

Implications of Exposure to Aphasia With No Training: The Nocebo Effect in a Controlled Trial

Aura Kagan | The Aphasia Institute
 Nina Simmons-Mackie | Southeastern Louisiana University
 J. Charles Victor | Institute for Clinical & Evaluative Sciences

American Speech-Language-Hearing Association Convention 2016



Introduction

'Nocebo' Effect – What's That?

Nocebo Effect: An adverse reaction experienced by someone who participates in a control or inactive form of treatment.

Nocebo effects might occur when participants are informed of potential side effects of a medication or procedure, or adverse effects might be created by the therapy context, participation expectations or experiences, or interactions between the participants and others involved in the research context (Hauser et al., 2012). For example, in testing a medical procedure, participants are told that discomfort is a side effect of the medication; patients on the placebo procedure experience the discomfort as described.

Rationale and Aim

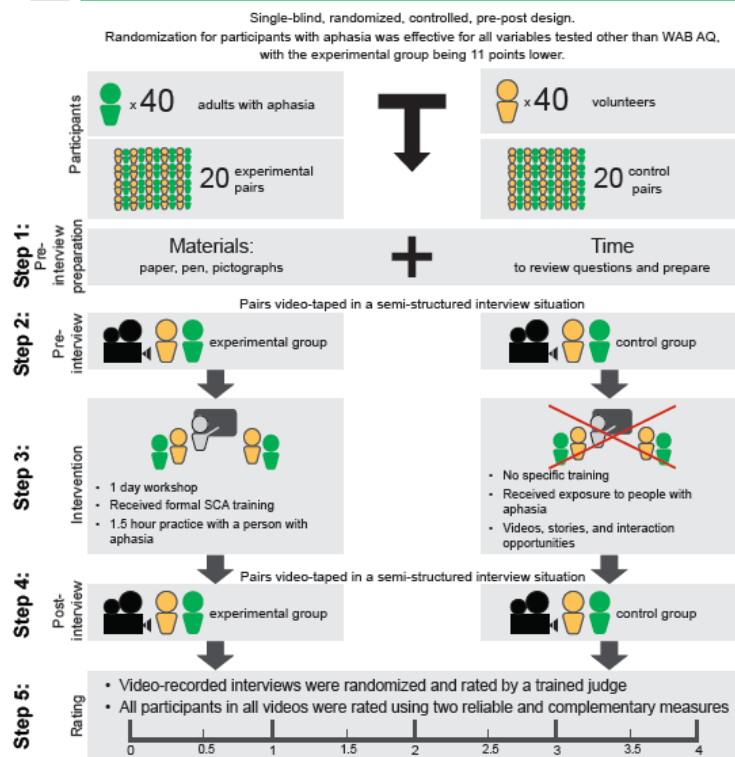
We were interested to examine more closely a possible nocebo effect in control participants who were involved in a controlled trial designed to test whether or not training in 'Supported Conversation for Adults with Aphasia' (SCA) improved the conversational skill of volunteers. Positive outcomes of training were reported for the trained volunteers and their partners with aphasia (Kagan et al., 2001), but we had an unexpected finding in relation to the control group.

Both the experimental and control groups participated in a pre-and post-intervention interview – with the experimental group receiving regular SCA training, and the control group having an exposure to individuals with aphasia in person and via video. The very reason for including a control group was to be able to attribute change to the specific intervention (SCA) as opposed to change related to just having exposure and an opportunity to learn from experience. However, this is not what happened for about one third of the control group. This provides food for thought.

Acknowledgements

Melodie Chan (Research & Development Coordinator, Aphasia Institute)
 Cristina Carnevale and Anna Huynh (Student volunteers, Aphasia Institute)
 Mannie Kagan (Personal communication)

Methods



Data Analysis

Descriptive statistics – including exact 95% confidence intervals (CI) – were calculated for the percentage of control group participants who got worse after exposure to individuals with aphasia.

Results

A number of control group participants demonstrated **WORSE** communication at the second interview. (See Table 1)

8 / 20 volunteer partners were rated **LOWER** on 'acknowledging competence'.

That is, approximately 40% volunteer partners became worse social communicators.

6 / 20 volunteer partners were rated **LOWER** on 'revealing competence'.

That is, approximately 30% of volunteer partners got worse at exchanging messages after exposure to aphasia.

7 / 20 participants with aphasia became worse in conversational interactions.

4 / 20 participants with aphasia became worse in conversational transactions.

Table 1: Control group ratings for participants who got worse at second interview

Factor	Controls doing worse	
	N	(95% CI)
Measure of Skill in Supported Conversation (MSC)		
(Rating of volunteer communication partners)		
Acknowledging competence	8/20	40.0 (19.1 to 64.0)
Revealing competence	6/20	30.0 (11.9 to 54.3)
Measure of Participation in Conversation (MPC)		
(Rating of participants with aphasia)		
Interaction	7/20	35.0 (15.4 to 59.2)
Transaction	4/20	20.0 (5.7 to 43.7)

Discussion

Expectations vs. Results

Expected: Trained volunteers improved on conversational ratings after training

Unexpected: A number of control participants demonstrated worse communication after exposure to aphasia

In other words, for a number of volunteer communication partners, nocebo effects appear to have been associated with exposure to people with aphasia through the first interview itself and/or through exposure to people with aphasia in the control condition. Moreover, results also indicated diminished conversational participation of several partners with aphasia for the control group.

Clinical Implications and Beyond

Consider the many situations in which people are 'exposed' to someone with aphasia.

In a hospital setting:

- When health care personnel experience a first interaction with someone with aphasia
- Potentially amplified impact in situations such as medical rounds where students observe interactions between patients and doctors

With families:

- Consider the potential impact on perceptions of competence and on subsequent interactions when families observe aphasia treatment

In the community:

- The behavior of laypeople who are ill-informed about aphasia might actually deteriorate with repeated, unsupported exposure to people with aphasia
- In other words, the observation of an adverse reaction among control participants suggests the possibility that initial interactions with someone with aphasia might negatively impact subsequent interactions. If this is accurate, even the lower limits of the confidence intervals in Table 1 are cause for concern since this suggests that almost 20% of partners became worse communicators.

This Begs the Question:

HOW MUCH exposure and WHAT TYPE of exposure will promote MORE POSITIVE interactions for people with aphasia?

If the results of this small study are in any way representative of what happens in real life, a focus on training of communication partners may be even more important than indicated from the positive results of training studies.

Future research is warranted to investigate this interesting and potentially important effect.

References

- Häuser, W., Hansen, E., & Enck, P. (2012). Nocebo phenomena in medicine: their relevance in everyday clinical practice. *Deutsches Arzteblatt international*, 109(26), 459-465.
- Kagan, A., Black, S. E., Duchan, J. F., Simmons-Mackie, N., & Square, P. (2001). Training volunteers as conversation partners using supported conversation for adults with aphasia (SCA): a controlled trial. *Journal of Speech, Language, and Hearing Research*, 44(3), 624-638.
- Kagan, A., Winckel, J., Black, S., Felson Duchan, J., Simmons-Mackie, N., & Square, P. (2004). A set of observational measures for rating support and participation in conversation between adults with aphasia and their conversation partners. *Topics in Stroke Rehabilitation*, 11(1), 67-83.