# Research Paper





# Burdens Among Wives of Disabled People in the Light of Some Social Variables

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# **ABSTRACT**

**Objectives:** This study aims to identify the burdens among wives of disabled people in the light of some independent variables.

**Methods:** In this descriptive cross-sectional study, 197 domestic wives were surveyed using a standardized questionnaire to measure the burden among wives of disabled people. Data were collected using the independent variables and Zarit caregiver burden scale (ZCBS) for burden. The study was conducted using interview techniques and analyzed via SPSS software, version 20 using descriptive and inferential statistical methods.

**Results:** The study results showed that the average age was 35 years old, 30-39 years old, 52.3% were secondary school graduates, 68.5% were families with 1-4 children, 43.1% had insufficient income, and 61.4% were employed. Significant differences were observed in wives' burdens in terms of their age, education level, family size, income, occupation, disability types, reasons, and duration (P<0.05).

**Discussion:** Wives of disabled people live under significant burdens influenced by different independent variables depending on individual differences. Decision makers should give employment priority to the wives of the disabled to protect the family and fulfill its needs, as well as the need to focus on societal awareness of disability and what the wife and family of the disabled suffer.

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# **Highlights**

- The burdens facing wives of disabled people were very significant.
- Wives younger than 40 years old who are illiterate and live in large families with limited income and unemployed whose husbands have mental disabilities, and long-term disability due to illness or accidents are considered a significant burden.

# Plain Language Summary

Women face many burdens and problems due to the differentiation between the genders based on traditional culture, and these burdens are more evident if the focus is on the wives of the disabled. The burdens vary according to individual characteristics, including age, educational level, family size, monthly income, employment status, and type and duration of disability. The role of various institutions, including the family foundation, and public and private institutions in the rehabilitation of people with special needs is highlighted in issues of material and moral support. Supporting the wives of the disabled to adapt and reduce these burdens, difficulties, and deficiencies in the support process is one of the vital priorities to ease the burdens and integrate them into society.

#### Introduction

uman societies in the world are increasingly interested in people with disabilities, and the interest has been due to the increase of the phenomenon in societies, scientific progress and the high level of health care, the increase in specialists and postgraduate studies in the field of disability [1], the high level of human awareness, and the international, regional and local legislation supporting the achievement of this goal. An increasing interest existed in the disabled and their families to invest in the potential [2]. To help him in social adaptation and psychological harmony to become a constructive element in his society, it is certain that the disabled person affects the surrounding environment in which he lives and is influenced by it. Also, the rights of the disabled as human beings, especially their right to life, marriage, and building a family are emphasized [3].

Because we live in a changing and evolving society, some countries, especially developed countries, were pioneers in the field of caring for people with disabilities, meeting their needs, and benefiting from their capabilities after their rehabilitation, which positively affects the societal view of disability [4]. In this sense, it requires us to understand the real needs of people with disabilities, as well as the needs of the supportive people whose lives they share. Among these people is the wife who suffers and faces the same problems and conditions as an ordinary wife; however, the burdens of the wives of the disabled are more complex and greater, which entail a lot of economic, psychological, and social burdens. Due to

the husband's disability, most women are forced to play the productive role in addition to the reproductive and educational role in managing the family [5], and the psychological burdens that society imposes on them based on the insignificant view of the disabled person and his family through the traditional cultural system, which makes the adjustment process difficult and arduous [6].

According to the literature review and studies on the impact of disability on the family in the local community (Iraq), few studies deal with the problems facing the wives of people with disabilities, only being interested in the disability itself and its support of the disabled [7, 8], despite the essential role of these wives in their family and husband's life with various burdens as a result of their husband's disability. This study clarified the burdens faced by the wives of the disabled according to some social variables. Therefore, it was essential to study those burdens that may sometimes cause the inability to bear them, and lead to despair and frustration, and hurt the family and the degree of its cohesion and continuity.

The researchers worked in the Ministry of Higher Education and the field of community health nursing, which necessitates linking up with rehabilitation institutions and providing social and psychological care because it noticed the problems that the disabled and their families, especially their wives suffer from. The researchers' fieldwork also allowed them to observe the increasing burdens suffered by the wives of the disabled and the increase in their complexities, whether the social, economic or psychological burden is directly or indirectly related to the disability.

