



## The Influence of Physical VS. Cognitive Disability on the Caregiver Lifestyle: Quality of Life Study in Jeddah, Saudi Arabia

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### Abstract

**Introduction:** Disability refers to impairments in body structure or function, difficulties in performing activities or actions, or limitations in participation in the environment [1]. Not only do such disabilities affect the patients themselves, but they also have an impact on those caring for them [1]. The severity and complexity of a disability require a higher level of care and effort from the caregiver. Our aim was to evaluate the quality of life of caregivers in Jeddah, Saudi Arabia who provide assistance to disabled patients. The study had two primary objectives, to assess the quality of life of caregivers for all disabled patients and to compare the quality of life of caregivers of physically disabled (dependent) patients with that of caregivers of intellectually disabled patients

**Methods:** This cross-sectional observational analytical study invited caregivers of physically or intellectually disabled patients who met the inclusion and exclusion criteria to participate in filling out a self-administered questionnaire about the physical, psychological, social, and financial effects on their lifestyle. We conducted the study at King Abdulaziz Medical City, Jeddah, and Abdul Latif Jameel Hospital for Medical Rehabilitation (ALJ), encompassing caregivers of patients diagnosed with physical or intellectual disability over a period of five years.

**Results:** There were 230 primary caregivers filled up the questionnaire and included in the final analysis. The type of patients' disability in the included caregiver were physical disability, 90 (39.1%), Intellectual disability, 69 (30%), and in 71 (30.9%) caregivers, it was both disabilities. There were 5 different categories of impact or limitations were identified for the caregiver of a disabled patient. Those include psychological, social, financial, abuse, and physical impact.

The quality of life mean scores for physical, intellectual, and both disabilities were 90.2, 89.3, and 91.2, respectively. The Intellectually disabled caregiver had a slightly lower mean score than other disabilities which indicates a slightly better quality of life; however, this difference was not statistically significant;  $F = 1.98$ ,  $df = 2$ ,  $p = 0.82$ .

**Conclusion:** Caregivers of intellectually disabled patients experience lower quality of life primarily in regards to psychological impact, whereas caregivers of physically disabled patients experience lower quality of life particularly in regards to financial impact. Caregivers of both physically and intellectually disabled patients experience lower quality of life across social, abuse, and physical impact dimensions. As a result, caregivers that care for both physically and intellectually disabled patients have a lower quality of life compared to caregivers that care for only one type of disability.

**Keywords:** Disabled Persons; Intellectual Disability; Physical Disability; Caregivers; Quality of Life; Cross-Sectional Studies; Psychosocial Impact; Social Support; Financial Impact

## Introduction

As caregiving is a widespread practice in nations all over the world, the importance of studying and assessing caregivers' quality of life cannot be overstated [1]. Disabled patients' conditions can range from mild to severe, and those with complex conditions often reside at home with parents, siblings, or spouses as their caretakers [1]. Previous studies have primarily focused on the impact of disability on the patients themselves, yet caregivers' quality of life is just as important [1]. Caregiving for disabled patients can be overwhelming and can have an impact on most aspects of their caregivers' lives, including their physical, psychological, social, and financial well-being [1,2].

Disabilities contain a wide range of subcategories, including physical disability, intellectual disability, learning disability, and hearing loss and deafness [3,4]. Physical disability affects various physiological systems and must substantially limit a significant life activity to be considered a disability [5]. On the other hand, intellectual disability affects behavior, skills, and communication, making a patient partly or wholly dependent on caregivers for basic tasks like activities of daily living (ADLs) [6,7]. Caregivers for patients with intellectual disabilities have lower quality of life concerning psychological impact, while caregivers for those with physical disabilities have poorer quality of life regarding financial impact [7,8]. Caregivers of patients with both physical and intellectual disabilities experience lower quality of life across social, abuse, and physical impact dimensions [7,8].

The caregiver's degree of burden heavily depends on six variables: caregiver and patient characteristics, stressors, stress appraisal, stress coping methods, and social support [1,9]. Caregiver characteristics include age, gender, race, marital status, education, income, relationship with the care recipient, and residence, while patient characteristics include performance status, age, gender, depression, type of illness, pain, and symptoms [1]. Primary stressors include the patient's amount of dependence on the caregiver, basic ADL assistance, the intensity and duration of care, and the type and overload of stressors, while secondary stressors include the caregiver's role changes, the caregiver's increased demands and responsibilities, interference with the caregiver lifestyle, and negative experiences [1,9]. These negative caregiver experiences are linked to exclusively living with the patient, anguish in relationships, total dependence of the patient on specific and basic tasks, high involvement in caregiving, and low income [2,9]. Coping methods, stress appraisal, and social support provide mediators and predictors of depression, life satisfaction, and self-related health [1,9].

