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Family Satisfaction with PSCLAB's Neuro-Linguistic Care for Alzheimer's Patients: Developing a Questionnaire

رضا الأسرة عن بروتوكول التحفيز المعرفي اللغوي العصبي لمرضى الزهايمر (PSCLAB): تطوير استبيان

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Abstract:

Our research focused on the impact of Alzheimer's disease on language information processing in bilingual individuals. Certain semantic aspects of their first language (L1) are found to be disordered according to the results. On the other hand, grammatical levels appeared to be relatively unaffected in oral speech in L1 but were disturbed in the second language. As a consequence, we developed a cognitive-language stimulation protocol for bilingual patients (PSCLAB) to address this disorder. The efficacy of this protocol in terms of rehabilitation was assessed in 30 patients by conducting discourse analysis before and after initiating it. The PSCLAB appears to have an effect on improving language behavior of patients with AD, as shown by the results. The objective of this survey study is to confirm the satisfaction of patients' relatives with the results of cognitive language training conducted by PSCLAB. A short instrument was created by us to gauge the satisfaction of family members. The results report that the patients' relatives are satisfied with the results of cognitive training by PSCLAB.

Keywords: Family Satisfaction, Alzheimer's Disease, Neuro-Linguistic Care, Levels of Language Production Processing.

ملخص:

ركز بحثنا على تأثير مرض الزهايمر على مستويات معالجة المعلومة اللغوية لدى الأفراد ثنائيي اللغة. اظهرت للنتائج اضطراب على المستوى الدلالي للغة الأم (L1) وعلى المستوى النحوي للغة الثانية (L2). قمنا بتطوير بروتوكول اعادة تأهيل لغوي عصبي موجه للمرضى ثنائيي اللغة (PSCLAB) لمعالجة هذا الاضطراب. تم تقييم فعالية هذا البروتوكول عن طريق إجراء تحليل الخطاب 30 مريضا قبل وبعد تطبيقه. أظهرت النتائج أن PSCLAB له تأثير على تحسين السلوك اللغوي للمرضى الذين يعانون من مرض الزهايمر. الهدف من هذه الدراسة الحالية هو التأكد من فعالية البروتوكول من خلال تقييم رضا أقارب المرضى عن نتائج التدريب اللغوي المعرفي PSCLAB. قمنا ببناء أداة لقياس رضا أفراد الأسرة وتطبيقها على 30 قريبا للمرضى. أشارت النتائج إلى أن أقارب المرضى راضون عن نتائج التدريب المعرفي PSCLAB.

الكلمات المفتاحية: رضا الأسرة؛ التحفيز المعرفي العصبي؛ الزهايمر؛ مستويات معالجة المعلومة اللغوية.

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1. Introduction

Following the results of the study by Sahraoui and Lefebvre (2019 a) illustrating the effect of AD on language information processing in bilingual patients, a cognitive-language stimulation protocol for bilingual patients with mild-to-moderate AD (PSCLAB) was developed Sahraoui and Lefebvre (2019 b). The effectiveness of PSCLAB in terms of rehabilitation of disturbed levels of language production processing was evaluated in 30 such patients through discourse analysis carried out before and after initiating the protocol. The results show that cognitive/language training using the PSCLAB appears to improve language performances of bilingual patients with AD. However, Alzheimer's disease is a source of disability with personal, social, and family repercussions for patients and particularly their relatives. Considering that the satisfaction of patients' relatives could make it possible to get a better evaluation of this protocol and improve its process, this Survey study aims to verify the satisfaction of patients' relatives with the results of cognitive language training by PSCLAB.

2. Key concepts' definition

2.1 PSCLAB

the PSCLAB protocol is a cognitive-linguistic stimulation care designed specifically for bilingual patients with Alzheimer's disease. The protocol is based on the analysis of disturbed levels of processing in language production of bilingual Alzheimer's patients and aims to stimulate the production of language in both languages spoken by the patient, French and Arabic.

2.2. Levels of Language Production Processing

An architecture can be used to represent how thoughts are converted into speech by organizing the levels of processing involved in speech production. According to most language modeling theories, speech is produced in three main processing stages: conceptualisation, formulation, and articulation. During the second phase, most studies suggest the existence of at least two independent processing levels: semantic/syntactic and phonological (Ferrand, 2002). In this work, we are mainly interested in the second stage related to the formulation of the message and we adopt the proposal of certain models (Caramazza, 1977; Paradis, 2004). We admit the presence of three levels of processing at the stage

of the formulation of the message (lexico-semantic level, syntactic level and the phonological level).

