

# TraPCAf & Parkinson's Africa Virtual Support Group Series 2024

## TOPIC: CAREGIVER SUPPORT

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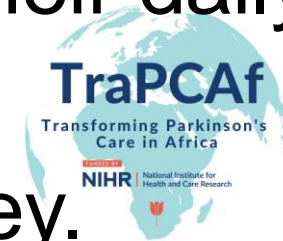
## Introduction:

- Introduction
- Define caregiver.
- Describe the role of a caregiver.
- Discussion of challenges of caregiving with case scenario.
- Discussion of recommendations.
- Previous study findings from the African (Ghana) setting.
- Conclusion.



## Outline of session:

- Parkinson's disease (PD) is a progressive neurodegenerative disease (Berg et al 2014).
- As the disease progresses, persons with PD find it very difficult to handle their own safety, perform activities of daily living, take their medications and even involve in social interactions (Bhimani, 2014) .
- As a result, persons with PD require help in their daily lives to maintain a good quality of life.
- This is where the caregiver's role becomes key.



## Definition of a caregiver

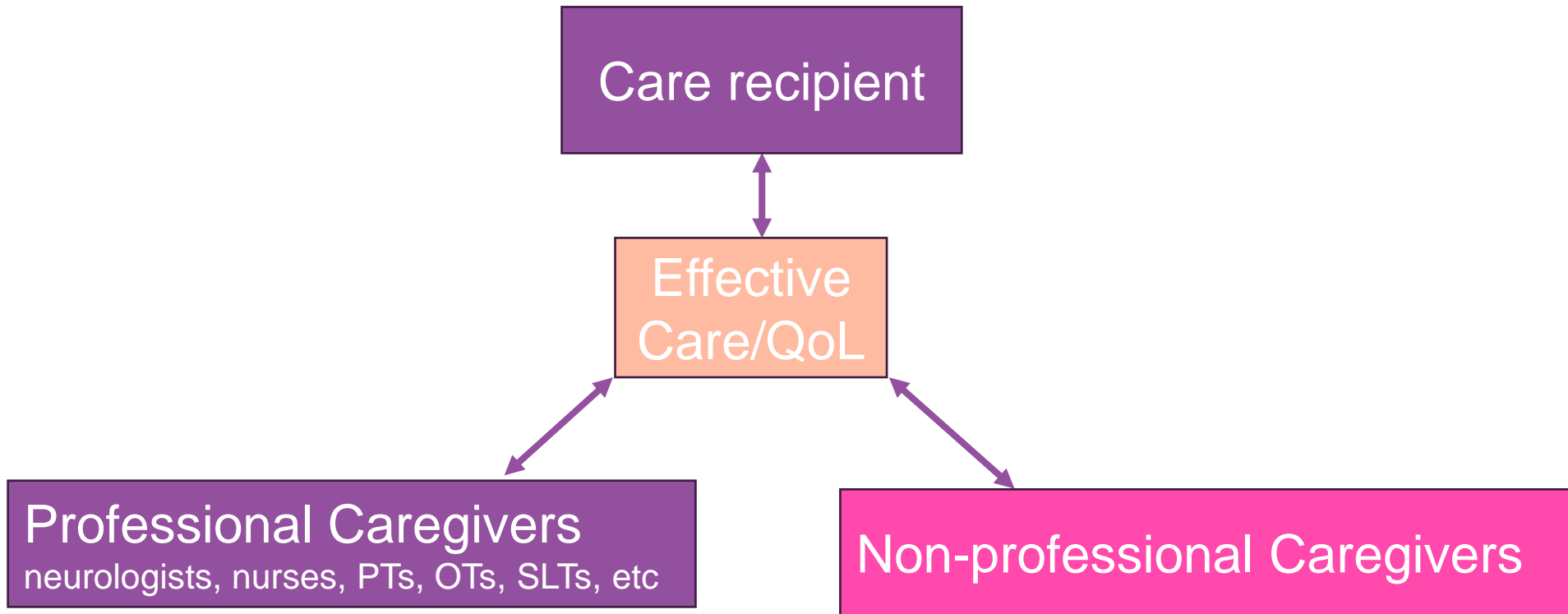
Discussion points;

Caregivers play a key role in the healthcare and daily activities of persons with Parkinson's disease. So,.....

Who is a caregiver?  
Are you a caregiver?



# Definition of a caregiver



## Definition of a caregiver

- **“a person who tends to the needs or concerns of a person with short- or long-term limitations due to illness, injury or disability” is a caregiver.**
- Caregiving could be paid or non-paid role.
- The non-paid caregivers are mostly family members, referred to as family caregivers or care partners (Bhimani (2014)).
- This could be a spouse, adult child, extended family members, close friends, members of congregation, or neighbors.



