

ORIGINAL ARTICLE

Quality of life in patients with mild acute brain injury and their carers' needs in Greece

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ABSTRACT

Background: Investigating quality of life (QoL) is of crucial importance for the scientific community as it could function not only as an indicator of prognosis and post-traumatic clinical and psychological changes in patients who have suffered from acute brain injury (ABI), but also as an indicator of the effectiveness of their treatment and social rehabilitation. In addition, it can highlight changes in the carer's health, social life and well-being. This study examined the QoL of patients following ABI and the needs of their carers.

Material and methodology: This study was conducted in patients suffering from ABI, who were admitted to the General Hospital of Attica "KAT" and to the National Rehabilitation Center and on their carers. Data collection including demographics and Quality of Life After Brain Injury Questionnaire (QOLIBRI) and the Family Needs Questionnaire (FNQ) was performed during patients' rehabilitation, while six months after release, a follow-up survey was conducted using the same questionnaires. Statistical analysis of data was performed using SPSS.

Results: We analysed 50 patients with mild ABI (GCS \geq of 13/15) during rehabilitation and six months after release and found that their QoL improves and is positively related to improvement of health status (i.e. in terms of thinking ability, QoL improves from $r = 2.33, p < .01$ to $r = 3.37, p < .001$). We also found that "Age" has the greatest impact on the patient's progress for recovery and the general QoL after ABI ($r = -0.423, p < .01$). In addition, it was found that carers of patients with ABI are confronted with the burden of care, while they record both fulfilled and unmet needs regarding their individual needs (i.e. only for 30% of the sample the need for help in preparing them for the worst is met).

Conclusions: Our study confirms previous findings that underline that ABI has a major impact on QoL of both patients and their carers providing them with long-term daily care. Although it has been found that over time there is an improvement in the QoL of patients with ABI, the absence of an official support network for carers from public health system, hospitals and rehabilitation centers may adversely affect the QoL of patients and their carers. Therefore, more structured, long-term family-wide monitoring and support is needed, focusing on identifying those at risk of social isolation and incomplete social networking.

Key Words: Quality of life, Acute brain injury, Quality of Life After Brain Injury Questionnaire, Family Needs Questionnaire

1. INTRODUCTION

Acute brain injury (ABI) is a serious public health problem in Greece and worldwide, not only because of its size, but also because it affects young people, working age population and the elderly. It causes cognitive, physical and behavioral

disorders, burdens the health care system and may endanger patients' quality of life (QoL) and their families. In addition, a significant part of the population remains outside the productive and social process.^[1]

Improving living conditions and the level of health care pro-

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vided has led to an increase in life expectancy, including patients who have suffered ABI. However, many of these patients face increasing physical, psychological, social and functional consequences, with increased personal and public costs.^[2]

In this context, QoL could serve not only as an indicator of prognosis and post-traumatic changes in patients with ABI but also of the effectiveness of treatment and their social rehabilitation. In addition, it can help bring about changes in carers' health status, social life and well-being.

As society seems to be unaware of the magnitude of ABI's socio-economic consequences, scholars consider it to be a "silent epidemic".^[3] In Greece, there are no established family programs or structured follow-up programs after acute craniocerebral injuries or strokes in the healthcare centers where patients are treated. This results in further difficulty in finding comprehensive findings about the QoL of both patients and their carers.

The theoretical approach used to explain how disease affects QoL was the theory of Social Function Production,^[4-6] highlighting how the symptoms and complications of illness or disability create binding constraints on the exercise of the means (activities, resources) to achieve functional goals. These constraints increase the cost (money, energy), make the achievement of operational objectives "costly", according to the criterion of cost-effectiveness, bring harm instead of benefit and therefore negatively affect a person's QoL.^[7] In addition, to provide a more holistic understanding of the effects of ABI on carers, family systems theory was chosen as the theoretical framework.^[8,9]

Studies related to the analysis of QoL are particularly useful for nursing practice to assess the physical, mental and social consequences of diseases and treatments in people's daily lives. They are also useful to analyze the effects of treatments or diseases as perceived by patients, as well as to identify their needs for psychological, physical and social support during the illness. However, further investigation is needed for the case of patients with ABI and their carers. Thus, the aim of the study was to investigate patients' QoL after ABI and the needs of their carers.