#### Materials and Methods

#### Study design

This study is based on the descriptive cross-sectional approach and is the most appropriate approach to achieve its objectives. This approach is concerned with determining the current situation of the problem, and then describing, analyzing, and interpreting it using statistical analysis.

#### Study sample

The study population included 205 wives of the disabled in the Babylon Province, Iraq, and this sample represents 10% of the study population. The sample was chosen by a simple random sampling from the list of spouses registered in the Babylon Rehabilitation Center for the Disabled. After visiting the families selected for the study, only 197 wives participated in the study because 8 women refused to answer the questionnaire, motivated by covering it up as a matter of privacy.

#### Study instruments

The study tool consisted of a questionnaire, which included two main parts:

- 1) Independent variables, such as wife age, education level, family size, monthly income, occupation, types of disability, reasons for disability, and its duration.
- 2) The Zarit caregiver burden scale (ZCBS): The ZCBS, created by Zarit et al. in 1980 [9], consists of 22 items that assess how providing care affects the caregiver. Each item is rated on a 5-point Likert-type scale as never (0), rarely (1), occasionally (2), rather frequently (3), and almost always (4). The scale's lowest possible score is 0, and its maximum possible value is 88. More wives' burden is indicated by a high score. Özer et al. looked at the Turkish validity and reliability of the scale; the internal consistency ranged from 0.87 to 0.94, and the test re-test reliability was 0.71 [10].

## Validity and reliability

The questionnaire was validated by nursing experts. The pilot study was conducted on 10% of the study sample, which consisted of 20 respondents, to test the reliability of the study tool. When the respondents visited the Babylon Rehabilitation Center for the disabled, the researcher introduced himself and asked them to participate in the study by expressing their opinions on the questionnaire. After that, the researcher gave an over-

view of the objectives of the study and its title to evaluate the clarity of the study and the ease of understanding the contents of the questionnaire. Each form was expected to take approximately 20 minutes to complete. The pilot study was not included in the sample after analyzing the data and no adjustments were made. In our investigation, the Cronbach  $\alpha$  coefficient for the scale was 0.89, which indicates a satisfactory level of reliability.

#### Data collection

Actual data collection lasted about one month from July to August 2022. The researchers interviewed all study participants individually at Babylon Rehabilitation Center for the Disabled to explain the purpose of the study and asked for oral consent. The data was collected through interviews with patients according to the following criteria: Wives who had a disabled husband for 6 months, and more; and Voluntary participation. Also, the confidentiality of collected information and the privacy of the participants were assured. Study participants have the right to refuse or withdraw from the study at any time without any constraints.

#### Statistical analysis

The IBM SPSS software, version 20 was used for all the subsequent analyses. Numbers and percentages [No. (%)] were used to categorize the variables, while the Mean±SD were used to characterize the continuous variables. Multiple comparisons (the least significant difference [LSD]) post hoc tests were used to compare independent variables on burdens (ZCBS). Statistical significance was defined as a two-tailed P<0.05.

# Results

The results showed the participant's socio-demographic characteristics, the mean age is 35, age 30-39 years old was recorded the highest (39.1%). In terms of education level, more than half of the participants (52.3%) graduated from secondary school. The results related to family size showed that most families (68.5%) have 1-4 children. The results related to monthly income showed that insufficient income with 43.1% was the highest record. In terms of occupation, 61.4% of the wives were employed. Mobility was considered the most common type of disability (40%) and caused by accidents (60%) for <10 years (62.9%) (Table 1).

