#### **Quality of Life for Patients with Parkinson's Disease**

# Eman Mohamed Moubark<sup>1</sup>, Doaa Mohamed Sobhy <sup>2</sup>, and Hedya Fathy Mohy El-Deen<sup>3</sup>

(1) B. Sc. Nursing (2013), Faculty of Nursing, Tanta University, and (2,3) Assistant professor of Community Health Nursing, Faculty of Nursing, Benha University

#### **Abstract**

**Background:** Parkinson's disease causes severe burden on patients and society and affect all aspects of patient's life so improving quality of life of patients keep them more adaptable to physical, psychological and social status. Aim of the study: This study was conducted to assess quality of life for patient with Parkinson's disease. **Research design:** Descriptive research design was utilized. Setting: The study was conducted at Neurology Outpatient Clinics at Benha University Hospital. Sample Type: Convenience sample of all patients with Parkinson disease, the total sample included 75 patients through 6 months. Tools: Three tools were used for data collection. (1): A structured interviewing questionnaire consisted of two parts to assess Sociodemographic characteristics and knowledge of patients regarding Parkinson's disease. (II): Scale of independency level of performing daily living activities, and (III): Scale of quality of life for patients with Parkinson's disease **Results:** 70% of studied patients had good level of knowledge related to Parkinson's disease. While 17% of them had an average level of knowledge. 62.7% of studied patients had a partial level of independence, while 37.3% of them had independence. 60% of studied patients had an average level of quality of life and 29.4% of them had poor level of quality of life, while 10.6% of them had good level. Conclusion: There was a highly statistically significant relation between total quality of life of studied patients and level of independency. **Recommendation:** Educational program should be developed and implemented for patients with Parkinson's disease to help them to be more coping with their physical, psychological and social status.

Keywords: Parkinson's Disease, Quality of Life.

#### Introduction

Parkinson's Disease (PD) is the most neurodegenerative common movement disorder. The pathological hallmarks of Parkinson's Disease are loss of dopaminergic neurons in the Substantia Nigra Pars Compacta and accumulation of misfolded asyncline, which is found in intra-cytoplasmic inclusions called Lewy bodies. In the normal state, basal ganglia play a pivotal role in controlling voluntary movements by way of receiving cortical inputs, processing information through the cortico-basal ganglia pathways, and returning processed information to the original cortices through the thalamus. When patients are first diagnosed, a substantial proportion of dopaminergic neurons became already lost, and neurodegeneration has spread to other central nervous system regions (Simon et al., 2020).

The prevalence of Parkinson's Disease is believed to be up to 10 million people worldwide. PD occurs most commonly in people aged over 60 years old. Parkinson's Disease is now the fastest growing neurological disorder globally. Parkinson's Disease is a debilitating and progressive condition that impacts the lives of individuals and their families. The global prevalence of Parkinson's Disease doubled between 1990 and 2016 and is projected to double again

over a similar interval. Parkinson's Disease is the fastest growing brain disorder affecting the world. Global Burden of Disease (GBD) study reported that incident cases of parkinson disease were 1.02 million in 2017 (GBD Neurology Collaborators, 2019).

Risk factors of Parkinson's Disease are multiple. Age is the biggest risk factor to Parkinson's Disease because the most affected patients with the disease are over 60 years of age. Sex is another contributing factor with men being disproportionately affected more than women. A wide number of studies have shown that known and unknown environmental factors can contribute to Parkinson's Disease risk. Environmental factors such as pesticide exposure, contaminated water consumption and head injury, also premotor symptoms including constipation and depression among others, have been associated with increased risk for Parkinson's Disease, while other factors such as tobacco, coffee, and alcohol usage have controversially shown possible protective associations with Parkinson's Disease (Ciga et al., 2020).

Parkinson's Disease symptoms occur due to the progressive loss of dopamine-producing neurons in the substantia nigra pars compacta region of the brain. Symptoms typically occur gradually over several years and divided into symptoms that affect movement (motor symptoms) and symptoms do not affect movement (non-motor symptoms). The most common motor symptoms of Parkinson's Disease are tremor (a form of rhythmic shaking), stiffness or rigidity of the muscles and slowness of movement (bradykinesia). The patient with Parkinson's Disease may also have trouble with posture, balance, coordination, and walking. Common nonmotor symptoms of Parkinson's Disease include sleep problems, constipation, anxiety, depression, and fatigue (William, 2020).