2. METHODS

2.1 Participants and setting

The study was conducted on a sample of 50 patients with ABI, who were admitted to the General Hospital of Attica "KAT" and to the National Rehabilitation Center (NRC) as well as on 50 carers. Research lasted 18 months, the data collection was performed during patients' rehabilitation, while six months after release, a follow-up survey was conducted

with the 50 patients. To participate in the study, patients and carers were required to meet the following inclusion criteria: 1) age 18 years or older, 2) able to read and understand Greek, 3) able to fill in the questionnaire and 4) ensuring their consent to be included in the research.

2.2 Measurements

We collected demographics and the characteristics of the patients including Glasgow Coma Scale (GCS), as well as the characteristics of the carers. The tools selected as suitable for conducting the study were the questionnaire for the Quality of Life After Brain Injury Questionnaire (QOLIBRI),^[10] and Family Needs Questionnaire (FNQ).^[11] In addition we asked for rest and sleep adequacy for carers and financial support at home after hospital discharge.

2.3 Data analysis

Descriptive statistics (frequency distribution, percentages, mean, median, standard deviation) and multivariate analysis (Cronbach's index, Pearson correlation coefficient, factor analysis) were used for data analysis. The Statistical Package of Social Sciences (SPSS) was used for statistical analysis. To test the reliability, a pilot study was conducted on a sample of ten people with the same characteristics as the sample of the main study. The pilot study did not show the need of any changes in the questionnaires. The validity of both the pilot and the main study was statistically tested using the Cronbach's index and proved to be statistically reliable.

2.4 Ethical consideration

Patients and carers received a document explaining the purpose of the study and the procedures used to ensure anonymity. To this end, participants would be assigned a code. Participants in the study had the right to withdraw from the research without consequence for their treatment, while they were afforded plenty of time to carefully consider their decision. Those who agreed to take part in the study were asked to sign an informed consent form that was then forwarded to the researchers.

3. RESULTS

3.1 Patients' sample characteristics

The sociodemographic characteristics of the 50 patients having mild ABI are shown in Table 1.

Most patients were females, married, high-school graduates, private employees and hospitalized for the first time for this reason and most of them for one month. There was also a relative uniformity of the sample, covering a wide range of ages, as each age group has its own needs and often respond differently to treatment.

Table 1. Characteristics of study population

Characteristics		N (%)
Sex	Females	31 (62)
	Males	19 (38)
Age (years)	Mean \pm SD	53.3 \pm 18.7
Range	Min–Max	19–89
Marital status	Single	19 (38)
	Married	23 (46)
	Separated	1 (2)
	Widowed	7 (14)
Educational level	Primary school	8 (16)
	Secondary school	5 (10)
	High school	21 (42)
	Technological institute	6 (12)
	University	10 (20)
Occupational status	Civil servant	4 (8)
	Private employee	18 (36)
	Self-employed	3 (6)
	Student	2 (4)
	Unemployed	6 (12)
	Retired	17 (34)
Duration of hospitalization	1–4 days	4 (8)
	1 week	8 (16)
	2 weeks	14 (28)
	3 weeks	8 (16)
	4 weeks	16 (32)
Hospitalization for a similar problem	Yes	3 (6)
	No	47 (94)
Interview place	KAT	22 (44)
	NRC	28 (56)
Treatment in a rehabilitation center	Yes	50 (100)
	No	-
Glasgow Coma Scale (GCS)	13	1 (2)
	14	2 (4)
	15	47 (94)

Note. KAT = Hospital; NRC = National Rehabilitation Center

Regarding GCS, all patients had mild head injury having a GCS > of 13/15. Specifically, the vast majority had a GCS of 15/15 (94%), while 2% and 4% had a GCS 13/15 and GCS of 14/15 respectively. Thus, we had a homogenous patient population having a mild ABI.

