

A Spouse Intervention Program: Planning,
Implementation, and Problems of Evaluation

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INTRODUCTION

It has been obvious for some time now that the occurrence of neurological insult affects not only the aphasic patient but also his or her family members. The assumption is made, therefore, that not only should we concern ourselves with assisting the aphasic patient, but we should also be concerned with providing service to the entire family constellation. Those of us involved in family work find that it is most often the aphasic patient's spouse with whom we have the greatest amount of contact. While speech and language pathologists appear to have recognized the need for counseling the aphasic patient's spouse there is little published research dealing with assessing the needs of this population, developing an appropriate intervention strategy and/or measuring the effects of such a program. This may in part be due to the fact that devising an adequate design for counseling research of any type is a perplexing endeavor at best. For example, assessing the needs of a spouse group, controlling for the members to be involved in the research study, preparing the goals to be met during intervention, and attempting to measure its benefits are factors quite difficult to handle from a scientific perspective. The impetus for such research is founded within the contention that only with a precise characterization of the spouse-of-aphasic-patient population can their needs be met by those of us who are to assist them. Our investigation was a preliminary effort in this regard. The purpose of this study, therefore, was three-fold: 1) to identify specific goals for interaction with spouses of aphasic patients; 2) to involve these spouses in a prescribed intervention program; and 3) to undertake the beginnings of the development of a tool by which the effects of an intervention program for aphasic patients' spouses could be measured.

Procedures

The subjects for the study were four spouses of aphasic patients who were enrolled, during the Fall 1977 term, in a comprehensive therapy program which is part of a VA Education and Training grant at Memphis State University. Patient data, including age, sex, date of traumatic insult, and initial level of functioning based on the Porch Index of Communicative Abilities (PICA) are given in Table 1.

Table 1. Patient data including age, sex, onset-date, and PICA overall percentile at initiation of therapy.

Patient Number	Age	Sex	Onset-Date	PICA Percentile
1	45	M	1-13-77	89
2	64	F	3-7-77	66
3	52	F	2-12-77	23
4	63	M	7-2-74	43

As can be noted, three were spouses of aphasic patients of recent onset while one was the spouse of a patient who was three years post-trauma. This latter individual we loosely called our "control" since she had been involved in previous spouse groups. Although there were other spouses who at times attended the group meetings, only four were able to attend regularly, and could therefore participate in the research study. There were two male spouses, one a retired executive, one a high school educated businessman. The two female spouses were high school educated housewives although one had been formerly trained as an LPN.

In an attempt to assess the needs of the experimental spouse sample, each spouse was separately interviewed for approximately one hour during the week prior to the initiation of the intervention program. All interviews were audio-recorded. The interview format was designed to determine a set amount of information in a relaxed atmosphere. The nine primary topics covered during each interview are contained in Table 2.

Table 2. Interview format: primary topics covered.

1. Spouse understanding of trauma resulting in communicative difficulty.
2. Spouse comprehension of related terms such as CVA, stroke, aphasia, dysarthria, apraxia, and spontaneous recovery.
3. From what source information was obtained by spouse.
4. Spouse view regarding the role of the speech pathologist.
5. Spouse opinion regarding patient's prognosis for recovery.
6. Spouse view regarding post-trauma personality and mental capability.
7. Spouse mode of communication with patient.
8. Spouse view regarding role changes resulting from trauma.
9. Spouse view regarding role in therapeutically assisting the patient.

Following the interview each spouse was given a questionnaire which was developed as an objective means of determining information about the spouse prior to spouse intervention and for evaluating the effectiveness of the intervention program upon its completion. We hoped that the questionnaire could be used to quantify spouse changes which might occur during the intervention period. Although we were somewhat limited by both time and knowledge of questionnaire construction, we were satisfied with the goal of an initial attempt, which might assist in determining the needs of a more desirable questionnaire at a later date. That is, we were concerned with identifying methodological problem areas which may have been inherent in the original conception of the questionnaire so that appropriate modifications could be made in future questionnaires.

The questionnaire consisted of 50 items, prefaced with "Do you. . ." such as "Do you talk with your spouse as before the accident?". Each spouse was instructed to respond by circling the appropriate marking on a seven-point rating scale ranging from very often to never. Many items were derived from pamphlets and books which are frequently given to the families of CVA patient. Basically, the questionnaire contained seven general categories of questions:

1. Communication strategies. Many of the items which sought to determine communication strategies employed by the spouse were taken from the "do's" and "don'ts" frequently found in pamphlets for the aphasic patient's family; for example, "Do you agree with what your spouse says when you may not understand it?" or "Do you talk for your spouse when he/she has difficulty?". Eleven of the 50 items were of this type.