2.2.1. The lexical-semantic level

The meaning of words and their semantic features are represented by an independent lexical-semantic network that organizes lexical knowledge (Ferrand, 2002). The selection of lexical items and specification of their underlying relationships occurs at this level (Rondal, 1997). Nouani (1996) argues that semantic relationships can be expressed through: the procedure based on the lexical implications of the terms; continuity, the presence of two successive messages which share a common meaning (for example: the weather is fine, I'm going out); the succession of opposing terms (for example: you go, I stay).

2.2.1. 1. Procedure based on the lexical implications of terms (PFIL)

PFIL is used to determine the lexical implications of terms. A lexical chain is formed by the use of lexically linked sequences of words in a discourse. Nouani (1996) explains that PFIL involves using word sequences that are semantically related in a discourse. For example, if the discourse contains the words orange and fruit, they must both appear in a chain, because an orange is a type of fruit. Similarly, in Nouani's (1996) example (when I'm in the country, I go for a walk...I like the sea), the words campagne/mer can appear in a chain, because these two words refer to places where people go for a walk. The organization of lexical chains in a discourse reflects the structure of the discourse or its main theme.

2.2.1. 2. Continuity

At the semantic level of a discourse which presents the unit carrying the message, continuity can appear in implicit form through the use of oral expressions characterised by an intonation whose content suggests the passage from one idea to another or a progression in the subject (succession of different ideas and events), for example questioning and requests for explanations.

2.2.2. The syntactic level

This involves the retrieval of grammatical information organised in a syntactic network representing the syntactic features of words (Ferrand, 2002). At this level, language is organized by a set of rules that govern the relationship between words and their combinations. According to Nouani (1996), syntactic micro-links are provided by the use of connectors, anaphors and deictics.

2.2.2. 1. Connectors "Linking words

Fayol (1997) defines the connector as a term used to group together different elements of grammatical status which have the common function of indicating precisely the nature of a relationship between two statements (grammatical sense). Connectors are frequently used to convey logical content (because, therefore, but, etc.), causal content (because, because, etc.), or chronological content (first, finally, etc.).

2.2.2. 2. Deictics

According to Dubois (1973), deictics are linguistic units that are inseparable from the place, time and subject of the utterance; they designate (the speaker, the place, the date, etc.) whose referent depends on the situation of utterance, for example: "here", "yesterday", "I", "you" are deictics. We can't know to whom they refer without knowing who the speaker is and to whom he or she is speaking, and the place and time of the utterance. Every utterance takes place in a given situation (the spatial and temporal coordinates). chronological content (first, finally, etc.).

2.2.2. 3. Anaphora (syntactic)

A syntactic anaphora is a word linked to another element (called an antecedent) in the sentence. Without this antecedent, the anaphora has no meaning (Goblin, 1995). The syntactic anaphora ensures the syntactic repetition of its antecedent without it being repeated. For example: Celle, ce dernier, la mienne ... etc. This is very useful for avoiding repetition and ensuring coherence and clarity of discourse.

2.2.3. The phonological level

It is through the process of phonological organisation that the linguistic message takes the form of a spoken message (Rondal, 1997). This level corresponds to the sounds or phonemes that differ from one language to another (sound representation) (Bertrand & Garnier, 2005)

3. Objective

Measuring the family members' satisfaction concerning the cognitive-language training by the PSCLAB may help improve the quality of healthcare. This survey's target is to investigate the relative's satisfaction of the cognitive language stimulation protocol for bilingual patients with AD (PSCLAB) and to explore its associated factors using a newly developed 9-item questionnaire. Our survey highlights the importance of patients' relatives' satisfaction and improves the assessment and the implementation of PSCLAB.

4. Hypothesis

While observing the relatives' comments therapy during the implementation of PSCLAB, we can assume that they are satisfied with the results of cognitive language training by this protocol.

5. Population

This study is conducted on a sample of 30 relatives of both genders. The following table 1 summarizes the characteristics of the participants included in this study. The 30 patients' relatives who took part in this study are usually family members living with the patients and appointed as those providing the most help. This could be a spouse or children (son or daughter).

Table 1. Characteristics of study participants: average (standard deviation)

	Minimum	Maximum	Characteristics
Number of participants	/	/	30
Gender	/	/	20 M/10 W
Relationship (1/Spouse- 2/Children)	/	/	1,76 (0,43)
Age	40	60	48,33 (7,07)
Stage of AD (patient's MMS)	16	25	15 AD L/15 ADM
Educational level (Primary 1/Secondary 2/ University 3)	1	3	1,86 (0,73)

6. Methods

In order to study the satisfaction of relatives of bilingual patients with AD after care administration by PSCLAB, it is recommended to develop a brief instrument that can be used by patients' relatives to measure the level of satisfaction.

