

Analysis of Positive Outcomes Experienced by
Caregivers of Adults with Aphasia

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REVIEW OF LITERATURE

A sizable body of research has explored various dimensions of taking care of someone with a chronic illness. This has resulted in the development of intervention studies designed to reduce negative aspects of caregiver stress (Kramer, 1997). Scientific studies that have focused more specifically on stroke-induced aphasia have also demonstrated the extreme effects of this condition on individuals and their families. Ongoing research at UCLL and elsewhere has begun examining in a broader fashion at positive dimensions of psychological function and the notion that individual differences in the caregiver experience are actually the norm (Greenburg, et al., 1993).

Current studies have focused on comparing the effectiveness of specific interventions designed to decrease caregiver stress and have begun identifying the dimensions of positive well-being associated with some caregivers. The specific challenges in the aphasia field have to do with the inability to communicate effectively with loved ones and the multiple role changes in families who experience these illnesses (Servaes, et al., 1999). Studies have found a host of negative consequences of caregiving including, “depression, anxiety, physical strain, social isolation, and conflict in family and marital relationships.” These factors have also

been shown to increase caregiver morbidity and mortality, and decrease subjective well-being (Servaes, et al., 1999). Nonetheless, caregiving is essential in providing rehabilitation to stroke patients and therefore understanding the stress and the negative effects of being a caregiver is crucial (Cumming, et al., 2008).

Studies have shown that the amount of caregiver strain has been linked with an unsupportive social circle, age, and gender. It has been found that caregivers who are older and female have greater intensities of anxiety and depression (Dennis, et al., 1998). Ryff (1989) specifically examined positive contours of well-being and cited six dimensions which include, "personal growth, purpose in life, autonomy, environmental mastery, positive relations with others, and self acceptance." Kramer's (1997) literature review of positive dimensions of caregiver experience shows that many respondents found greater meaning in life as a result of helping a loved one. 90% of respondents of another study looking at how caregivers grow reported that through caregiving they found meaning in life (Farran, et al., 1991).

Caregivers who started at earlier and spent more time engaged in caregiving activities experienced greater behavior uplifts (Kinney and Stephens, 1989). Caregiver strain scores (Care Work Satisfaction Scale)

were higher when difficulty with tasks and behavioral issues was greater (Orbell and Gilles, 1993a) There is also a suggestion that with greater time post stroke, caregivers may become more adjusted to the role of caregiving. One study reported a decrease in caregiver strain 3 years post-stroke (Visser-Meily, et al., 2008). Another recent study found that 14 or more hours a week of caring for a spouse is connected to a significant decrease in caregiver mortality (Brown et al., 2009).

Subjective well-being is an essential part of quality of life; It is how well the physical, emotional, and psychological needs of a person are being maintained. Subjective wellbeing is linked with success, jubilation, and utility of a person (Constanza, et al., 2008). Caregivers often make their loved one's needs first priority. Their own needs become secondary, which in turn impacts their subjective wellbeing and quality of life. Caregivers of patients with aphasia are shown to have significantly lower personal well-being than caregivers of stroke patients without aphasia (Forsberg-Wärleby, et al., 2004).

One study looking at an aphasia caregiver support group, found that the crucial parts of peer learning, respite for position as caregiver, and a relaxing and secure environment allowed caregivers to feel a sense

of strength and new community, an improved state of being, and a greater degree of acceptance (Fox, et al., 2004).

With all of these studies highlighting the positive as well as negative dimensions of the caregiver experience, this study seems particularly valuable as an extension of the exploration of factors associated with caregiver wellbeing. This study is primarily interested in the attitudes and expectations of individuals in this role and over time hope that further research will explore the behaviors and possibly psychophysiologic responses of a comparable group.

OBJECTIVE

This study was done to provide a better understanding of the strain and subjective wellbeing experienced by caregivers of persons with aphasia and the positive aspects of caregiving. The hypothesis includes many parts:

1) Overall, the average score will be above 3. This will mean that caregivers experience positive aspects of caregiving.

2) The greater time post onset (TPO), the higher the scores will be on the questionnaire. Caregiving can be looked at like a skill, which improves over time.