2. Change in life-style and social pursuits. This category contained six of the 50 items and included questions such as "Do you try to keep your spouse from other people?" and "Do you encourage friends to visit your home as before the stroke or accident?".

3. Spouse feelings in response to the patient's disabilities. In this category were questions such as "Do you become angry when your spouse cannot communicate something?" and "Do you get impatient with your spouse's speech difficulties?". There were four of these items.

4. Extent to which spouse feels he/she understands the disability. Seven of the 50 items were of this category; for example, "Do you feel you have been given enough information about strokes?" and "Do you feel the need to talk to someone about your spouse's problems?".

5. Extent to which spouse exhibits true comprehension of the disability. This category differed from category 4 in that the seven items allowed for an objective look by us at what the spouse understood regarding aphasia. Questions in this category included: "Do you think the stroke or accident resulted in a hearing loss?" and "Do you tell your spouse that his/her speech will return to normal one day?".

6. Degree to which spouse encourages patient independence. There were eight items in this category. Examples included: "Do you leave your spouse alone when you go shopping?" and "Do you encourage your spouse to pursue his/her interests and hobbies?".

7. Advice sought by spouse from professionals and friends. Examples in this category include: "Do you talk with friends about your spouse's speech difficulties?" and "Do you seek advice from your spouse's speech pathologist?". Seven of the 50 items were represented in this category.

The experimental spouse group met once weekly, for a 50-minute period,

for seven consecutive weeks. All members were in attendance for all meetings, and each meeting was audio-recorded to allow for analysis of the content at a later date. The meetings were led by the primary investigator. The functions to be served were adapted from Webster (1967):

1. to convey information that spouses of aphasic patients need in order to cope with the aphasic patient, themselves and the family;
2. to obtain information from spouses so as to better help the aphasic patient and all those concerned with the patient;
3. to help spouses clarify their attitudes, ideas and understanding of themselves, the aphasic patient and the information they are given; and
4. to help spouses experiment with ways of changing their behaviors in relation to the aphasic patient.

The approach to counseling was based on the investigator's assumption that individuals involved in groups can best be served by allowing them to take the lead with regard to questions of interest and topics for discussion. Therefore, following the establishment of a counselor-spouse contract, the groups followed a format largely determined by the spouses. Terms such as "warmth," "acceptance," "genuineness," etc., which are frequently heard in relation to most counseling, are appropriate in describing the atmosphere which the investigator/counselor attempted to maintain. At the termination of the experimental sessions, all spouses were again given the questionnaire to complete.

Results

Spouse Interviews

Although all of these spouses were in the fourth, fifth or sixth decades of their lives, only the one who was an LPN knew what a stroke was prior to the occurrence of stroke in their families. Furthermore, although these were spouses of patients who ranged from six months to three years post onset, answers to "What does stroke mean to you now?" were still quite nebulous. For example, one gentleman said "Well a stroke means something serious to me now." As to etiology, all four spouses made reference to a "blood clot." This seemed to be the one piece of information each had obtained from their physicians, but their understanding was not deep and they usually indicated this. For example, one woman said ". . . it is very vague to me how it happens, how it gets there, I mean where it comes from . . . how they move." All spouses had received pamphlets while the patient was hospitalized. Two had gone to the library and read books such as Stroke and Patricia Neal's life story. None knew the meaning of CVA, apraxia, dysarthria or hemiplegia. All four connected the term aphasia with communication but definitions were personalized to reflect each respective patient's difficulty. For example, the spouse of a patient whose difficulty was primarily expressive said, "I understand that it means that the victim practically always knows what they are trying to say but it doesn't come out the way they are trying to say it." None attempted to discriminate between mild, moderate and severe aphasia. All understood there was brain damage and three thought another area of the brain would take over the communication function. The term "spontaneous recovery" was only familiar to two spouses and each of them took the term literally. To quote the retired executive: "That all of a sudden the victim of aphasia becomes normal again." Opinions

varied regarding the role of the speech pathologist in the rehabilitation process but one spouse, whose wife was nine months post onset gave an interesting description.

I guess (a speech pathologist is) someone that is trained to encourage her to say words that she's not now saying and to boost her morale to the point that she would want to do that- improve her attitude so she would be able to help herself.

To be sure the investigator understood correctly, she probed further: "Not so much that we're here to train her to do a special thing?" He responded, "No- to encourage her."

Generally, the interviews revealed a group of individuals who were less than well-informed, who were confused regarding prognosis, who had assumed a number of new roles, who had already developed "guessing game" strategies in an attempt to communicate, and who continued to be most frustrated by the inability to converse with their aphasic spouses as pre-onset. One spouse said: "I guess the best way to put it is I miss my wife. Even though she's right beside me, I just plain miss her."