3.2 Patients' QoL

Our data show that ABI has a major impact on the QoL of both patients and their carers making it difficult for them to integrate socially and professionally. In Table 2, we present the dimensions of QoL of patients with ABI over time showing an improvement after six months. Using multivariate analysis (Pearson Correlation, Spearman's rho Correlations) we found that, the factors that affect QoL positively were marital status ($r = 0.311, p < .05$); GCS ($r = 0.346, p < .05$) and negatively are educational level ($r = -0.282, p < .05$) and previous hospitalization for a similar reason ($r = -0.289, p < .05$).

We also found that "Age" has the greatest impact on the patient's progress for recovery and the general QoL after ABI ($r = -0.423, p < .01$). Finally, "gender" is related to patients' ability to manage their personal finances, with men being negatively affected by their loss of ability to manage them and with negative consequences for the assessment of their QoL ($r = -0.186, p < .05$).

3.3 Carers' characteristics

The sample of carers consisted of 50 persons, 42 female and 8 male, who provided unpaid care, the majority (72%) of whom were first-degree relatives of patients while only 28% of carers were not first-degree relatives (see Table 3).

3.4 Carers' needs and disease burden

Our data show that carers of the patients with ABI face the burden that arises from provision of care, while they have both fulfilled and unfulfilled needs in terms of their individual needs.

Table 2. Patients' QoL at baseline and after six months

Factor	Mean (SD) A Phase–baseline	Mean (SD) B Phase 6 months after
Thinking ability	2.33 (0.441)	3.37 (0.489)
Feelings about oneself	2.08 (0.516)	3.25 (0.689)
Functioning in everyday life	0.57 (0.731)	2.26 (0.680)
Social relationships	2.83 (0.626)	3.24 (0.628)
Emotions	1.36 (0.636)	1.84 (0.572)
Physical problems	2.37 (0.494)	2.10 (0.477)

Table 3. Carer's relationship with the patient

Relationship	N (%)
Husband/Wife	15 (30.0)
Child	9 (18.0)
Parent	12 (24.0)
Other	14 (28.0)

Table 4. Factors' affecting carers' needs

Factor	Mean (SD)	Effect
Psychological Support	3.57 (0.239)	Positive
Individual Needs	2.73 (0.274)	Negative
Support Network	1.46 (0.303)	Negative
Emotional Coverage	2.27 (0.519)	Negative
Reward-Acceptance	2.04 (0.443)	Negative

Using factor analysis and after the removal of the variables that were not statistically significant, we found that there were five factors with a statistically significant effect on the total number of responses received. These factors affected either positively or negatively carers' needs as shown in Table 4. The provision of care, ranging from physical assistance to psychosocial support, had a great impact on their psychology, emotional state, work, social burden (insecurity, loneliness, depression) ($r = -0.553, p < .05$).

Carer's needs for adequate rest and sleep was not covered for 38% of them while 62% of them reported only partially satisfied further contributing to unsatisfied life and disease burden especially due to long-term care at home after hospital discharge. Also, 66% of our patients reported lack of financial support regarding rehabilitation programs, physiotherapy, counseling and work counseling after discharge. In addition, only 2% of the carers reported sufficient financial or legal advice, daily care, counseling, and nursing care at home. Finally, only 30% of the patients reported psychological and sentimental support preparing them in case that further problems emerge further contributing to whole disease burden.

4. DISCUSSION

Several studies in the past revealed on the one hand the heavy burden on both physical and psychological level of the patients and on the other hand, the heavy burden on carers.^[12-14] Our data showed that that the QoL of patients with mild ABI is significantly affected by their illness, making it difficult for them to integrate socially and professionally. However, in the long run all participants expressed an improvement of QoL, confirming those studies that emphasize that the gradual improvement of physical condition leads

to positive changes in mental health, as well as people's QoL.^[15] Thus, positive changes are recorded in terms of the ability to think, feelings about oneself, functioning in daily life and social relationships.

