



Alexithymia, the Emotional Blindness among Stroke Survivors: A Preliminary Study

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Author's contribution

The sole author designed, analyzed and interpreted and prepared the manuscript.

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ABSTRACT

Stroke patients suffer from emotional disturbances. Alexithymia is a common impairment after stroke. To date, no Arabic study has examined the potential comorbidity of alexithymia and stroke in a rehabilitation outpatient setting.

Methods: Quantitative and qualitative methodologies were used to collect information from stroke survivors. Subjects were recruited from the outpatient rehabilitation clinic at King Fahad Medical City - Rehab Hospital (KFMC-RH), during their follow up.

Results: Stroke survivors (n= 33) were compared with healthy control subjects (n= 35) on the Toronto Alexithymia Scale-20 (TAS-20); Hospital Anxiety and Depression Scale (HADS); and the Short Form Health Survey (SF-36) of Quality of Life (QoL). Alexithymia was significantly associated with stroke survivors. Alexithymia was reported to be a predictor of poorer QoL, even when depression and anxiety were controlled. Qualitative studies (n=15) followed, in order to obtain in-depth information about post-stroke alexithymia. Emotional change was one of the most frequently voiced complaints of stroke survivors and their caregivers.

Conclusions: The conclusion encourages the assessment of alexithymia in rehabilitation settings for stroke survivors. Increased awareness of the potential mediating role of alexithymia in post-stroke psychological symptoms will facilitate effective diagnoses and better rehabilitation intervention for better outcomes.

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1. INTRODUCTION

Alexithymia was first defined as the lack of words to express feelings. Alexithymic people cannot utter their feelings naturally and show a level of emotional blindness and empathy deficits. Alexithymia includes having difficulty in fantasizing and symbolically expressing, and it was formulated to be a dysfunction of defining emotions [1] and disturbances in behavior and thinking [2], including difficulties in identifying, describing, and discriminating feelings from bodily sensations of emotional arousal [3].

Alexithymia has a high prevalence in patients with certain medical illnesses and a possible correlation with neurological dysfunctions [4]. Although the causes of alexithymia are unknown, it has been suggested to be acquired or secondary to unspecified brain damage such as stroke [5-7].

Stroke is a condition that requires long-term management and strategies which address psychological treatments and psychological rehabilitation [8]. Many stroke survivors do not make a full recovery from their stroke and are left with residual long-term consequences, such as limitation of physical fitness, psychological symptoms, impaired cognition, and other post-stroke symptoms [9].

Emotional changes are a frequent and lasting complaint voiced by families of stroke survivors [10]. Depression and anxiety have received particular attention [11], whereas other emotional problems which follow stroke, such as emotional ability [12], or an inability to control anger and aggression have been relatively less investigated [13].

Several previous studies concluded that stroke is associated with reduced life satisfaction and QoL [14,15]. However, several of the factors that could predict QoL post-stroke need to be clarified; the alexithymia role needs to be tested. To date, no study has explored the potential relationship between alexithymia and QoL post-stroke. This is a very important factor to be examined, given that alexithymia has been connected to increased depression and reduced social integration [16].

To date, the relation between alexithymia and stroke remains unexplored. Identification of

reliable correlation between stroke and alexithymia could not only aid the diagnostic process, but could also influence intervention of associated disorders.

2. RESEARCH METHODS AND PROCEDURES

2.1 Sample

The purposive sampling technique was used to recruit typical patients with definite criteria for exclusion or inclusion as participants. All stroke survivors from the outpatient rehabilitation clinic, KFMC-RH in Al-Riyadh capital city, Saudi Arabia, were identified. To be approached by the researcher for inclusion into the study, A) patients had to have suffered a stroke at least three months prior; B) over age 18; C) able to submit consent; D) have a normal mental state, obtaining a minimum score of 27 according to the Montreal Cognitive Assessment (MoCA) [17]; E) have no history of psychological problems; and F) agree to be interviewed. This is only for the qualitative sample, those who will be interviewed with their caregivers. Those with severe dysphasia, confusion and those who were medically unstable due to another medical condition were excluded. Patients were informed that this survey was not related to their treatment program. The right to participate and confidentiality were assured.