Diagnosis of Parkinson's Disease is commonly based on medical observations and assessment of clinical signs, including the characterization of a variety of motor symptoms. Machine learning methods have been implemented for the classification of PD and healthy controls and patients with similar clinical presentations (Meil & Desrosiers, 2021).

Treatments of Parkinson's Disease can vary from drugs, surgeries, therapy, or a combination of different treatments such as physiotherapy, speech and occupational treatments therapy. Common include levodopa which can improve dopamine level. Treatment of Parkinson's Disease using available drugs has positive symptomatic effects; available therapies is used to slow the progression the disease of Therefore. treatment begins at the discretion of the patient and the physician when symptoms begin to impair function or provide social embarrassment (Tori et al., 2021).

World Health Organization (WHO) defined Quality Of Life (QOL) as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to goals, expectations, standards, and concerns." QOL encompasses physical, psychological, autonomy, cognitive, social relations, and environmental factors. Parkinson's Disease negatively impacts quality of life of patients. Motor and non-motor symptoms Parkinson's Disease can contribute to changes in many aspects of ability and lifestyle. Diminished capacity to function normally and independently can be challenging for patients with Parkinson's Disease through a multitude throughout of challenges disease. Improving quality of life for Parkinson's patients is important to understand new strategies for prevention, control and rehabilitation programs (**Meng et al., 2022**).

Community Health Nurses (CHN) are responsible for assessing changing needs and provide a referral to local specialist nurse or Parkinson's team to ensure that patient is reviewed in a timely manner. CHN play a vital role in the care of people with Parkinson's and can also offer information and advice to families of people with Parkinson's and other health and social care professionals involved in a patient's care and work closely with the clinical team and provide valuable help in supporting people coming to terms with Parkinson's diagnosis, offer guidance on managing medication and make appropriate referrals on to other professionals such as speech and language therapists and physiotherapists (Shin & Habermann, 2022).

#### Significance of the study:

Parkinson's Disease is considered the 14th leading cause of death in United States (U.S). The highest recorded Crude Prevalence Rate (CPR) of Parkinson's Disease is along the River Nile in Egypt, especially governorates of Upper Egypt and ranged from 53 to 557/105 inhabitants (all ages). The highest age -specific CPR showed a tendency to be more higher among people > 70 years. The estimated global prevalence of PD was doubled (from 2.5 to 6.1 million) between 1990 and 2016, and experts estimate that it could reach 12 million by Accompanying this increase, the societal and economic burden of PD will increase, unless more effective treatments, cures or means of prevention are identified (Siddiqui et al., 2020).

#### Aim of the study

The aim of the study was to assess the quality of life for patients with Parkinson's disease in Benha City.

#### **Research questions**

- What is the knowledge of patient about Parkinson's disease?
- What is the patients' dependency level regarding Parkinson's disease?
- What is the quality of life of patients with Parkinson's disease?
- Is there relation between dependency level and the quality of life?

## Subjects and method

#### Research design:

Descriptive research design was utilized to conduct this study.

#### **Setting:**

The study was conducted at Neurology Outpatient Clinics at Benha University Hospital. **Sampling:** 

A convenient sample of all Parkinson's patients including all stages of the disease attending to the previous mentioned setting through 6-months The total sample was 75 patients.

#### **Tools of data collection:**

Three tools were used in this study-:

# Tool (I): A structured interviewing questionnaire:

This tool was designed by the researcher in a simple Arabic language after reviewing a related literature and composed of two parts-:

**First Part:** Was concerned with sociodemographic characteristics of the studied patients which included 8 items as age, sex, marital status, education level, occupation, residence and income.

**Second part:** Was concerned with studied patient's knowledge regarding Parkinson's disease which included 11 questions.

**Knowledge scoring system:** It was calculated as follow 2 score for correct and complete

answer, while 1 score for incomplete and correct answer and 0 score for don't know. For each item of knowledge, the score of questions was summed up and the total divided by the number of questions, which converted into a percent score. The total score for all questions categorized into three levels as following:

Note: Except source of knowledge

#### **Total scores of knowledge** = 20 points

- **Good** when the total score was 75% to 100% (>18 points).
- **Average** when the total score was 50% to less than 75% (12-18 points).
- **Poor** when the total score was less than 50% (<12 point

**Tool** (**II**): Activity of Daily Living activities scale adopted from (**Schwab & England**, **1969**) and modified by (**Machado**, **2022**) used to assess patients' ability to perform activities of daily living. It consists of 19 items.