Regarding the interview format as an indicator of needs of spouses of aphasic patients it is our personal belief that there is no substitute. An unhurried time, and atmosphere in which the spouse feels free to relax and confide, an organized interview format, and a clinician skilled in communication lend themselves quite well to obtaining objective and effective information which will prove beneficial in planning a spouse intervention program.

Spouse Intervention

Analysis of the seven intervention sessions was approached in two ways: 1) how the four functions of the leader are used to contribute to an effective program and 2) the content of the topics raised by the spouses. Almost 25 years ago, Turnblom and Myers (1952) suggested that families of aphasic individuals need education regarding aphasia and the rehabilitation process. Others have advocated providing families with factual information first. Unfortunately all too frequently we, as speech pathologists, seem to view information giving as our only role. Analysis of the tapes showed that during the first of the seven sessions the investigator served the information giving function (see Webster's four functions, earlier) 80% of the 50-minute session. This finding reveals that the group members chose to use the first session as an opportunity to get some answers to questions or issues about which they were confused. Since we frequently choose to hide behind questions in uncomfortable situations, we cannot overlook the possibility that this may have influenced the overwhelming nature of this first information giving session. More likely, however, these spouses would not be able to move into new territories until a certain amount of information was obtained. The breakdown of question content for this first session included five regarding therapy and one each for referral procedure, the meaning of Broca's area, and etiology, three regarding the purpose of the group meetings and three regarding differences in patients. During each of the remaining six sessions the investigator served an information giving function at least once per session; however, it was never again the case that much information was sought by this group.

Serving the second function, obtaining information from the spouses

(Webster, 1976), occurred on only three occasions, each initiated by clinicians who desired certain information for planning therapy for the aphasic patient. Twice this was concerned with assessing the aphasic patient's independence and once regarding a psychiatric disturbance pre-onset.

The third counselor function, clarification (Webster, 1976), was the on-going role which was served by all the group members. During the final six sessions the group functioned nearly autonomously. The investigator was merely the catalyst which brought them together. Although hopefully some sense of direction was added by her presence, the group was theirs. Of 17 topics raised, 10 could be categorized as dealing with frustration regarding communication; for example, how to get the patient to understand, how to understand the patient, and continuously the desire that the patient "could only remember my name." Five of the other seven topics were concerned with patient independence: getting the patient to shop for clothes, to shave, to cook, to bathe alone, etc. The final two topics were concerned with the spouses finding time for themselves. For example, one gentleman said: "If I could just sit down in the morning and read the paper without her blah-blah-blahing for even ten minutes!" More often than not, as an issue was raised by one group member, suggestions for resolution came from other group members. The investigator served to clarify suggestions, summarize, and to lead the topic to a logical conclusion. Generally, however, spouses seemed to benefit most from one another's true-life experiences of living with an aphasic patient.

The fourth function, experimenting with ways of changing interaction with the aphasic patient (Webster, 1976), took place in the sixth session where the group role-played a spouse (husband) getting his wife to bathe alone. Although this was the only time we did on-the-spot training, on five different occasions spouses came to the group and shared their experience with trying a suggestion made during a former group meeting. We feel the goals of the counselor are sufficiently comprehensive. All the functions which were served could be readily categorized into one of the four which have been outlined. It is probably the case that in other groups the percentage of time spent serving a given function will vary. For the purposes of providing services and/or conducting research, however, we believe the functions as described are certainly adequate.

Spouse Questionnaire

You are referred once again to the title of this paper, the last part of which is "problems of evaluation." To reiterate, we considered the questionnaire, our method of evaluation, to be in its very beginning stages. Therefore we tend to take our results rather lightly. On reliability of before and after responses, 60% of all responses were the same. However, 19% of the items showed a shift of two or more points. For example, two spouses on the item "Do you think about the complexity of your own speech when you talk to your spouse?" changed their ratings from 1.0 to 6.5 and 4.0 to 7.0, respectively. Interestingly enough, the other two spouses showed shifts from 3.0 to 4.5 and from 5.0 to 6.0, and this was an information segment which had been presented to them on three different occasions. This finding indicated that the spouses were doing less thinking about the complexity of their speech than pre-intervention. As another example, two spouses in response to the item "Do you think your spouse does not pay attention to you when you say something?" shifted from 6.0 to 2.5 and 6.0 to 2.0, respectively. In other words, these spouses seemed to have grasped an essential element regarding aphasic behavior; that is, processing deficits

changed by two or more points. On nine of these 25, two subjects shifted by two or more points. On only one item, did 3 of the 4 subjects change by two or more points. This was "Do you encourage friends to visit your home as before the stroke or accident?" All three shifted in the direction of decreasing frequency of this behavior during the intervention period. Therefore, nine of 50 items showed a tendency to detect change of two or more points for more than one of four subjects. While in any seven week period, only so much information will be given and only so many topics raised, in revising the questionnaire we will want to concentrate on items which will best reflect the types of behavioral changes which are realistic to expect, and which are measurable to a two-point shift.