The primary quantitative study approached 52 stroke survivors. There were 12 patients – 4 males and 8 females – who refused to participate. The main reason given by those who refused was discomfort about discussing their emotional problems, and some refused without giving a reason. There were 7 stroke survivors who did not meet the inclusion criteria (Table 3). The final sample was composed of 33 stroke survivors, 25 males and 8 females, ranging between 25 and 64 years ($M= 46.2$, $S.D. = 11.3$). The time after discharge from the inpatient stroke rehabilitation wards is between 3 and 11 months ($M= 6.5$, $S.D. = 1.8$). None of the inclusion patients reported a history of psychological problems before their stroke. There were 35 healthy participants (27 males, 8 females) who served as controls. The 66% of control participants were caregivers of the stroke survivors. The remainders were recruited from King Khalid University. Finally, the qualitative study approached 15 stroke survivors with their

caregivers. There were 11 males and 4 females from 41 to 58 years. They were discharged from the inpatient rehabilitation services at least 3 months up to 20 months before this study. All of them were interviewed, along with one of their close family members.

3. ASSESSMENTS

3.1 Toronto Alexithymia Scale (TAS-20)

This is a self-assessment scale of 20 items, 5-point Likert; high point indicates a high alexithymic level. Total scores ≥ 61 are categorized as the cut-off recommended for clinical alexithymic [18]; while scores of 52–60 are moderate alexithymic; and scores below 52 are non-alexithymic [19]. The TAS-20 is a reliable and valid measure of emotional processing in adults, and includes total score (TAS) and three subscales: Difficulty Identifying Feelings (TAS-DIF), Difficulty Describing Feelings (TAS-DDF), and Externally-Oriented Thinking (TAS-EOT). The TAS-20 has been translated and validated in more than 19 languages [20], including Arabic [21]. The TAS-20 reliability for this study was determined as Cronbach's alpha .87.

3.2 The Hospital Anxiety and Depression Scale (HADS)

A brief scale, the Hospital Anxiety and Depression Scale (HADS), was utilized in this study to clarify the relationship between depression/anxiety and alexithymia. The HADS has 14 items in two subscales, one for anxiety and one for depression, and each question is rated from 0 to 3. High score indicates a high level of depression or/and anxiety. The validity and reliability of the Arabic version of HADS have been confirmed previously [22]. For this study, Chronbach's alpha for the total, anxiety and depression scales were .92, .89 and .87, respectively.

3.3 Montreal Cognitive Assessment (MoCA)

The brief cognitive instrument that was selected for the current study was the Montreal Cognitive Assessment (MoCA), which is designed to detect subjects with mild cognitive dysfunction. The MoCA may be more sensitive than other general screening instruments [23]. The MoCA is a one-page test with a maximum score of 30 points and cutoff point of 26. The MoCA has been translated and validated in several languages, including

Arabic [17]. The MoCA reliability for this study was determined as Cronbach's alpha .86.

3.4 The Short Form Health Survey (SF-36)

Stroke survivors' perceptions of their health-related QoL were measured by the Arabic version of the SF-36 Health Survey [24]. The SF-36 is the most widely used instrument to assess health-related QoL [19]. It was developed by Ware and colleagues in 1995 [25]. The SF-36 is 36 questions, clustered to yield 8 health status scales. The SF-36 scores are linearly converted to a 0 to 100 scale, with higher scores indicating higher levels of functioning or QoL. Chronbach's alpha for the total scale is .93.

3.5 Statistical Analysis

Data were analyzed using SPSS for Windows. A probability (P) value of .05 was considered statistically significant. All values are reported as the mean (M) and standard deviation (S.D.) unless otherwise stated. Preliminary analyses examined the presence of outliers and the assumptions of normality, linearity, and homoscedasticity, and unless stated otherwise, parametric analysis was performed on the data set. The baseline characteristics were compared between the two groups using the chi-square (χ^2) and ANCOVA for categorical variables and comparison between the two groups in alexithymia. Analysis of (T-test) was performed to further investigate the three cut-off levels of the alexithymia, TAS-20, and between the two groups. Hierarchical regression techniques were performed to investigate the relationships between alexithymia, anxiety, depression and SF-36.