5.1. - Development of the questionnaire to measure the relatives' satisfaction with the results of cognitive language training by the PSCLAB

To get an appropriate instrument to measure the relatives' satisfaction with PSCLAB we elaborate a brief questionnaire for relatives based on relatives' satisfactions' research (Whittamore & al., 2014; Jiang & al., 2019) and on the PSCLAB' s objectives (Sahraoui & Lefebvre, 2019 b). Then we provide the content of the questionnaire to experts to logically examine it and to obtain feedback about the assessments of the extent to which the questions represent the content. A revised version was completed based on the feedback (adding questions about age and relatives ' education level). Then, it is tested in a small sample (N=4), and some of the responses' scales were revised again based on the feedback. We, then, replace the simple responses formats (a choice between Yes or No) by complex responses formats (choosing an answer among three response options: trichotomous categorizations of the change scores stability/degradation/ improvement) in the questions dealing with benefit of PSCLAB in improving the patient's language abilities.

In the developed questionnaire, our concern focused on the content validity by determining the content meaning that we want to measure and by formulating questions representing this meaning, based on the achievement of the PSCLAB objectives and the relatives' satisfaction with this achievement that represents the content meaning of the questionnaire. The developed questionnaire, in the most important part, focuses on the relatives' satisfaction about the benefit of PSCLAB in improving the patient's language abilities, in particular, those targeted by this protocol (Word finding, asking for explanation, organizing sequences of ideas or topics in speech, completing coherent sentences). Moreover, it also discusses other aspects as the benefit of the PSCLAB in improving patients' quality of life and patients' cognitive abilities (attention and

memory).

Recent relatives' satisfactions' research (Whittamore & al., 2014; Jiang &al., 2019) suggest that the common reasons for dissatisfaction of family members include aspects related to the therapist-patient relationship, absence of information or communication, technical skills of healthcare. Consequently, the developed questionnaire contains questions about the relative's point of view concerning the course of therapy sessions and about the quality of explanations provided.

We start the questionnaire by three informative to ask for relatives' information (age, kinship, patients' stage of disease) and two closed questions regarding how Alzheimer's disease affects patients' cognitive abilities and relatives' quality of life to put the relatives in the context of our survey.

The final version of the questionnaire consists of both opened and closed questions concerning relatives' satisfaction. It briefly discusses the general benefits of the protocol by using four closed questions. The first question requests its benefits in improving patients' quality of life, the second regards its benefits in reducing the evolution of cognitive degradation, the third probes relatives' opinion about the course of therapy sessions, whereas the fourth question concerns relatives' opinion about the recommendation of the use of this protocol.

In the most important part of the questionnaire that discusses relatives' satisfactions about the benefit of the PSCLAB in improving patient's language abilities we use one question containing six closed sub-questions discussing the improvement or not of the above-mentioned language abilities (Word finding…etc.) via the trichotomous categorizations of the change scores (1=degradation, 2= stability, 3=/improvement) (Sherri, 2014). The other response formats used in this survey vary depending on the type of question asked. Some questions are scored on a Five-Point Likert scale (Kamper & al., 2009) with the following options: (1=very dissatisfied, 2= Dissatisfied, 3=Neither, 4= Satisfied, 5=very satisfied), other questions are scored on a simple scale as a choice between three responses: (3=Yes, 2= fair or 1 =No) (see table 1 below). We convert the response to a scale to make the values more meaningful and more appropriate for statistical analyses (Wall, Engelberg, Downey, Heyland & Curtis, 2007). We conducted the survey to assess the satisfaction of 30 patients' relatives. The Satisfaction data collection is collected separately. We calculate the averages and the percentages of the obtained scores of each item, and then we carry out the quantitative analyses. We hope the data

may clarify the factors leading to relatives' dissatisfaction and the ways to modify them, so as to help us to improve the quality of therapy.

7. Results

We found a high satisfaction score in sub-questions' responses regarding the estimation of the benefit of PSCLAB in improving patient's language abilities, this satisfaction is shown in the values of average, which varies between 2,4 and 2,9 (1=degradation, 2= stability, 3=/improvement) (See table 2).