Table 1. Sociodemographic characteristics of children (SDVs)

SDVs	Classification	No. (%)/Mean±SD
	20-29	64(32.5)
A = 0 (v)	30-39	77(39.1)
Age (y)	≥40	56(28.4)
		35.0±6.556
	Illiterate	35(17.8)
Education local	Primary	41(20.8)
Education level	Secondary	103(52.3)
	College	18(9.1)
	Non	25(12.7)
Family size	1-4 child	135(68.5)
	≥5 child	37(18.8)
	Insufficient	85(43.1)
Income/month	Somehow	84(42.6)
	Sufficient	28(14.2)
	Employment	121(61.4)
Occupation	Free work	48(24.4)
	Unemployment	28(14.2)
	Mobility	126(64.0)
- C 11 1 1111	Visually	31(15.7)
Type of disability	Mentally	29(14.7)
	Auditory	11(5.6)
	Conditions	59(29.9)
Reasons of disability	Accidents	120(60.9)
	Genetic	18(9.1)
	From birth	14(7.1)
Duration of disability (y)	<10	124(62.9)
	>10	59(29.9)

SDVs: Sociodemographic characteristics of children.

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According to Table 2, the degree of burdens faced by the wives of the disabled in Babylon Province was significant because the percentage of the response reached (77.7%).

According to Table 3, the burdens among wives of disabled aged 20-29 years are not different from those aged 30-39 years (P=0.095); and it is different from those aged  $\geq$ 40 (P=0.018). The burdens among wives of disabled aged 30-39 years are not different from those aged 20-

**Table 2.** Burden among wives of disabled people

Burdens	Levels	No. (%)
	Low	2(1.0)
ZCBS	Moderate	42(21.3)
	High	153(77.7)

ZCBS: Zarit caregiver burden scale.

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Table 3. Comparison of the ZCBS based on age groups

(I) Age	(J) Age	Mean Difference (I-J)	Std. Error	Sig.
20.20	30-39	-0.14715-	0.08771	0.095
20-29	≥40	-0.22723-	0.09488	0.018
20.20	20-29	0.14715	0.08771	0.095
30-39	≥40	-0.08009-	0.09106	0.380
≥40	20-29	0.22723	0.09488	0.018
	30-39	0.08009	0.09106	0.380

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29 years (P=0.095) and those aged  $\geq$ 40 years (P=0.380). The burdens among wives of disabled aged  $\geq$ 40 are different from those aged 20-29 years (P=0.018), and it is not different from those aged 30-39 years (P=0.380).

According to Table 4, the burdens among wives of disabled who are illiterate are different from those who are primary (P=0.000), secondary (P=0.000), and college (P=0.002) graduates. The burdens among wives of

Table 4. Comparison of the ZCB based on education level

(I) Education	(J) Education	Mean Difference (I-J)	Std. Error	Sig.
	Primary	-0.54620-	0.11315	0.000
Illiterate	Secondary	-0.47769-	0.09620	0.000
	College	-0.43794-	0.14261	0.002
	Illiterate	0.54620	0.11315	0.000
Primary	Secondary	0.06851	0.09079	0.451
	College	0.10827	0.13902	0.437
	Illiterate	0.47769	0.09620	0.000
Secondary	Primary	-0.06851-	0.09079	0.451
	College	0.03975	0.12561	0.752
	Illiterate	0.43794	0.14261	0.002
College	Primary	-0.10827-	0.13902	0.437
	Secondary	-0.03975-	0.12561	0.752

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Table 5. Comparison of the ZCBS based on family size

(I) Family Size	(J) Family Size	Mean Difference (I-J)	Std. Error	Sig.
	1-4 child	0.60173	0.10575	0.000
Non	4 child	0.62072	0.12574	0.000
4.4.1.1.1	Non	-0.60173-	0.10575	0.000
1-4 child	>4 child	0.01899	0.09012	0.833
>4 child	Non	-0.62072-	0.12574	0.000
	1-4 child	-0.01899-	0.09012	0.833

Table 6. Comparison of the ZCBS based on monthly income

40.	40.	()	a. 1 =	
(I) Income	(J) Income	Mean Difference (I-J)	Std. Error	Sig.
Insufficient	Somehow	0.05536	0.06782	0.415
	Sufficient	-0.78749-	0.09605	0.000
	Insufficient	-0.05536-	0.06782	0.415
Somehow	Sufficient	-0.84286-	0.09619	0.000
Sufficient	Insufficient	0.78749	0.09605	0.000
Sufficient	Somehow	0.84286	0.09619	0.000

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disabled who are primary graduates are different from those who are illiterate (P=0.000); and it is not different from those who are secondary (P=0.451) and college (P=0.437). The burdens among wives of disabled who are secondary graduates are different from those who are illiterate (P=0.000), and it is not different from those who are primary (P=0.451) and college (P=0.752). The burdens among wives of disabled who are college graduates are different from those who are illiterate (P=0.002), and it is not different from those who are primary (P=0.437) and secondary (P=0.752).