3.6 Qualitative Data

The current study used a combined procedure of integrating quantitative and qualitative methods in order to have full investigation about stroke survivors emotional issues post-stroke.

Stroke survivors were told the survey was interested in finding out more about their emotional feelings and experiences post-stroke. Open questions as well as prompting questions were used to have in-depth information from stroke survivors and their caregivers (Table 1).

The method of analyzing qualitative information was inductive. The five-step (see Table 1) thematic framework approach was utilized to

categorize the in-depth interview information from patients and their caregivers into transcripts [26]. Transcripts and categories were examined to ensure the data connected to each category. Data was linked to category headings and agreement was ensured. Quotes were selected to summarize and illustrate the patients' or their caregivers' points of view about their emotional experiences post-stroke.

4. RESULTS

4.1 Results of the Quantitative Study

The stroke group was constituted mostly of males (75.80%), and most of the patients were married (60.60%). As observed in Table 2, no statistical differences were found between gender, age, educational levels, occupational status and MoCA. But, there was a difference in marital status ($\chi^2=11.069$, P .000).

As it can be seen in Table 3, the stroke group and the control group were divided into three levels based on their TAS-subcales. The stroke group reported a significantly higher level of clinical alexithymia (66.6%). Also, they reported more moderate alexithymia (27.27%) and less non-alexithymia (6.10%). Alexithymia in the stroke group was significantly different from the control group proportion ($t= 7.124$, P .0001).

Table 4 summarizes M and S.D. on the TAS subscales, HADS and SF-36 for the stroke patients and the control subjects. According to the effect sizes, stroke patients reported more alexithymia on all subscales of the TAS-20, with effects ranging in magnitude from ($d=.38$) for the subscale TAS-DDE to ($d=.72$) for full scale of the TAS-20. The stroke group also reported being strongly more depressed than controls ($d = .74$), and more anxious ($d = .23$).

Table 1. Illustration of the five steps thematic approach with questions guide for interviews

The five-step thematic framework approach	Interviews' questions guide
1 Step 1: Familiarization with the raw data. 2 Step 2: Thematic framework and drawing concepts 3 Step 3: Indexing by coding themes. 4 Step 4: Charting 5 Step 5: Interpretation by abstraction and synthesis	1. In general, what do you regard as the most important characteristics of what we may call "emotional symptoms", post-stroke? 2. Have you been more tearful in the past months than you were before your stroke? What is your experience about this? 3. Have you been unable to stop yourself crying in front of other people? Is that a new experience for you? 4. Could you please describe a typical case history of your child? 5. Is it difficult for you to find the right words for describing your feelings? Why has this happened? 6. Have you been more upset or angry in the past months than you were before your stroke? Describe your experience. 7. In your own words, describe your emotions and feelings post-stroke. 8. Does weepiness come suddenly at times when you aren't expecting it? If yes, why?
	<p>Probes:</p> <ul style="list-style-type: none"> • How have these issues affected your symptoms? • Why do you think this could make your recovery your child's problem? • Did your doctor inform you about post-stroke emotional issues? • What do you think about that?

Table 2. Social demographics and the characteristics of stroke patients vs. healthy control subjects

Demographic		Stroke survivors (n=33)		Control subjects (n=35)		Significance Tests (P)
		n	%	n	%	
Gender	Male	25	75.80	27	77.14	X = 1.073 (0.290)
	Female	8	24.24	8	22.90	
Educational level	Primary	8	24.24	8	22.90	X = 3.913 (0.081)
	High school	16	48.50	15	42.90	
	University	9	27.30	12	34.30	
Occupational status	Employed	22	66.70	21	60.60	X = 4.811 (0.061)
	Unemployed	7	21.21	8	22.90	
	Retired	4	12.12	6	17.14	
Marital status	Single	9	27.27	17	48.60	X = 11.069 (0.000)
	Married	20	60.60	9	25.71	
	Divorced	1	1.03	6	17.14	
	Widowed	3	9.09	3	8.60	
Age	Mean (SD) -Range-		46.2 (11.3) 25-64	48.6 (8.5) 26-57	t= 2.870 (0.130)	
MoCA	Mean (SD) -Range-		28.1 (1.0) 27-30	29.7 (0.20) 29-30	t= 1.340 (0.170)	
Affected hemisphere	Right-sided lesions	14	42.42			X = 2.017 (0.192)
	Left-sided lesions	19	57.57			
Type of stroke	Ischemic	28	84.84			X = 1.433 (0.223)
	Hemorrhagic	5	15.15			