3) Profile 2 (partially independent) of communication dependency will report the highest scores. The extremes of either profile 1 (independent), or profile 3 (partner dependent) will produce lower scores. Patients who are very independent may be both impaired and yet hard to manage. Caregivers may worry more when their loved one is out in the world. When patients are partner dependent, one would expect no free time for the caregiver and less closeness due to the lack of communication.

METHODS

This study will examine the relationship between time post onset of aphasia and communication dependence level on the report of the positive aspects of caregiving. This will be done using correlations and ANOVAs.

A questionnaire was created with respect to previous research. It focuses on the positive dimensions of caregiving. The questions emphasize the six dimensions of positive wellbeing (Ryff, 1989).

- Question 8, “Caring for my loved one with aphasia has led to greater self-acceptance,” looks at self-acceptance.
- Questions 6, “Caring for my loved one with aphasia has developed my character,” as well as question 10, “Through my experiences as a caregiver I have learned valuable lessons about myself and others,” addresses personal growth.
- Question 12, “I realize that I enjoy giving more than receiving,” and question 1, “I feel good about the time I spend helping my loved one with aphasia,” focus on positive relations with others.

The likert scale was used on questionnaire. (1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, and 5 = Strongly Agree).

The first part of the study included selecting patients enrolled in UCLL from the past year and a half. They had to have a legitimate caregiver and have evaluated aphasia. Questionnaires were sent out with prepaid envelopes for their return. Upon response data was entered into excel tables with each variable and question separated.

All analyses will be calculated for the entire group as well as with respect to individual characteristics. This will allow us to determine

whether, for example, caregivers with a longer time post onset of stroke experience a lesser degree of strain in their role as caregiver. In addition to time post onset, other demographic variables including age, gender, relationship to client, number of sessions attended, etc. will be analyzed.

Once data was entered, the relationship between time post onset of aphasia and communication dependence level was examined using correlations and ANOVAs. Frequencies and standard deviations were run to describe the data. Correlations with two continuous variables were done to measure significance and presence of correlations. To look at the hypothesis concerning profile levels, bar graphs were employed to clearly show which communication dependency profile produced on average the highest score.

The questionnaire was mailed to 76 patients. The final number of respondents was 15 participants. This response rate was 19.7 %. The caregiver and client genders, relationship to client, aphasia types, and communication dependency levels can be shown in Table 1 below.

TABLE 1
Characteristics of Study Population (N = 15)

		Client Gender			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	female	6	40.0	40.0	40.0
	male	9	60.0	60.0	100.0
	Total	15	100.0	100.0	

		Relationship To Client			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	spouse	13	86.7	86.7	86.7
	parent	2	13.3	13.3	100.0
	Total	15	100.0	100.0	

		Caregiver Gender			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	female	10	66.7	66.7	66.7
	male	5	33.3	33.3	100.0
	Total	15	100.0	100.0	

		Aphasia Type			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Global	1	6.7	7.1	7.1
	Broca's	1	6.7	7.1	14.3
	Wernicke's	2	13.3	14.3	28.6
	Conduction	4	26.7	28.6	57.1
	Anomic	6	40.0	42.9	100.0
	Total	14	93.3	100.0	
Missing	System	1	6.7		
Total		15	100.0		

Note. Types of aphasia vary. Global aphasia is characterized by difficulty understanding and forming words and sentences. Broca's aphasia is characterized by difficulty forming complete sentences. Wernicke's aphasia is characterized by severe comprehension difficulties. Conduction aphasia is characterized by difficulty with speech and repetition. Anomic aphasia is characterized as difficulty selecting words to use. (Jakobson, 1966).

		Communication Dependency Level			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Independent	3	20.0	20.0	20.0
	Partially Independent	7	46.7	46.7	66.7
	Partner Dependent	5	33.3	33.3	100.0
	Total	15	100.0	100.0	

Note. These descriptive frequencies categorize the subjects based on gender, relationship to client, aphasia type, and communication dependency level.

RESULTS

Hypotheses 1, stating that the average score will be above 3, was shown true for all questions except for question 8, “Caring for my loved one with aphasia has led to greater self-acceptance.” Table 2 shows how the mean score for this question was 2.93 whereas all other mean scores were greater than 3.