# Total score of independence of activity of daily living =36

- **Dependent**: level of a performing activity of daily living was considered dependent when total score was less than 50% (>18 point)
- **Partially dependent**: When the total score was from 50% to less than 75% (12-18points).
- **Independent**: When the total score was from 75% to 100% (<12points).

**Tool III:** Parkinson Disease Questionnaire (PDQ39): developed by (**Peto & Jenkinson**, **1995**) and adapted by (**Christopher & Beck**, **2017**). It is a British scale used to assess health related quality of life in Parkinson disease. It consists of 39 items.

Scoring system of quality of life adapted as following: the scoring system was graded according to the items of questionnaire. The scoring system of quality of life for patients with Parkinson disease scale score was calculated as zero score for never, one score for occasionally ,score two for sometimes ,score

three for often, score four for always .for each area of quality of life the score of items was summed- up and the total divided by the numbers of items giving the mean score of the part these scores were converted into a percent score.

The total quality of life was considered good If the score was >75% (146.25) points while considered average if the score was50-75%(79.5-146.25)and considered poor if it <50% (97.5 points).

#### **Content validity:**

The tools validity was done by five of Faculty's staff Nursing experts in the field of Community Health Nursing staff who reviewed the tools for clarity, relevance, comprehensiveness, applicability as well as the time needed.

#### **Content reliability**

The reliability of tools was applied by the researchers for testing the internal consistency of the tools and was measured by using structured interviewing questionnaire the reliability proved to be high based on the value of Cronbachs' Alpha coefficient test which revealed that the internal consistency for patients' knowledge was 0.870 and reliability for quality of life of patients with Parkinson disease was 0.90.

#### **Ethical considerations:**

Formal permission has been obtained from each Parkinson disease patient before conducting the interview and the patients with Parkinson disease were informed about the purpose and benefits of the study at the beginning of the interview and informed that participation was voluntary and had the right to withdraw from the study at any time without given any reasons. Patients were also reassured that all gathered information would be treated with confidentiality and used only for the aim of the study. No names were required on the forms to ensure anonymity and confidentiality.

#### Pilot study

A pilot study was conducted on 10% (7patients) of the studied patients with Parkinson disease to test the tool content, applicability and simplicity using interviewing questionnaires. Based on the pilot study, the modification of the tools included rephrasing, rearrangement of some questions and items, and those who shared in the pilot study were included in the studied sample.

#### Field work:

Data were collected over a period of 6 months from the beginning of December 2021 to the end of May 2022. The researcher was introduced to each patient and after explaining the purpose of the study. The researcher visited the Benha University Hospital 2 days/week (Saturdays, and Thursday) which are the days of work at out patient clinic from 9.00 a.m. to 12.00 p.m. and the researcher collected the data from the patients, the average numbers of interviewed patients was between patients/day depending on their response and cooperation to the interviewer, each interviewed patient took about 30 minute to fill the tools depending on their understanding and response

#### **Statistical analysis:**

All data collected were organized, categorized and tabulated and analyzed using appropriate statistical methods. The data were analyzed by using the Statistical Package for Social Science (SPSS) version 21, which was applied to calculate frequencies and percentages as well as test statistical significance and associations by using chi-square test and person correlation test to detect the relation between the variables for (p value). Statistical significance is considered as:

- Significant when p- value < 0.05.
- Highly significant when p- value < 0.001.
- No significant result when p value > 0.05.

#### Results

**Table (1):** Shows that 42.7% of studied patient s their age >60 years with mean age Mean  $\pm$  SD 42  $\pm$  11.77, 65.3% of them was male, 30.7% of them had basic education, 56.0% of them live in rural area, 42.7 % of them didn't work, 61.3% of them were Widow and 54.7% of them had enough income

**Figure (1):** Illustrates that 70% of studied patients had good level of knowledge related to Parkinson's disease. While 17% of them had an average level and 13% of them had poor level of knowledge.

**Figure (2):** Illustrates that 62.7% of studied patients had partially independent level of independence, while 37.3% of them had independency.