According to Table 5, the burdens among wives of disabled who have no children are different from those who have 1-4 children (P=0.000) and >4 (P=0.000). The burdens among wives of disabled who have 1-4 children are different from those who do not have children (P=0.000), and it is not different from those who have >4 children (P=0.833). The burdens among wives of disabled who have >4 children are different from those who do not have children (P=0.000), and it is not different from those who have 1-4 children (P=0.833).

According to Table 6, the burdens among wives of disabled who have insufficient income are not different from those who are somehow sufficient (P=0.415); and it is different from those who have sufficient income (P=0.000). The burdens among wives of disabled who are somehow sufficient are not different from those who are insufficient (P=0.415), and it is different from those who have sufficient income (P=0.000). The burdens among wives of disabled who have sufficient income are different from those who are insufficient (P=0.000) and those who have somehow sufficient income (P=0.000).

According to Table 7, the burdens among wives of disabled who are employed are not different from those who have free work (P=0.689); and it is different from those who are unemployed (P=0.000). The burdens among wives of disabled who have free work are not different from those who are employed (P=0.689), and it is different from those who are unemployed (P=0.000). The burdens among wives of disabled who are unemployed are different from those who are employed (P=0.000) and those who have free work (P=0.000).

Table 7. Comparison of the ZCBS based on occupation

(I) Occupation	(J) Occupation	Mean Difference (I-J)	Std. Error	Sig.
Employment	Free-work	-0.03270-	0.08169	0.689
	Unemployment	-0.63002-	0.10043	0.000
Free-work	Employment	0.03270	0.08169	0.689
	Unemployment	-0.59732-	0.11388	0.000
Unemployment	Employment	0.63002	0.10043	0.000
	Free-work	0.59732	0.11388	0.000

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Table 8. Comparison of the ZCBS based on type of disability

(I) Disability	(J) Disability	Mean Difference (I-J)	Std. Error	Sig.
	Visually	-0.02881-	0.10257	0.779
Mobility	Mentally	0.35751	0.10537	0.001
	Auditory	0.00746	0.16084	0.963
	Mobility	0.02881	0.10257	0.779
Visually	Mentally	0.38632	0.13216	0.004
	Auditory	0.03627	0.17954	0.840
	Mobility	-0.35751-	0.10537	0.001
Mentally	Visually	-0.38632-	0.13216	0.004
	Auditory	-0.35005-	0.18116	0.055
Auditory	Mobility	-0.00746-	0.16084	0.963
	Visually	-0.03627-	0.17954	0.840
	Mentally	0.35005	0.18116	0.055

According to Table 8, the burdens among wives of disabled husbands with motor disabilities are not different from those who have visual (P=0.779) and audio (P=0.963) disability; and it is different from those who have mental disability (P=0.001). The burdens among wives of disabled husbands with visual disability are not different from those who have a motor (P=0.779) and audio (P=0.840) disability, and it is different from those who have a mental disability (P=0.004). The burdens among wives of disabled husbands with mental disability are different from those who have a motor (P=0.001), and visual (P=0.004) disability, and it is not different from those who have audio (P=0.055) disability. The burdens among wives of disabled husbands with audio disability are not different from those who have motor (P=0.963), visual (P=0.840), and mental (P=0.055) disability.