As the population of interest faces significant challenges with poor availability of resources and local communities' low specificity to their needs, research focusing on the impacts of disabilities on caregivers' quality of life is necessary [10]. The study aims to assess the impacts of disabilities on caregivers' quality of life from their physical, psychological, social, and financial perspectives. It also aims to identify the unique challenges and stressors caregivers of physically and intellectually disabled patients face while caring for their patients. This study will ultimately provide insight into

the need for caregivers of disabled patients and identify areas for improvement in their quality of life.

## Materials and Methods

### Study design

The current study is an observational analytical cross-sectional study aimed at investigating the quality of life of caregivers of physically or intellectually disabled patients through a self-administered questionnaire.

### Recruitment

Upon receiving the approval from the Institutional Review Board of KING ABDULLAH INTERNATIONAL MEDICAL RESEARCH CENTER - KAIMRC - (ID number SP18/391/J), caregivers of physically or intellectually disabled patients who met the inclusion and exclusion criteria were invited to participate in the study. The study was conducted at King Abdulaziz Medical City, Jeddah, and Abdul Latif Jameel Hospital for Medical Rehabilitation (ALJ), encompassing caregivers of patients who were diagnosed with physical or intellectual disability in a period of five years. Both male and female caregivers of disabled adult patients (>18 years old) were included in the study, while paid caregivers were excluded.

### Sample size and sampling technique

Targeted population sample was obtained in non-probability consecutive sampling technique where all caregivers who met the inclusion criteria were eligible to participate in the study. The primary calculated sample size was 390 participants that are required to be 95% confident with 5% margin of error. However, 285 responses were conducted and 230 of which were included in the study after omitting the responses with errors and missing information.

### Questionnaire

The Informal Caregiver Burden Assessment Questionnaire (QASCI) was used to assess the physical, psychological, social, and financial effects on caregivers' lifestyles. The QASCI questionnaire consists of seven dimensions and 32 items, including Implications for personal life (11 items), Satisfaction with the role and the family member (five items), Reactions to demands (five items), Emotional burden (four items), Family support (two items), Financial burden (two items), and Perception of efficacy and control mechanisms (three items). Each item is assessed using an ordinal frequency

scale ranging from one to five answer categories: "No/Never", "Rarely", "Sometimes", "Almost always", "Always". The final score is obtained by summing the scores of each item related to each field (possible range from 32 to 160) and dividing it by the total number of domains or by the mean of items (range from one to five) after the reversal of scores in the items of the three positive dimensions. Higher scores indicate higher levels of burden.

### Data analysis

The data collected through the QASCI questionnaire were analyzed using the SPSS program. Simple descriptive statistics were reported as frequency and percentages for qualitative data, mean and standard deviation for normally distributed quantitative data, and median and interquartile range for skewed quantitative data. For bivariate analysis, using a two-tailed test, with the level of significance set at 0.05, analysis of variance (ANOVA) was calculated to detect the significance between the three categories and the mean score value.

## Results and Discussion

### Results

#### Categories and overall scores

A total of 230 primary caregivers of disabled patients were included in the final analysis after filling up the questionnaire. Three different categories of disabilities were included: physical disability 90 caregivers (39.1%), Intellectual disability 69 (30%), and both disabilities 71 (30.9%).

There were 5 different categories of impact or limitations were identified for the caregiver of a disabled patient. Those include psychological, social, financial, abuse, and physical impact. We calculated the mean scores for each category, the higher the score, the higher the impact with worse quality of life. The mean score and total score for each category are displayed in table one.

#### Psychological impact score

There were 11 different questions addressing the psychological impact on the caregiver of a disabled patient with a total (worst) score of 55. The mean score for physical, intellectual, and both disabilities were 34.7, 36.1, and 34.6, respectively. Intellectual disability caregivers had a slightly higher mean score which indicates a worse quality of life, however, those scores were not statistically significant;  $F = 1.4$ ,  $df = 2$ ,  $p = 0.25$ .

### Social impact score

There were 8 different questions addressing the social impact on the caregiver of a disabled patient with a total (worst) score of 40. The mean score for physical, intellectual, and both disabilities were 24.8, 24.3, and 25.2, respectively. Intellectual disability caregivers had a slightly lower mean score which indicates a slightly better quality of life in comparison to other categories, however, those scores were not statistically significant;  $F = 0.7$ ,  $df = 2$ ,  $p = 0.48$ .