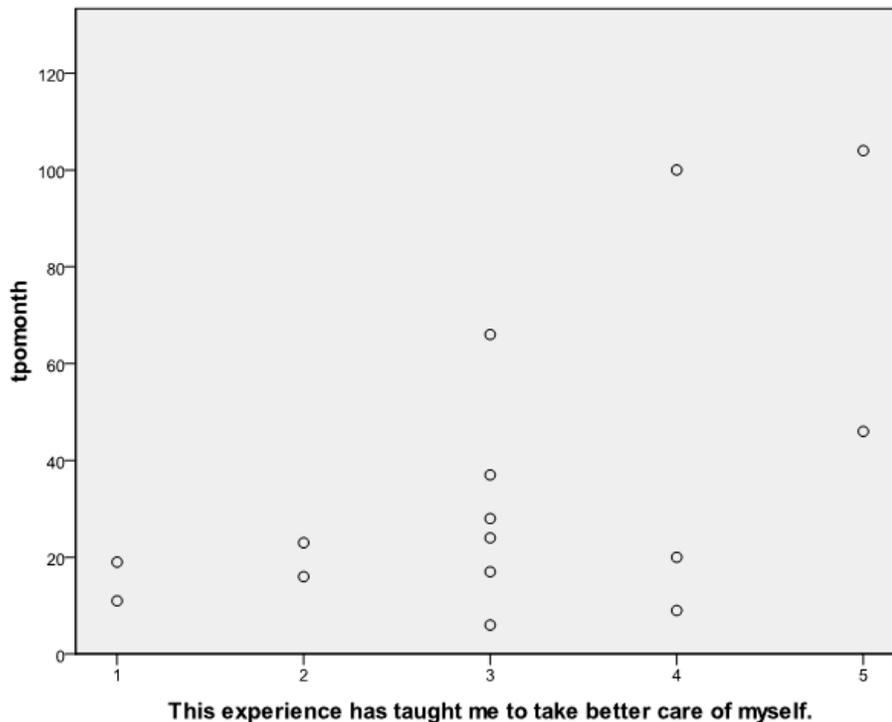
TABLE 2
Mean Scores

	N	Minimum	Maximum	Mean	Std. Deviation
I feel good about the time I spend helping my loved one with aphasia	15	3	5	4.40	.632
Being a caregiver has taught me to live in the moment.	15	3	5	4.07	.961
This experience has taught me to take better care of myself.	15	1	5	3.07	1.223
This experience has made me feel appreciated.	15	2	5	3.53	.915
Being a caregiver has given me purpose in life.	15	2	5	3.07	.799
Caring for my loved one with aphasia has developed my character.	15	3	5	3.80	.676
I feel closer to my loved one with aphasia as a result of caring for him or her.	15	2	5	3.60	.910
Caring for my loved one with aphasia has led to greater self-acceptance.	15	2	4	2.93	.704
I feel confident looking forward that I can handle my caregiver responsibilities.	15	3	5	4.27	.704
Through my experiences as a caregiver I have learned valuable lessons about myself and others.	15	3	5	4.13	.516
I enjoy feeling needed by my loved one.	15	1	5	3.27	1.100
I realize that I enjoy giving more than receiving.	15	2	5	3.67	.816
Valid N (listwise)	15				

Note. Likert scale ranges from 1 – 5.

In hypothesis 2, which states that the greater time post onset (TPO), the higher the scores will be on the questionnaire, when correlations concerning time post onset and each individual question were conducted, only question 3, “This experience has taught me to take better care of myself,” revealed statistical significance. The correlations found the Sig (2-tailed) to be .033 and the Pearson correlation to be .552.