**Figure (3):** Shows that 60% of studied patients had an average level of quality of life and 29.4% of them had poor level of quality of life, while 10.6% of them had good level.

**Table (2):** Show that there was highly statistically significant relation between total quality of life of studied patients and level of independency.

Table (1): Frequency distribution of studied patients regarding socio-demographic characteristic(n=75)

| Socio-demographic characteristics |  |    | %    |  |  |  |  |
|-----------------------------------|--|----|------|--|--|--|--|
| Age (years)                       | < 40                                     | 14 | 18.7 |  |  |  |  |
|                                   | 40 ≥ 60                                  | 29 | 38.6 |  |  |  |  |
|                                   | >60                                      | 32 | 42.7 |  |  |  |  |
|                                   | $Mean \pm SD 		 42 \pm 11.77$            |    |      |  |  |  |  |
| Sex                               | Male                                     | 49 | 65.3 |  |  |  |  |
|                                   | Female                                   | 26 | 34.7 |  |  |  |  |
| Educational level                 | No read or write                         | 20 | 26.7 |  |  |  |  |
|                                   | Basic education                          | 23 | 30.7 |  |  |  |  |
|                                   | Secondary education or technical diploma | 21 | 28.0 |  |  |  |  |
|                                   | University and above                     | 11 | 14.6 |  |  |  |  |
| Residence                         | Rural                                    | 42 | 56.0 |  |  |  |  |
|                                   | Urban                                    | 33 | 44.0 |  |  |  |  |
| Occupation                        | Work                                     | 16 | 21.3 |  |  |  |  |
|                                   | Doesn't Work                             | 32 | 42.7 |  |  |  |  |
|                                   | Retirement                               | 27 | 36.0 |  |  |  |  |
| Marital<br>status                 | Single                                   | 7  | 9.3  |  |  |  |  |
|                                   | Married                                  | 15 | 20.0 |  |  |  |  |
|                                   | Divorced                                 | 7  | 9.3  |  |  |  |  |
|                                   | Widowed                                  | 46 | 61.3 |  |  |  |  |
| Income                            | Enough and save                          | 30 | 40.0 |  |  |  |  |
|                                   | Enough                                   | 41 | 54.7 |  |  |  |  |
|                                   | Not Enough                               | 4  | 5.3  |  |  |  |  |

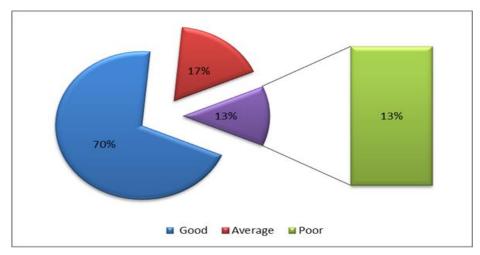


Figure (1) Percentage distribution of total level of knowledge among the studied patients about Parkinson's disease (n=75).

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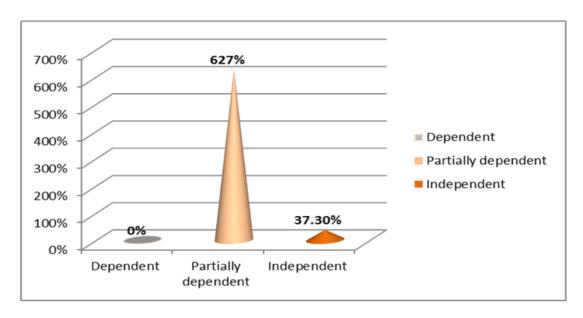


Figure (2) Percentage distribution of total independence level among studied patients (n=75).

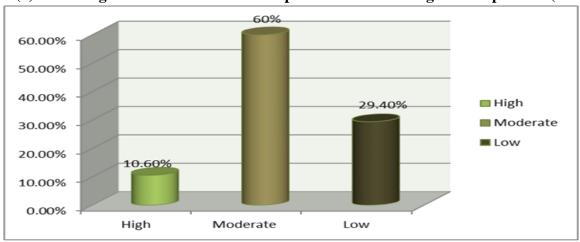


Figure (3) Percentage distribution of total quality of life level among studied patients (n=75).