### Financial impact score

There were 5 different questions addressing the financial impact on the caregiver of a disabled patient with a total (worst) score of 25. The mean score for physical, intellectual, and both disabilities were 12.0, 9.9, and 11.6, respectively. Again, Intellectual disability caregivers had a lower mean score which indicates less financial impact in comparison to other categories. The difference in scores was statistically significant;  $F = 3.4$ ,  $df = 2$ ,  $p = 0.03$ .

### Abuse score

There were 5 different questions addressing the feeling of abuse of the caregiver by the disabled patient with a total (worst) score of 25. The mean score for physical, intellectual, and both disabilities were 9.9, 10.5, and 10.6, respectively. It showed that the caregiver of the physical disability patient feels less abused than other categories. Whoever, the difference was not statistically significant;  $F = 0.85$ ,  $df = 2$ ,  $p = 0.42$ .

### Physical impact score

There were three different questions addressing the physical impact on the caregiver of a disabled patient with a total (worst) score of 15. The mean score for physical, intellectual, and both disabilities were 8.9, 8.5, and 9.1, respectively. Intellectual disability caregivers had slightly lower mean scores which indicate slightly less physical impact, however, those scores were not statistically significant;  $F = 0.46$ ,  $df = 2$ ,  $p = 0.63$ .

### Total quality of life score

There were 32 different questions addressing all different types of impact on the caregiver of a disabled patient, with a total (worst) score of 160. The mean score for physical, intellectual, and both disabilities were 90.2, 89.3, and 91.2, respectively. Overall, the Intellectually disabled caregiver had a slightly lower mean score

than other disabilities which indicates a slightly better quality of life, however, this difference was not statistically significant;  $F = 1.98$ ,  $df = 2$ ,  $p = 0.82$ .

### Discussion

Disabilities refer to a broad range of conditions that can affect an individual's physical, cognitive, sensory, or intellectual functions. Disabilities can be present at birth, develop later in life or result from an injury or illness. According to World Health Organization (WHO), more than one billion people live with some form of disability worldwide.

Physical disabilities refer to impairments in the body's physical structure or function, such as mobility difficulties, paralysis, chronic pain or loss of limbs. Cognitive disabilities affect an individual's ability to process, retain, or recall information and understand abstract ideas. Examples of cognitive disabilities include intellectual disability, learning disabilities, and dementia. Both types of disabilities can affect an individual's quality of life, social interactions, and emotional wellbeing.

Physical disabilities can cause several challenges for individuals such as mobility limitations, chronic pain, and increased risk of falls, thus leading to a decrease in the individual's physical functioning. The physical disabilities may also result in a loss of independence and reduced social involvement. Additionally, individuals living with physical disabilities may face several difficulties in daily life activities such as transportation, self-care, and household activities.

Cognitive disabilities can affect an individual's ability to understand and communicate in daily life activities. For instance, individuals living with intellectual disabilities may struggle with abstract reasoning, vocabulary, and problem-solving. Therefore, cognitive disabilities can lead to limited educational and employment opportunities, social isolation, and emotional disturbances.

Disabilities do not only affect the individual living with a disability, but it also imposes a significant burden on the caregivers who provide care and support. Caregivers refer to individuals who assist and provide support to disabled individuals in their daily living activities. Caregiving can be a demanding and challenging experience as it requires significant time, energy, and emotional investment.

Caregivers can face several challenges when caring for an individual with a disability, such as increased risk of burden, stress, financial strain, lack of social support, and decreased physical and psychological wellbeing. Caregiving responsibilities can result in a significant impact on the caregiver's quality of life, including their mental health, social relationships, and physical health.

Physical disabilities also impose an additional burden on caregivers. Caregivers of individuals with physical disabilities may experience significant physical and emotional stress due to the increased demand for care and assistance, including lifting, transferring, and repositioning the patient. This can lead to physical exhaustion, injuries, and increased risk of chronic conditions such as depression, anxiety, and cardiovascular disease. Similarly, a study was conducted on family caregivers of patients with spinal cord injuries. It emphasizes on the fact that taking care of a spinal cord injury patient can impact the levels of leisure and social activities of the caregiver, which in turn can influence caregivers' depression.

Likewise, caregivers of individuals with cognitive disabilities may face increased stress and burden due to the lack of social and educational opportunities, leading to reduced employment options, and financial hardship. It can significantly impact the caregiver's quality of life, including emotional stress, sleep disturbances, and difficulty in managing personal responsibilities.