However, in the assessment of patients with mild ABI in terms of satisfaction with those aspects of their social relationships, there is a negative change in the degree of satisfaction of patients' relationships with friends and partners. These negative changes, on the one hand, may be related to the changes that ABI brings to patients' daily lives and their potential inability to find or communicate with friends as before the event. On the other hand, results confirm other studies^[16, 17] that emphasize the problems and/or conflicts that occur in the marital relations during hospitalization and/or recovery after traumatic episodes.

Literature also suggests that patients with ABI assess caring for their mental and social status as important as caring for their physical condition. Regarding the degree of annoyance of patients with ABI with feeling sad or depressed, the negative change recorded confirms the findings of other studies that highlight the worsening of depressive states over time in patients with various disabilities.^[18-20]

Regarding patients carers and their needs, we found that they face a heavy burden of caring. The problems associated with brain damage are very serious and require a lot of energy both physically and mentally from carers to be able to stand by the patients. Carers, as components of the family system, after the sudden event of ABI, adapt to the new situation which can be described as a new phase of life for the whole family and their social network.

Lack of psychosocial support of carers by specialists during patients' treatment and rehabilitation, lack of formal support network of carers from hospitals, rehabilitation centers or other official institutions generates strong negative emotions. This also has negative consequences in terms of their ability to remain optimistic about patients' future but also to prepare for the worst, confirming those studies that show that loneliness, insecurity, depression are common consequences of providing care to patients with ABI.^[21, 22] Unmet needs from formal support networks forces carers to seek help from both their immediate family environment and the wider social circle of the patients to support and reward them for how well they treat and care for their patients. Thus, thanks to the family, as a social institution which still remains strong in Greece, but also to the informal solidarity among relatives and friends that is strongly reflected, the carers find the necessary support required to respond to the care, treatment and rehabilitation needs of the patients.

In addition, an interesting aspect of our research concerns

the non-coverage from the public social security system of the necessary resources during treatment and rehabilitation, which highlights the high cost of private health care, thus confirming those studies that emphasize this “open wound” of the health system in Greece.^[23] The non-coverage of the necessary financial resources for themselves and their families confirms the assumption of paying a large enough amount of money for the treatment and rehabilitation of patients, which, to be covered, is taken from the needs of the other members of the household.

4.1 Limitations

This study presents a number of limitations. First, our analyses were based on a convenience sample that was not representative of the entire population of Greek ABI patients. Therefore, the results of this study cannot be generalized. Second, our design for carers provided a description at a given point in time only. Repeated measures would afford a more detailed representation of the relationships between the variables considered. Third, we used one instrument to measure patient QoL. The use of two instruments, one specific and one not, as recommended by several scholars, would have provided a more detailed picture of this element.^[24]

However, results of this study can contribute to the relevant literature to the extent that they highlight the role of enhanced care and rehabilitation, holistic oriented to family. This is because an approach that focuses on the family (patient and carer) will not only make patients and carers more prepared for the future, but will prevent the great burden they both feel in the long run.

5. CONCLUSIONS

The QoL of patients with ABI is significantly affected by the negative physical and psychological consequences of ABI. However, over time, positive changes are recorded in patients’ assessment of QoL. This is due to the objective clinical improvement but also and most importantly to the environment of the family through which carers provides their support.

For carers themselves, however, the degree of burden due to long-term care is high. In addition, the absence of a formal support network for carers on behalf of public health system, hospitals, rehabilitation centers or other official institutions, negatively affects the QoL of patients and their carers.

Therefore, structured long-term follow-up of the whole family, focusing on identifying those at risk of social isolation and exclusion, is essential. Thus, policy-makers should focus on incorporating ABI related issues and costs in public security system, facilitate and improve access and highlight the importance of rehabilitation process after ABI for both patients and their carers.^[25] To this, actively engaging nurses to provide long term support (i.e. home care) covered by the public insurance system could play a significant role.

However, we suggest that a more structured, long-term family-wide monitoring is needed, focusing on identifying those at risk of social isolation and incomplete social networking for prompt and adequate support.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare they have no conflicts of interest.

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