Table 2. Relatives' satisfaction about the benefit of PSCLAB (see scales: p 2)

Estimation of the benefit of PSCLAB	Sub-questions	N	Min	Maxi	Average	Standard Deviation
Improving Patient's Language Abilities	- Word Finding (WF)	30	2,00	3,00	2,40	0,49
	- Organizing Sequences of ideas or Topics in Speech (OSOIOTS)	30	2,00	3,00	2,90	0,30
	- Completing Coherent sentences (CCS)	30	2,00	3,00	2,86	0,34
	- Asking for Explanation (AFE)	30	2,00	3,00	2,73	0,44
- Quality of Life	/	30	4,00	5,00	4,26	0,44
- Does the PSCLAB reduce the evolution of cognitive degradation?	/	30	3,00	300	3,00	0,00
- Recommendation of the use of PSCLAB	/	30	3,00	3,00	3,00	0,00
- Relatives' opinion about the course of therapy sessions	/	30	3,00	3,00	3,00	0,00

86,70% of relatives estimate that there is an improvement in word finding ability and only 13,30% of them estimate the existence of stability. 73,33% of relatives estimate an improvement in asking for an explanation and 26,66% estimate the existence of stability; 90% of relatives estimate an improvement in organizing sequences of ideas or topics in the patient's speech and 10% estimate the existence of stability. 90% estimate an improvement in completing a coherent sentence and only 10% estimate the existence of stability. However, none of relatives (0%) estimated a degradation in each one of language abilities discussed in this questionnaire: Word finding, asking for an explanation, organizing sequences of ideas or topics in speech, completing a coherent sentence (See table 3).

Table 3. Relatives' satisfaction about the benefit of PSCLAB in Improving Patient's language abilities (percentage)

Estimation of the Benefit of PSCLAB	Sub-questions	Degradation	Stability	Improvement
Improving patient's language ability	- Word Finding	0%	13,30%	86,70%
	- Organizing sequences of ideas or topic in speech	0%	10,00%	90,00%
	- Completing coherent sentences	0%	10,00%	90,00%
	- Asking for explanation	0%	26,66%	73,33%

The results show a high level of overall satisfaction. It shows that 100% of relatives are satisfied with the course of therapy sessions (See table 4). 100% recommend the protocol and all of them (100%) are satisfied with its benefits in reducing the evolution of cognitive degradation (See table 5). 100% report a benefit of PSCLAB in improving attention and stabilizing memory. On the other side, a high satisfaction of relatives about patient's quality of life after the training by PSCLAB is shown in the values of scores' average 4,26 (1=very dissatisfied, 2= Dissatisfied, 3=Neither, 4= Satisfied, 5=very satisfied), where 73.37% of relatives are satisfied and 26.7% of them are very satisfied (See table 4).

Table 4. Relatives' satisfaction about the benefit of PSCLAB in other aspects

Satisfaction of relatives about:	very dissatisfied	Dissatisfied	Neither	Satisfied	very satisfied
Course of therapy sessions	0%.	0%.	0%.	100%	0%.
Benefit of PSCLAB in improving attention and stabilizing memory	0%.	0%.	0%.	100%	0%.
Benefit of PSCLAB in improving patient's quality of life	0%.	0%.	0%.	73.30%	26.70%

Table 5. Relatives' opinion about recommendation of the use of PSCLAB

Recommendation of use of the protocol.	Yes	Fair	No
	100%	00%.	00%

However, relatives report that Alzheimer's disease affects patients' and relatives' quality of life (See table 6): 56.7% of relatives estimate that it is sometimes difficult to live with AD patients; 30% estimate that it is often difficult and only 13.3% estimate that it is a lot of difficult to live with AD patients, they

recognize the burden and the handicap associated with the AD that considerably restricts their daily activities (See table 6).

Table 6. Relatives report about patients and relatives' quality of life

Does Alzheimer's disease affect patients' and relatives' quality of life?	sometimes difficult to live with AD patients	it is often difficult to live with AD patients	it is a lot of difficult to live with AD patients
	56.70%	30%	13.30%

8. Discussion

Confirming our hypothesis, the results suggest that patients' relatives seem to be satisfied with the results of cognitive language training by the PSCLAB protocol hence their opinions related to the PSCLAB are positive and partially similar.
The opinions of patients' relatives towards PSCLAB are positive and similar. These positive results are due to the correct explanation of the purpose of the protocol which corresponds to the results of recent research on the satisfaction of relatives (Whittamore & al., 2014; Jiang et al., 2019) suggesting that common reasons for family members' dissatisfaction include aspects related to the therapist-patient relationship and lack of information and communication.

9. Clinical Implication

Finally, our study emphasizes the importance for health professionals to consider the expectations of patients and their relatives in order to maximize the therapeutic alliance and efficiency of the PSCLAB.

10. Conclusion

Patients' relatives are satisfied with the results of cognitive language training by the protocol. PSCLAB seems effective in the rehabilitation of disturbed levels of language production processing in bilingual patients with Alzheimer's disease from early to medium stage, although controlled studies with larger samples may be necessary to enhance the therapeutic efficacy of this protocol.

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