Table 3. Alexithymia comparison between the two groups: Stroke survivors vs. healthy controls subjects

TAS-20	Stroke (n=33)		Control (n=35)		t. test (p)
	n	%	n	%	
≥ 61 ^a	22	66.67	3	8.61	
52-60	9	27.27	5	14.30	7.124
≤ 51	2	6.10	27	77.14	(.0003)

^a Clinical alexithymia

ANOVA carried out in order to investigate the differences between stroke patients and the control group in the TAS-subcales, HADS and SF-36. As it is shown in Table 4, stroke patients reported significantly more alexithymia in the total scale TAS-20 (F= 6.74; P 0.006), but no significant differences between the two groups in the other TAS-subcales. The stroke group again reported significantly more depression (F= 7.23; P 0.003), but no significant differences between the two groups in the anxiety subscale. As was expected, the stroke group scored lower in QoL according to SF-36, with significant negative correlation (F= 6.11; P 0.001).

As shown in Table 5, hierarchical regression analysis was performed across stroke patients and control subjects in order to examine the

extent to which SF-36 variance could be explained by TAS-20, TAS-DIE, TAS-DDE and TAS-EOT scores. Depression and anxiety scores were entered as the first and second predictors in each of the regression analysis, in order to explain that shared variance. Then, each step was followed by an entry into one of the TAS-20 subscales. These analyses were also conducted for both the stroke and control groups. The results indicate that, in addition to the depression and anxiety scores, the total score of TAS-20 and only the subscale TAS-DIE are significant predictors for SF-36 variance. Significant amounts of variance were, F(1, 68) = 1.364, P 0.018 and F(1, 66) = 4.211, P 0.001, respectively. The other TAS-subcales were also entered in analysis 3 and 4, but these did not make a significant unique contribution. The results are presented in Table 5.

4.2 Results of the Qualitative Study

During the analysis of the stroke survivors' perceptions about the emotional and psychological issues they faced after stroke, three themes were classified: social cognition, personality, and emotion. These themes were reported together by patients and their caregivers.

Table 4. TAS-20, HADS and SF-36 scores for stroke survivors vs. healthy controls subjects

Scales		Stroke survivors (n=33)		Control subjects (n=35)		Effect sizes <i>d</i>	ANOVA <i>F</i> (1, 65) (P)
		M	SD	M	SD		
TAS-20	TAS	68.2	6.71	46.2	5.63	.72	6.74 (.006)
	DIF	21.5	4.39	15.1	4.02	.61	6.83 (.004)
	DDE	13.7	3.30	10.7	2.84	.38	4.01 (.043)
	EOT	17.8	3.12	13.6	4.83	.58	5.31 (.021)
HADS	Depression	11.3	2.90	5.32	2.01	.74	7.23 (.003)
	Anxiety	7.7	4.82	3.42	1.72	.23	2.04 (.314)
SF-36		47.2	9.91	62.7	5.32	-.56	6.11 (.001)

Table 5. Hierarchical regression analysis: HADS: Anxiety, HADS: Depression, TAS-20 sub-scales and SF-36

	Variable set	R	R ²	R ² change	F change	B	B_ value	t_ value
Analysis 1	Step 1: Depression					0.618	4.731	0.011
	Step 2: Anxiety	0.781	0.570	0.016	1.364	0.098	0.715	0.601
	Step 3: TAS-20					0.705	5.021	0.018
Analysis 2	Step 1: Depression					0.592	4.514	0.009
	Step 2: Anxiety	0.771	0.581	0.027	4.211	0.103	0.431	1.140
	Step 3: TAS-DIE					0.194	2.501	0.001
Analysis 3	Step 1: Depression					0.643	4.611	0.007
	Step 2: Anxiety	0.753	0.564	0.001	0.100	0.125	1.201	1.101
	Step 3: TAS-DDE					0.037	0.297	1.291
Analysis 4	Step 1: Depression					0.630	4.831	0.005
	Step 2: Anxiety	0.721	0.566	0.003	0.311	0.152	1.341	0.713
	Step 3: TAS-EOT					0.025	0.243	1.242

p* < .05, *p* < .005

Theme 1: Social cognition. Awareness about post-stroke psychological symptoms showed limitations after being discharged from stroke rehabilitation. Patients indicated they were not sufficiently educated about the experience of post-stroke symptoms.