This study aimed to investigate the impact of physical vs. cognitive disability on the quality of life of caregivers in Jeddah, Saudi Arabia. The study explored the physical, psychological, social, and financial aspects of the quality of life of caregivers for different types of disabilities.

The results showed that caregivers of patients with both physical and cognitive disabilities had lower quality of life than those caring for only physical or only cognitive disabilities. Specifically, caregivers of both types of disabilities reported lower quality of life on social, abuse, and physical impact. These findings are similar to a previous study on Direct support professionals of developmental disabilities patients. The study results showed the negative impact on the caregivers' quality of life due to patient aggression. Moreover, the study found that the caregivers who are the primary source of human contact to their patients suffer more from violent behaviors.

Moreover, the study reported that caregivers of patients with intellectual disabilities had lower quality of life on psychological impact while caregivers of patients with physical disabilities had poorer quality of life on the financial impact. Caregivers for both types of disabilities experienced a significant burden on their physical and emotional well-being due to the time and effort they contributed in taking care of their relatives.

The population of interest in Jeddah, Saudi Arabia is a particularly challenging group as they have limited access to resources and awareness of the needs of caregivers. The findings of this study can be used to inform policies and interventions aimed at improving the quality of life of caregivers in Saudi Arabia. Additionally, these findings can help raise awareness of the impact of disabilities on caregivers and the need for resources and support for those caring for disabled individuals.

The study encountered several challenges during the data collection process, which could have impacted the validity and reliability of the results. Firstly, there were issues with non-compliance from some departments and facilities to distribute and ask caregivers to complete the survey, which could have resulted in a biased sample. Moreover, some institutions refused to give permission to conduct the study, which further limited the sample size and generalizability of the findings.

Another limitation was the scheduling and session distribution protocol, which resulted in patients being seen more than once a week, making it less efficient and time-consuming to interview a larger number of caregivers. The social workers were also not cooperative, which made it challenging to contact and recruit eligible participants for the study.

Furthermore, other unmeasured and uncontrolled factors could have influenced the study's outcome, such as the caregivers' level of education, geographic location, and socio-economic status. These factors could have impacted the study's external validity and the generalizability of the findings to other populations.

The findings of this study have several important implications for improving the lives of both caregivers and disabled individuals in Saudi Arabia. One of the strengths of this study is the novelty of the topic. Limited studies address caregivers' quality of life, particularly in the Kingdom of Saudi Arabia. The unique focus on

comparing the quality of life of caregivers for physically versus cognitively disabled persons in the Kingdom of Saudi Arabia adds to the growing body of knowledge on this important topic. Furthermore, the study's inclusion of five different impacts allows for more accurate comparisons between the participants. This comprehensive measurement approach provides greater insight into the specific areas where caregivers experience the most significant challenges.

Based on the findings of this study, several recommendations can be made to improve the quality of life of caregivers for disabled individuals. Policies and interventions should be developed to provide more support and resources for caregivers of both physically and cognitively disabled persons. These resources could include educational programs, relief care, counseling services, and financial support.

Additionally, healthcare professionals should be educated about the impact of disabilities on caregivers and should provide emotional and practical support to caregivers. One way to achieve this is through training programs for healthcare workers, social workers, and caregivers that focus on caregiving and promoting self-care.

The study's results also underscore the need for increased public awareness in the Kingdom of Saudi Arabia about the challenges faced by caregivers, particularly those caring for individuals with physical and cognitive disabilities. This could be achieved through public education campaigns, social media outreach, and community-based events. Another important implication of this study is the need for greater collaboration between health and social care providers in the Kingdom of Saudi Arabia. This would help ensure caregivers have access to the necessary resources and support, such as referrals to support groups or relief care services, to help ease their burden.

Furthermore, this study could be used as a basis for further research on the quality of life of caregivers for disabled individuals in other regions of the Kingdom of Saudi Arabia. This could help identify additional challenges and barriers unique to other regions and guide the development of tailored interventions to meet the specific needs of caregivers in these regions.

## Conclusion

This research demonstrated that disabilities not only affect the patients but also the caregivers, and the severity of the disability demands higher levels of care and effort. The findings of this study highlight the importance of support and resources for caregivers of disabled individuals, particularly for those caring for patients with both cognitive and physical disabilities.

## Conflict of Interest

The authors declare that there are no conflict of interest or financial interests related to this study.

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