We believe a questionnaire such as this has potential for pre-post and ongoing assessment of the spouse counseling process. We offer these suggestions which we hope to implement, to improve the questionnaire.

- 1) Clearer definitions of subject matter to be covered are needed. The questions must be constructed to clearly relate to each area so that answerable hypotheses can be developed and related to possible response patterns.
- 2) The number of questions per area or variable must be equated.
- 3) The responses should be operationally defined so that changes can be interpreted as desirable or undesirable.

Whether scientific measurement is indeed even possible remains to be seen. Intervening variables are difficult to control. The need for continuing spouse intervention seems clear enough, however. We are now quite aware that emotional disturbances in the family will be reflected in the patient's outlook and motivation. Groups such as we've described help these spouses in ways that vary tremendously and may never be completely measurable. Closing with some words passed on by a group member during our final session:

It's nice to find out you're not alone. You get ideas in here of ways to cope. I've learned to enjoy my wife in spite of her stroke. I feel closer to her now.

References

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Discussion

- Q. Could you elaborate on why you think spouses decreased thinking about the complexity of their speech post-intervention?

- A. It seems that perhaps one of the benefits of involvement in a program such as this is acquiring the knowledge that the aphasic patient is capable of a higher level of communication than the spouse may have thought previously. Additionally, particular types of speech modifications were stressed time and again, each being germane to a different patient-type. Hopefully, the spouses learned appropriate ways in which to simplify their speech rather than oversimplification in response to their respective patient's processing deficits.
- Q. Did you say you tape recorded the seven sessions?
- A. Yes, I did.
- Q. What about taking questions from the tapes and including them in a revision of the questionnaire? Include those which might be considered positive attitudes and those which might not be.
- A. The problems remain quite the same. Are the seven sessions representative? What is a "positive" comment? What is not?
- Q. You commented that after the initial session spouses did not seem to want information. Would you agree they needed more information?
- A. No, I don't. Until recently I would have agreed that these individuals needed more information to enable them to better cope. However, Hatzenbuehler and Webster found that spouses of patients no longer in therapy reported that information had not been important to them. For example, to paraphrase, one spouse had reported "So what if you understand it was a bloodclot? It doesn't make his hand normal or his legs begin to walk again."
- Q. I'm talking more of information for coping techniques, facilitative communication, etc.
- A. We may be dealing here with a semantic issue. Perhaps some of what we refer to as clarification could be otherwise termed providing information, where we are dealing with coping mechanisms. Generally, however, the spouse's perspective was given the utmost priority and although alternatives were discussed, the spouse made the choices. Consequently, we do not view this as information giving per se.
- Q. It is amusing that your spouses were searching for communication techniques when we have often lamented the fact we cannot coerce spouses we see to use such techniques.
- A. To clarify this, understand that these spouses did not report a desire for new communication techniques; rather they often spoke of the frustration that they feel because of the inability to communicate with their respective patients as pre-onset.
- Q. An interesting aspect of this is that spouses are frequently not seen for at least one month post-onset. It might be helpful to utilize the concept of crisis-intervention teams who could go in immediately to work with the whole family the day of, or after, the stroke.
- A. This would perhaps be similar to the manner in which speech pathologists deal with the laryngectomy patient pre- and post-surgery.
- Q. It seems to me that many spouses do well from a communication standpoint without any intervention. These were probably involved in well adjusted relationships pre-onset. It would seem we would have a lot to learn through observation of these spouses in their home environment, to see what works for them. These data could be used to counsel others.
- A. It remains the case that generalizations would be difficult to make. Certainly in matters of this type, however, natural observations may be important.
- Q. I am concerned that some marital relationships were so bad pre-onset that the condition is irreversible.

- A. I don't think that I would ever look at it as irreversible. Primarily because I am not viewing my work as an attempt to change the marital relationship. It may be the case that just as we see negative pre-onset personality traits amplified in the patient, we may observe the same phenomenon in the spouse. One of the reasons I see for a spouse to be involved in a group is to allow himself or herself to cope better regardless of the marital condition pre-onset, although such may affect the outcome. It may, however, be the impetus for improvement through the group interaction.

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