According to Table 9, the burdens among wives of disabled husbands caused by conditions are not different from those who are disabled caused by accidents (P=0.722); and it is different from those who are disabled caused by genetics (P=0.000). The burdens among wives of disabled husbands caused by accidents are not different from those who are disabled caused by conditions (P=0.722), and it is different from those who are disabled caused by genetic are different from those who are disabled caused by conditions (P=0.000), and it is different from those who are disabled caused by accidents (P=0.000)

Table 9. Comparison of the ZCBS based on the reasons for disability

(I) Reasons	(J) Reasons	Mean Difference (I-J)	Std. Error	Sig.
	Accidents	-0.02719-	0.07643	0.722
Conditions	Genetic	-0.75728-	0.12942	0.000
Assidonts	Conditions	0.02719	0.07643	0.722
Accidents	Genetic	-0.73009-	0.12149	0.000
Genetic	Conditions	0.75728	0.12942	0.000
	Accidents	0.73009	0.12149	0.000

Table 10. Comparison of the ZCBS based on the duration of disability

(I) Duration	(J) Duration	Mean Difference (I-J)	Std. Error	Sig.
	<10 years	0.52884	0.14335	0.000
From birth	>10 years	0.52744	0.15115	0.001
<10 years	From birth	-0.52884-	0.14335	0.000
	>10 years	-0.00140-	0.08041	0.986
>10 years	From birth	-0.52744-	0.15115	0.001
	<10 years	0.00140	0.08041	0.986

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According to Table 10, the burdens among wives of disabled husbands from birth are different from those who are disabled for <10 years (P=0.000), and >10 years (P=0.001). The burdens among wives of disabled husbands for <10 years are different from those who are disabled from birth (P=0.000); and it is not different from those who are disabled for >10 years (P=0.986). The burdens among wives of disabled husband for >10 years are different from those who are disabled from birth (P=0.001), and it is not different from those who are disabled for <10 years (P=0.986)

#### Discussion

Analyzing the diverse characteristics of respondents is a pivotal factor when it comes to understanding and assessing the challenges faced by individuals with disabilities and their families. This information serves as a vital foundation for devising strategies for economic and social development and crafting effective policies. These initiatives are aimed at fostering comprehensive development that empowers these families to not only adapt socially but also to unearth and refine their hidden potentials, transforming them into active and productive

contributors to society instead of being passive service recipients. Furthermore, this approach has the added benefit of enabling other family members to lead dignified lives, fulfill their needs, and tackle various challenges and obstacles. The examination of these distinct characteristics also provides essential insights for policymakers, facilitating the creation of informed, targeted solutions for a wide range of issues.

Living with a sick or disabled relative has a detrimental emotional, social, and financial impact on the person. Strong family relationships and the preservation of traditions can be found in Iraq. Therefore, family members share both joy and sorrow. The care for crippled individuals continues throughout their life due to this distinctive aspect of Iraqi civilization. The caregivers (wives) in this procedure are mostly first-degree relatives. They occasionally assist with the care of the disabled and offer emotional support. This gives the caretaker emotional gratification; however, unfavorable living conditions may result in many problems. Therefore, we found that the degree of burdens faced by the wives of the disabled in Babylon Province was significant due to the lack of support and care provided to the disabled and their fami-

lies by state institutions and society. Since the disabled in Babylon Province do not receive sufficient support from society and government institutions [8], more studies should be conducted to assess the quality of services provided to the disabled in rehabilitation centers.

In this study, a significant relationship was observed among the wives of disabled age and their burden. The burden is significant among wives of disabled aged <40 years old because they are in productive ages and have more hope for life than others. That is, the young ages do not bear the burdens. Consistent with Malaysian findings, the young women have a negative perception of burdens [11]. Papastavrou et al. reported that the caregiver load considerably increased with the caregiver's age [12], which is consistent with the results of this study. Bradley et al. showed that older caregivers are more likely to feel a caregiver burden [13]. Daly et al.'s study revealed that the burden increased at a young age. In this study, young spouses carried a heavier burden since they felt they had fewer obligations beyond caring for their families [14]. The needs of young people should be considered.

Educational status is one of the factors affecting burdens among wives of disabled people. The burdens among wives of disabled who are illiterate are different from those who are primary, secondary, and college graduates. That is, the lower the educational level, the higher the burden. The impact of the educational level is due to the economic situation; therefore some of those who have not been formally educated do not have a job and face economic challenges. Hence, we found no difference in the burdens according to those with poor and moderate incomes, as those with high incomes have fewer burdens than those with limited incomes. As a result of the high level of education and minimal caregiver burden, the results from the literature are consistent with the results of this study. Papastavrou et al. found that primary school graduates had a disproportionately high caregiver burden [12]. Stenberg et al. suggested that caregivers with a bachelor's degree experienced a disproportionately low financial caregiver burden compared to others [15], and Shieh et al. suggested that high levels of education predicted a disproportionately low caregiver burden [16]. Additionally, the research conducted by Park et al. revealed that people with high levels of education had much higher levels of family support [17]. These results suggested that caregiver burden decreases with higher income and education levels because carers are less influenced by the burden of the impairment and care. The amount of the family's monthly income may be one of the crucial economic indicators to describe the extent of the family's material needs, the standard of living, and