Table (2): Relation between total quality of life and dependence level among the studied patients (n=75)

|           | Total dependency level |                          |      |                                  |      |                   |      |                |     |
|-----------|------------------------|--------------------------|------|----------------------------------|------|-------------------|------|----------------|-----|
| Variables |                        | Independent (n=0)        |      | Partially<br>dependent<br>(n=47) |      | Dependent (n= 28) |      | X <sup>2</sup> | Р   |
|           |                        |                          |      |                                  |      |                   |      |                |     |
|           |                        | Total quality<br>of life | Good | 0                                | 0.0  | 6                 | 12.7 | 2              | 7.1 |
| Average   | 0                      |                          | 0.0  | 37                               | 78.7 | 8                 | 28.6 |                |     |
| Poor      | 0                      |                          | 0.0  | 4                                | 8.5  | 18                | 64.3 |                |     |

#### Discussion

Parkinson's Disease (PD) is the second most common neurodegenerative disorder and a neurological disease that is progressive and associated with a decrease in dopamine production in the brain. The loss of dopamine production lead to a multitude of physical symptoms, including tremors, rigid and slow movements, troubles maintaining balance, shuffling and difficulties walking, troubles with speech and swallowing, and a loss of facial expression and psychological or mental health symptoms including depression, anxiety, apathy, difficulties sleeping, delusions, hallucinations, cognitive impairment, including impaired control that affects inhibitory decisionmaking and behavior flexibility. Parkinson disease is the fastest growing neurological affecting about 10 million condition. people worldwide (McKinley & Perkins, 2019).

Regarding the socio demographic characteristics of studied patients with Parkinson disease the current study revealed that less than two fifth of studied patients their age was more than 60 years with mean age was  $42 \pm 11.77$ . This result was the same line with Palladino et al., (2021) who studied "Age- and sex relationship between prodromal symptoms and disease phenotype in Parkinson's disease, Italy". (n=1142) and reported that less than two fifth (48.4%) of studied patients their age was with median age (67 years-old in men and 68 years-old in women ,while this result disagreed with Camerucci et al., (2021) who studied "Early-Parkinsonism and Early-Onset Onset Parkinson's Disease, U.S.A" (n=69) and reported that less than two fifth (38%) of studied patients their age was less than 55 years. This might be due to differential diagnosis (misdiagnosis) of early cases of Parkinson's disease before appearance of symptoms and there are some diseases with confused idiopathic Parkinson's Regarding the level of education of studied patients the present study revealed that, about one third of studied patients had basic education. This result agreed with Islam et al., (2019) who studied "Socio-demographic Characteristics of Parkinson's Disease Patients Dhaka city, Bangladesh" (n=40) and reported that one third (33.3%) of studied patients had primary level of education.

The current study revealed that about two thirds of studied patients were male .This finding was the same line with Salinas et al., (2020) who studied "Patient perceptions and knowledge of Parkinson's disease and treatment, Istanbul" (n=188) and reported that more than half (56.9%) of studied patients were male and less than half (47.4%) were female this might be due to for this higher exposure of men to toxins at work, head trauma, neuro protection by estrogen for female or linkage of genetic risk factor while this result disagreed with Park et al., (2019) who studied " Trends in the incidence and prevalence of Parkinson's disease, Korea" (n=73,726) and reported that less than half (46.3%) of studied patients were male and more than half (57.8%) was Regarding the level of education of studied patients the present study revealed that, about studied patients had basic one third of education. This result agreed with Islam et al., (2019) who studied "Socio-demographic Characteristics of Parkinson's Disease Patients Dhaka city, Bangladesh" (n=40) and reported that one third (33.3%) of studied patients had primary level of education.

Regarding total level of knowledge about Parkinson's disease the current study reported that more than two thirds of studied patients had good level of knowledge about Parkinson's disease. This finding disagreed with **Jitkritsadakul et al., (2017) who** studied "Knowledge, attitudes and perceptions of Parkinson's disease: A cross-sectional survey of Asian patient", Asia (n=108) and noticed that less than one third (31.5%) of studied patients showed higher level of knowledge about Parkinson disease. This might be due to direct contact of patients with physician and physiotherapist who are considered the main sources of knowledge.

Regarding total dependency level among patients with Parkinson's disease the current study revealed that three fifth of studied patients had partial level of dependency, while more than one third of studied patients were independent. This result is in the same line of Bjornestad et al., (2017) who studied " Loss of independence in early Parkinson disease; A 5-year population-based incident cohort study, Norway " (n= 189) and revealed that less than half (47%) of studied patients were partially dependent in performing activities of daily living and around two fifth (43%) of studied patients were independent in performing activities of daily living. This might be due to moderate disturbed cognitive functions at first degree of Parkinson's disease such as visuo spatial function, memory and motor functions so the patient level of independency is moderate.

