125. Navran (1967) reported the mean scores for happily married couples (105) and unhappily married couples (81).

The mean marital communication scores for each participant group across the visits are presented in Table 3. Overall, the average scores of marital communication as perceived by the spouse group are consistently higher than the PALS group at both the first and second visits, but only marginally higher at the last visit. It is important to note that the mean PCI scores obtained for both groups at the first visit were below 105, the mean score for "happily married" couples. In addition, the scores for both groups decreased across the visits, to a classification of "unhappily married" at the last visit.

It is postulated that the diagnosis of ALS has devastating consequences on the functioning of couples and that severe psychosocial strain on this relationship is inescapable

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Table 3. Primary Communication Inventory (PCI) Scores Across All Visits

	Spouses			PALS		
Couple/*M* and *SD*	Visit 1	Visit 2	Visit 3	Visit 1	Visit 2	Visit 3
1	93	84	82	72	74	85
2	108	90	98	92	86	94
3	86	82	84	85	83	77
4	99	102	53	105	93	60
M	96.5	89.5	79.3	88.5	84.0	79.0
SD	9.3	9.0	18.9	13.8	7.9	14.4

PALS = person with amyotrophic lateral sclerosis.

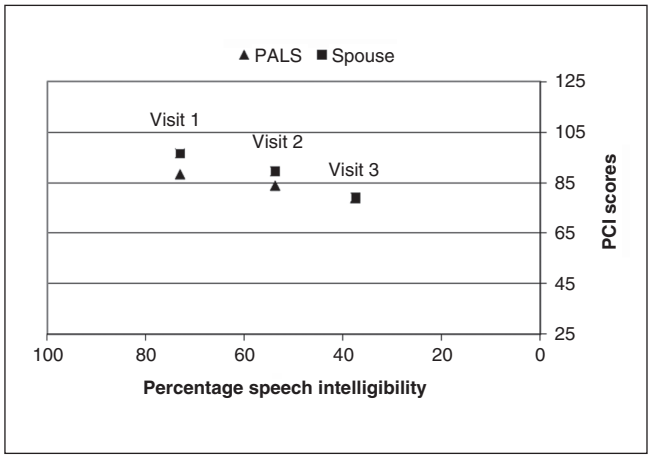


Figure 2. Speech intelligibility and marital communication: mean scores per participant group across visits.
PALS = persons with amyotrophic lateral sclerosis; PCI = *Primary Communication Inventory*.

(Rolland, 1999). The depression and social isolation that accompany debilitating medical conditions can account for some of the deterioration in communication between spouses (Rolland, 1999). The quality of the marital relationship and communication prior to the illness determines how couples cope with the ongoing challenge of disability. Aspects that supported marital communication prior to the disability may now become insufficient when couples face illness and disability (Cutrona, 2004).

Speech Intelligibility and Marital Communication

To address the association between the deteriorating speech of PALS and the couples' perceptions of marital communication, the mean scores were used to determine the existence of a possible relationship. Figure 2 is a graphic version of the results of this analysis (PALS SIT scores and PCI ratings made by both the PALS and spouse), indicating a positive relationship between declining speech intelligibility scores and lower ratings of marital communication by PALS and their spouses.

As communication is a collaborative activity, the PALS' communication partner must often assume an additional share of the communicative burden so that meaning can be constructed with less effort from the PALS (Linebaugh, Kryzer, Oden, & Myers, 2006). Although couple's history of shared interactions should facilitate understanding of each other's facial expressions, idiosyncratic gestures, vocalizations, and feelings (Kahn, 1970; Murphy, 2004), it seems that decreased speech intelligibility and communication effectiveness have a negative impact on the couples' perception of their marital communication.

This negative impact of decreased communication effectiveness has been confirmed by research conducted on communication problems and quality of marital relationships in the areas of dementia, aphasia, and traumatic brain injury (Blais & Boisvert, 2007; Flaskerud, Carter, & Lee, 2000; Linebaugh et al., 2006; Savundranayagam, Hummert, & Montgomery, 2005). Self-reports by caregivers of people with dementia indicated that the communication breakdowns experienced by the couple often led to frustration. This ineffective communication had a significant negative impact on the quality of the relationship (Savundranayagam et al., 2005). A study conducted on couples of whom one partner had a traumatic brain injury indicated that the positive perception of the affected partner's communication skills was the factor most strongly linked to marital satisfaction (Blais & Boisvert, 2007).

Conclusion

The review of the findings of this exploratory study suggested a positive relationship between declining speech intelligibility and the couple's perception of declining marital communication, despite the degree to which speech intelligibility was compromised by disease progression. The results of this study should be cautiously interpreted in light of its exploratory nature and small sample size. Future research should address the replication of this study with a larger sample size. As the current design did not make provision for the retrospective measurement of marital communication prior to the onset of ALS, including such a measurement in future

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research could add to our understanding of the complexity of the situation and the role that speech intelligibility plays in this regard. In addition, as marital communication is embedded in sociocultural contexts, it is recommended that this study be conducted using various cultural groups.

Communication as a means of facilitating and maintaining intimacy in the marital relationship is particularly pertinent to PALS and their spouses. It is therefore important that health professionals take a holistic approach to intervention and address not only the communication needs of the individual with ALS but also those of the spouse. To maintain close marital communication, the couple should be provided with appropriate information and support by health professionals (Murphy, 2004). All essential areas of communication (as described by Light, 1988) that are important to the PALS and spouse should be identified before AAC strategies are implemented. AAC strategies that are tailor-made for each couple can assist them in maintaining intimate marital communication despite the PALS' declining communication abilities. Training to become familiar with the proposed AAC strategies and ongoing evaluation is essential to ensure successful intimate communication for the couple.

Declaration of Conflicting Interests

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