"I thought that my post-stroke symptoms are limited to that weakness in the left side of my body... but when I returned to my work I found it difficult to remember feelings or expressing feelings when I sit with my colleagues." Stroke 10.

When the cognitive limitations emerged, patients were concerned that they had another stroke or other undiagnosed problems.

"I was ok, you know; later I faced memory problems at home. I feel there is something wrong again in my brain. I can't understand my feelings; sometimes there is no link

between my feelings and my everyday situation. They [the doctors] could have misdiagnosed something else in my brain." Stroke 15.

Faulty cognition leads to uncontrolled feelings.

"My father calls me with the wrong names. Even when he called my children he struggled to remember their names, and then he became angry or cried." Caregiver 11.

Theme 2: Personality. With lack of education about post-stroke psychological symptoms, patients in this study were left to develop incorrect conclusions.

"I thought that stroke is a purely physical disease, and that changes in personality and emotional response are common after a stroke. But I did not know that at all. I got the information from the internet. Changes in my

personality and mood after my stroke were effects, but not only affected one person. It affects me, my wife and even my children. I thought that I hated my family." Stroke 13.

Changes in personality and the inability to control feelings were reported frequently.

"I can't control my feelings now; I don't know why. In five minutes I am crying, ahhh, but in seconds I could shift to a smile. There is something wrong in my brain, and I believe my doctor doesn't know, and they don't want to hear from me. I asked for an MRI in my last clinic visit but my doctor refused." Stroke 2.

Theme 3: Emotional. Emotional changes are one of the most frequently voiced complaints of stroke survivors' caregivers.

"They [Doctors] didn't understand my husband's emotional problem. I have not seen him cry for almost 28 years, but after his stroke he is weeping all the time. When he cries, I don't know what I should do." Caregiver 1.

"My wife is still struggling to accept that she is now ok. To be honest, physically she is good now; her major problem is her emotional and psychological sides. She is crying one minute then laughing in the next." Caregiver 5.

"He shouts at our kids saying bad words, then there is turnover in seconds. He cries, saying he doesn't know why he was shouting and why he was angry." Caregiver 8.

Emotional ability is something important for stroke survivors.

"I lost my feelings. I was able to identify what my husband wanted from his eyes and face. But now no. I wish I could be back like before." Stroke 7.

Another patient said:

"People around me say 'oh, you are almost there, you are nearly recovered... but they do not know that emotional recovery is the most important feature of being recovered. I want to live peacefully by controlling my shouting and anger." Stroke 4.

5. DISCUSSION

The main purpose of the present study was to focus on the relationships between alexithymia and stroke. The results showed that stroke survivors scored higher on alexithymia than the control group. Stroke survivors were impaired in the ability to identify their own negative and positive emotional responses, as indexed by the full TAS-20 scale and the TAS-DIE subscale. This result confirms the association between stroke and alexithymia reported in previous studies [7,27,28,29]. An earlier study suggested that alexithymia does not simply reflect a deficit in the ability to symbolize emotion, but a more general deficit in the ability for emotion information processing [30]. It might be claimed that the full TAS-20 or the TAS-EOT subscale is picking up aspects of cognitive functioning which tap into a different aspect of emotional abilities than is measured by the TAS-20. Therefore, further research is needed to precisely clarify the nature of the underlying emotional impairment in stroke survivors.

Like earlier studies [31,32], the current results show high levels of depression among stroke survivors. It is worth mentioning that depression may develop here as a psychological reaction to the loss of previous abilities.

For example, perceiving the limitation of self-efficacy post-stroke is strongly related to depression [33]. This could lead to the fact that we might assess depressive symptoms rather than post-stroke depression [34]. Post stroke depression, as it is stated above, could be explained by alexithymia. Such an explanation requires different rehabilitation psychological interventions.