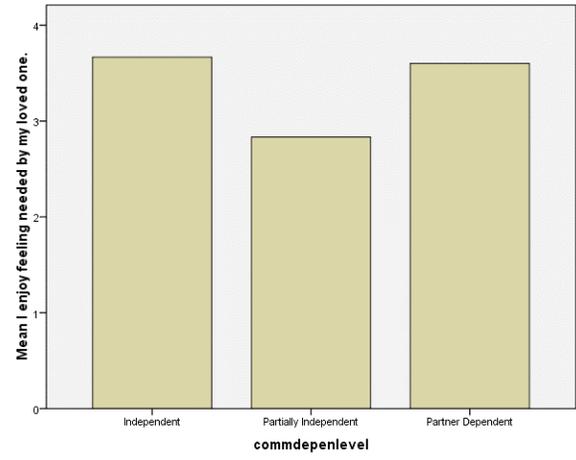
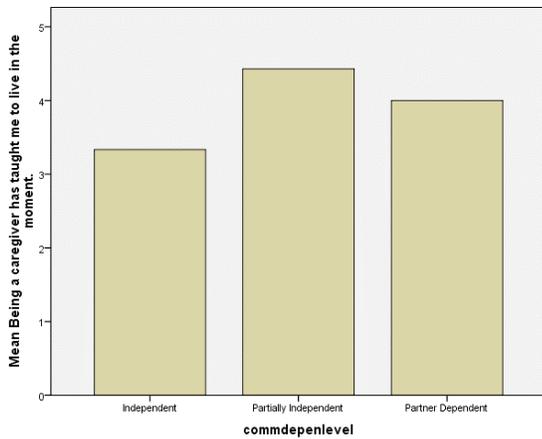
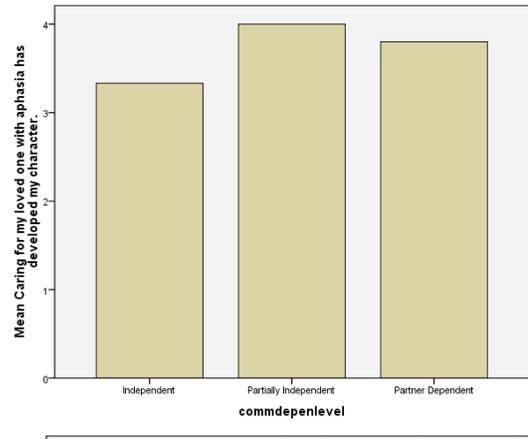
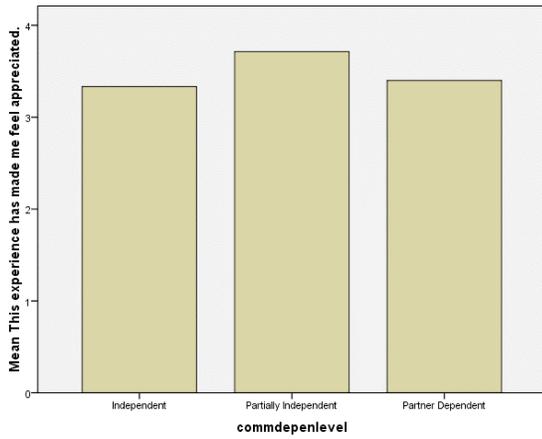
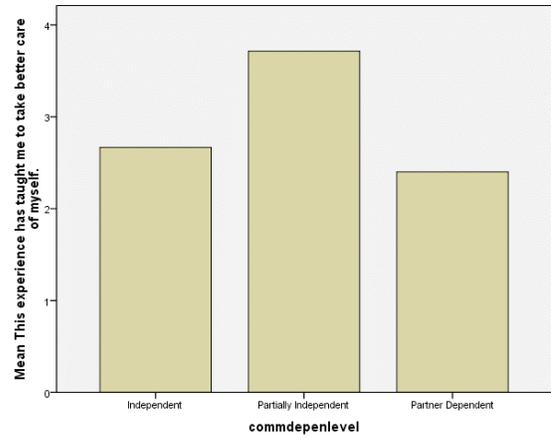
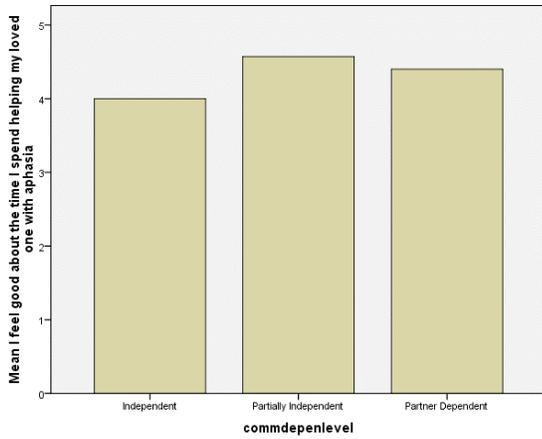
TABLE 3
TPO and Q3 Correlation



Note. Scatter plot is shown. 0.552 is a positive number so as TPO (Time Post Onset) increases, the responses to the questions increase.