the extent and psychological and social stability of it. Therefore, the burdens are significant for those who are insufficient and somehow sufficient.

The term family size, as adopted by the Iraqi Department of Statistics, refers to the number of individuals who live and eat together under one roof, and share the budget of the house. In this study, logically from the standpoint of the nature of support, people or heads of ordinary families can support other members of their families other than their children, such as parents or one of them, unmarried sisters, or one of the relatives. And he needs someone to help him support them from relatives or institutions. Therefore, burdens among wives of disabled with 1-4 and more children are significant than those without children because the larger the family, the greater the burdens [18].

The burdens among wives of disabled who are employed are not different from those who have free work, and it is different from those who are unemployed. Through data collection, many women have expressed their desire to work if suitable work is available that can contribute to the family's income and help them get rid of their poor economic conditions. Among the sectors in which wives of the disabled work, it turns out that women are working in the government sector, and this number works. In the private sector, two wives work as freelancers, such as a small grocery store. As for the others, we found a wife who works cleaning the homes of some neighbors, while one wife practices begging. According to this study, Stenberg et al. study revealed that carers who were jobless had a much higher financial burden and significantly less family support than those who were employed [15]. Given the circumstances, it can be concluded that carers who are employed enjoy greater economic power, a more sociable atmosphere, and better access to social support.

The most mobile type of disability is considered to be 64%, followed by people with visual disability (15.7%), mental (14.7%), and auditory (5.6%) disabilities. Among the type of disability, the mental disability was significantly associated with wives burdens [19]. It is now clear that many reasons lead to the occurrence of disabilities, as the data indicated that 29.9% of the disabilities occurred due to illness (conditions), while various accidents (road accidents and work accidents) contributed approximately (60.9%) while the lowest percentage of disability is genetic factors (9.1%). The burden is significant with disability caused by illness and accidents [8]. Thus, disability occurs in different stages of a person's life, as disability appears with a person's birth or, perhaps by accident during his life cycle. Disability rates are often greater in the early stages of life due to diseases and accidents, or they

appear in the later stages of life due to diseases of aging and laziness of some body systems. The higher duration of disability is a significant burden [11]. The data showed that most disabilities occurred in the youth stage, and this is evidence that most disabilities are motor disabilities that resulted from injuries from various sources, such as work injuries, car accidents, or injuries due to war [21].

#### Conclusion

Wives of the disabled live under enormous burdens in various economic, psychological, and social aspects, influenced by different independent variables. Material assistance and psychological and social support significantly contribute to reduce these burdens so that disabled people and their families can live with dignity. Decision makers must give the employment priority to the wives of the disabled to protect the family and fulfill its needs, as well as the need to focus on societal awareness of disability and what the wife and family of the disabled suffer through courses and seminars towards a new culture that respects the disabled person and his rights.

#### Study limitation

Many wives of the disabled refused to participate in the study due to haste and lack of consideration for the researchers or their reservations, which made it difficult to gather the participants in the study.

## **Ethical Considerations**

#### Compliance with ethical guidelines

The ethical approval was obtained from the Research Ethics Committee of Kut Technical Institute, Middle Technical University (No.: 612, dated 25/5/2022). All experimental protocols were approved by the Health Directorate, and all experiments followed approved guidelines.

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#### Authors' contributions

Conceptualisation and supervision: All authors; Data collection: Mohammed Malih Radhi; Data analysis: Mohammed Malih Radhi; Investigation and writing original draft: Mohammed Malih Radhi; Review and editing: Gossoon Juma Elywy and Qasim Abbas Khyoosh Al-Eqab.

#### Conflict of interest

The authors declared no conflict of interest

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