The current study shows a clear relationship between alexithymia, depression and stroke. It could be that alexithymia is caused by brain damage due to stroke; another possibility would be that stroke causes depression, which then might be accountable for raised alexithymia. This also needs further research and investigation.

A strong correlation was observed in several studies between QoL and stroke [35]. In this study, a decrease in QoL correlated with depression, and to some degree with alexithymia, as it could be seen in these results. Always though, depression was among the first predictors of reduced QoL [35]. This could be the first study which explores the relationship between alexithymia and QoL post-stroke.

It is essential here to know that alexithymic patients are further impaired in the perception and processing of speech prosody [36]. At a communicative level, alexithymic patients demonstrate problems in language production and comprehension [37]. In particular, alexithymic patients display a limited ability to talk about interpersonal relationships [38]. One neuropsychological model of explaining alexithymia links the condition to a poor transfer of emotional information from the right hemisphere to the language areas of the left hemisphere of the brain [39].

Integrating quantitative and qualitative methods were respectively used in this study to investigate and collect data. It was recommended to use the same approaches within the same line of inquiry, but at different stages in the process leading from data collection [40].

The qualitative sample in this study recruited patients with their caregivers in order to have a broader view of post-stroke emotional problems. Repeatedly, stroke victim's families complain of emotional changes that accumulate post-stroke [10]. Having the input of stroke survivors' caregivers adds an important value to the data of this study. Usually, the interview procedure allowed patients maximum opportunity to express their post-stroke feelings in terms of their own values and experiences [41,42]. Previous Saudi studies stated the advantage of gathering data from in-depth qualitative interviews [43]. The qualitative design provided a greater understanding of the particular experiences of this population, rather than what could be captured with standardized instruments.

Families of stroke survivors face several psychological challenges. Caregivers continued to feel frustrated over stroke survivors' emotions, such as mood swings, anger, yelling, cursing and apathy [44]. Many families do not get the support they need to understand post-stroke psychological symptoms. They are not receiving the correct or full information and support they need to help them adjust to life after a stroke, in order to support the victims' long-term rehabilitation recovery [44]. Managing emotional changes of stroke survivors was reported as a high priority by families looking for professional support after discharge.

In Saudi Arabia the Ministry of Health (MOH) has established several rehabilitative services. Most

of these programs are within the existing modern and sophisticated health care service system and infrastructure [45], and with good psychological services such as KFMC-HR. However, as has been cited in previous studies, some other Saudi rehabilitation settings view rehabilitation psychology as a luxury, with less attention given during rehabilitation, along with the psychological issues. Consequently, rehabilitation goals are affected [46,47].

6. CONCLUSION

The data of this study suggest an involvement of alexithymia in stroke survivors. In terms of clinical implications, these findings suggest that rehabilitation efforts should be focused on remediation of this specific deficit, particularly since alexithymia could make a significant contribution to QoL. The current finding, therefore, recommends establishing early rehabilitation intervention that is specifically designed to overcome the problems associated with stroke and alexithymia.

7. LIMITATIONS

A limitation of the present study is that only a single measure of alexithymia (TAS-20) was used. Alexithymic patients have difficulty in identifying their own inner feelings. The authors of the TAS-20 have recommended assessment of alexithymia with several tools using different methods [48]. Furthermore, stroke survivors frequently have post-stroke depression, similar to our results, and tend to perceive themselves negatively [49]. Therefore, Lumley [50] mentioned that when both alexithymia and depression were assessed by self-reports, the perceived relationship between them could be an artifact. Another limitation in this study is regarding the stroke type including infarct type, size and lesion area which are not mentioned. Alexithymia could be affected by all of these factors. Therefore, the current results need to be viewed according to this limitation. Finally, we limited the participants of the current study to those who were on regular post-stroke follow up at KFMC-RH, in Riyadh the capital city of Saudi Arabia, and who could complete the questionnaires unaided. Therefore, further investigation is needed, with broader samples before making generalizations on the basis of our results.

ETHICAL APPROVAL

Ethical approval was obtained from King Khalid University.

COMPETING INTERESTS

Author has declared that no competing interests exist.

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