Hypothesis 3, which stated that communication dependency Profile 2 (partially independent) will report the highest scores, was shown true in questions 1, 2, 3, 4, 6, and 11 profile 2.

TABLE 4
Communication Dependency Level Bar Graphs



DISCUSSION

The majority of studies done on caregivers of adults with aphasia focus on caregiver “strain” (Servaes, et al., 1999). These studies highlight how depressing and demoralizing it is to take care of someone who cannot communicate. These reports describe the psychophysiological consequences of being a caregiver (e.g. depression, increased mortality and morbidity) and look at different components and degrees of communication difficulties (Ryff and Keyes, 1995).

This study is associated with the counterintuitive smaller set of studies that described how some individuals with a certain set of values actually seemed to feel good about helping their loved ones.

In this study hypothesis 1, stating the average score for the questions will be above three, was shown true for all questions except for question 8. This question dealt with self-acceptance. Considering most of the other questions focused on the interactions a caregiver has with their loved one and the impact of their caregiver responsibilities, a possible reason why the mean score was below 3 could be the fact that it was primarily about the caregiver and their own initial beliefs. If a person has little self-acceptance to begin with it is only natural that constantly taking care of a

loved one would not increase it. The other results present great potential since they achieved the primary focus of the study, to determine if there was a positive side to caregiving.

Hypothesis 2, that the greater time post onset (TPO), the higher the scores, found statistically significant results for Question 3, “This experience has taught me to take better care of myself.” The analysis showed that the greater time post onset (TPO), the higher the scores. Considering caregiving can be looked at as a skill, and thus improving over time, it is possible that since a caregiver gets more efficient in taking care of their loved one throughout a greater span of time, they in turn are able to take better care of themselves.

Hypothesis 3, which stated that communication dependency Profile 2 (partially independent) would produce the highest scores, displayed very mixed results. Question 1, “I feel good about the time I spend helping my loved one with aphasia” found profile 2, partially independent, received the highest scores. Since the aphasic person would not be completely dependent on their caregiver yet still need help in some aspects of communication, the results are extremely plausible. Question 11, “I enjoy feeling needed my loved one,” yielded the same results. It is possible that because there is a balance between having the loved one rely on the

caregiver and not having to rely on the caregiver, the relationship that exists is less stressful and more positive. Questions 2, 3, 4, and 6 also displayed similar results. Each question deals with issues concerning time spent with the loved one. Question 4, "This experience has made me feel appreciated," shows how considering the loved one is not entirely dependent on the caregiver, the caregiver feels needed and valued but is not resentful of the dependence.

The biggest limitation in the study was the number of participants. With a larger number of responses, there is great evidence in the current findings that there could be statistical significance. Another limitation was the amount of time available to conduct the research as well as the means of sending out the questionnaire. The questionnaires were mailed out. If a person receives it and puts it aside that first day, it is very unlikely that they will ever come back to it. Another limitation is the sacrificing of personal information required of the patient at UCLL. Many participants did not understand the significance of this information and were insecure concerning how anonymous it would stay. The questions were also extremely personal. Some participants greatly enjoyed filling out the questionnaires and liked the shift in attention to the caregivers but others felt the questions too invasive.

CONCLUSION

This study cemented several ideas for future research concerning communication dependency level and time post onset in relation with personal growth in caregivers. Caregiving is an extremely important job. It is very unrecognized in today's society. Research on caregivers is crucial to the expansion of treatment methods (Toseland and Rossiter, 1989). Research regarding caregivers of aphasic patients is especially important considering the knowledge of relationships with a lack of communication could greatly change the way one perceives human behavior and possibly add to research in psychology.

This study shows great prominence in field of caregiving and sets focus for future research in the same area. Since several people regard caregiving positively, as shown in this study, these results can be applied to programs designed to reduce caregiver stress. Caregivers who view caregiving positively could teach people who do not. They would be able to show how their positive caregiver reactions apply to people who are struggling.

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