Concerning total quality of life level. The current study revealed that three fifth of studied patients had average level of quality of life. This result in the same line with **Fan et al., (2021)** who studied "Determinants of quality of life in Parkinson's disease, China"(n=298) and explained that more than half (54%) of studied patients had moderate level of quality of life. This might be due to the patients become more adaptable and acceptable to debilitating nature of

Parkinson's disease and do their effort to face symptoms positively.

The current study revealed that more than quarter of the patients studied patients had poor level of quality of life, and tenth of them had good level. This result agreed with **Irene & Reverteri**, (2017) who studied "Quality of life and self-care in patients with Parkinson, Spain "(n=27) and found that nearly one quarter (24.3%) of studied patients had poor level of quality of life, and only less than fifth (14%) of studied patients had good level of quality of life poor level of quality of life, and tenth of them had good level.

The current study demonstrated that there was a high statistically significant relation between total quality of life and total level of dependency. This result agreed with Klietz & **Tulke**, (2018) who studied "Impaired Quality of Life and Need for Palliative Care for Advanced Parkinson's Disease Patients, Germany" (n=76) and found that there was high statistically significant difference between total level of dependency of studied patients and their quality of life. This might be due to higher level of dependency of patients with Parkinson's disease didn't allow the patient to perform his activities of daily living alone such as difficult to move easily, communicate or even feel satisfied, and so decrease overall quality of life.

#### Conclusion

More than two thirds of studied patients had good level of knowledge related to Parkinson's disease. While less than one fifth of them had average level of knowledge about Parkinson's disease and less than one fifth of them had poor level of knowledge about Parkinson's disease. More than three fifth of studied patients were partially dependent in performing activities of daily living, while less than two fifth of them were independent. Three fifth of studied patients had moderate

level of quality of life and less than one third of them had low level of quality of life, while more than tenth of them had high level. The results also show that there was highly statistically significant relation between total quality of life of studied patients and their level of dependency (p<0.001).

#### Recommendations

1-Educational program should be developed implemented and for patients Parkinson's disease to help them coping with their physical, psychological and social status. 2-Enhance patients' awareness about safety measures and ensure safe home environment 3-Enhance public awareness about the World Day of Parkinson's which discusses new trends of Parkinson's disease management 4-Design a colored booklet and distributed to every patient in neurologic outpatient clinics that contain summary of Parkinson's disease and how to cope with it.

5-Further studies needed to be focusing on improving quality of life for patients with Parkinson's disease for large sample and more setting

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# جودة حياد المرضى المصابين بمرض الشلل الرعاش المرضى المرضى المرضى المرضى المرضى المرضى المرك ـ امانى محمد سعد ـ دعاء محمد صبحى السيد ـ هدية فتحى محى الدين

يسبب مرض الشلل الرعاش عبنًا شديدًا على المرضى والمجتمع ويؤثر على جميع جوانب حياة المريض ، لذا فإن تحسين نوعية حياة المرضى يجعلهم أكثر قابلية للتكيف مع الحالة الجسدية والنفسية والاجتماعية لذلك أجريت هذه الدراسة لتقييم جودة الحياة للمرضى المصابين بمرض الشلل الرعاش وقد تم استخدام تصميم بحث وصفي وأجريت هذه الدراسة في العيادات الخارجية للأعصاب في مستشفى جامعة بنها وقد تضمنت العينة الملائمة 75 مريضًا خلال 6 أشهر وقد أظهرت نتائج هذه الدراسة أن أكثر من ثلثي المرضى الخاضعين للدراسة لديهم مستوى جيد من المعرفة بمرض الشلل الرعاش وأكثر من ثلاثة أخماس المرضى الخاضعين للدراسة يعتمدون جزئيً علي الغير ا في أداء أنشطة الحياة اليومية وكان أكثر من عشرهم يتمتعون بمستوي مرتفع من جوده الحياه وبناءا ع ذلك تم عمل توصيات بتطوير وتنفيذ برنامج تعليمي للمرضى لمساعدتهم على التكيف بشكل أكبر مع حالتهم الجسدية والنفسية والاجتماعية.