## Role of the Caregiver

- The caregiver provides support for the day to day activities of daily living for, and act as a valuable source of information about, the persons with PD.
- The extent of care provided could depend on the stage of PD or level of disability.



## Role of the Caregiver

- These include but not limited to;
  - Taking patient for medical appointments
  - Purchasing and/or organizing medications.
  - Communicating with healthcare professionals.
  - Advocating on patients' behalf with providers and agencies





## Role of the Caregiver

- Assisting patients in and out of beds/chairs
- Assisting with dressing, bathing/showering, laundry/ironing, grocery/shopping.
- Helping with housework.
- Preparing meals.
- Managing finances.



## Challenges of caregiving with case scenario - Caregiver Journey of MA

MA is a 50 year old woman, married with 3 children, aged 20 yrs, 15 yrs and 7yrs.

Her husband, Mr. Tanko (MT), 60years, has been diagnosed with PD (5years now). Mr. Tanko voluntarily retired at 58 yrs due to PD and other co-morbidities (hypertension & diabetes).

MA now bears more of the financial burden at home as all their children are still in school and the need to buy medications/pay for other health services.

Due to hospital appointments, MA has to constantly seek permission from work to accompany her spouse to the hospital.

She is responsible for everything in the home and can hardly attend her women's fellowship meetings.

MA sometimes gets frustrated by MT's demands.



# What are the pressing issues for MA?

Lets discuss



## Challenges of caregiving with case scenario - Caregiver Journey of MA

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MA now bears more of the **financial burden** at home as all their children are still in school and the need to buy medications/pay for rehabilitation.

Due to hospital appointments, MA has to **constantly seek permission from work** to accompany her spouse to the hospital.

She is **responsible for everything** in the home and **can hardly attend her women's fellowship meetings.**

MA sometimes gets **frustrated** by MT's demands.



## Discussion of recommendations to reduce the burden of care

What suggestions/recommendations can be given to MA?



## Discussion of recommendations to reduce the burden of care

- Financial support from family/friends (get government social supports if available).
- Advocate for PD medications and care to be fully covered by health insurance.
- Get assistance from others (family/friends).
- Accept help and make conscious arrangements to attend functions as much as possible.
- Have frank and open conversations about things that frustrates her.
- Exercise patience and understand the patient's needs.



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**Objective:** To determine the burden of caregivers in caring for persons with Parkinson's disease and establish the relationship between the burden of care and the caregiver's quality of life (QoL).

## Background

- PD is a neurodegenerative disease presenting with motor and non-motor symptoms, that limits ability to function independently, hence require the help of caregivers [1].
- The disease does not affect only the patients, but also has an impact on the caregivers and places a huge burden which directly affects their QoL.
- Therefore, it is essential to identify the burden of caregiving and find ways of maximizing the QoL of the caregiver as this directly affects their care for the patients [2].

## Methods

- A cross sectional survey was conducted and participants were purposefully sampled into this study.
- The Modified Caregiver Strain Index (MCSI) questionnaire and the PD Carer Questionnaire (PDQ – Carer) were used to assess the burden and QoL respectively.
- The study population included all primary caregivers of persons diagnosed with PD who visited the Physiotherapy and Neurology units of the Korle-Bu Teaching Hospital.
- The data collected was keyed into Microsoft Excel 2016, and analyzed using Jamovi (version 1.8.4).
- The results were summarized with tables and figures.
- The ordinal logistic regression analysis was used to analyze the relationship between participants' burden of care and their QoL. The level of significance was set at  $\alpha \leq 0.05$ .

## Results

- A total of 21 caregivers with 17 females (table 1) were recruited.
- The ages ranged from 24 to 71 years with 42.9% of the caregivers being spouses.
- The overall mean MCSI score was 14.1 ( $\pm 5.76$ ) and ranged from 4 to 24.
- Twelve (57.1%) participants recorded moderate level of stress, three (14.3%) were highly stressed and six (28.6%) were not stressed.
- The top three causes of burden were the inconvenience that came with caregiving, upsetting behaviors of patients and work adjustments.
- The mean score obtained on the PDQ-Carer was 40.7 ( $\pm 16.3$ ) and ranged from 10.4 to 68.9.
- Majority of the participants (n=19/21, 90.5%) had a normal QoL while two (9.5%) had severely compromised QoL life.
- There was a significant relationship ( $Z=2.366$ ,  $p=0.018$ ) between the overall QoL and burden of care.

## Conclusion

Some caregivers of persons with PD in Ghana are moderately burdened with a few demonstrating severely compromised QoL. Also, the overall QoL of the caregivers is significantly influenced by the burden of caregiving.

Table 1: SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

	Variables	Number (n)	Percentages (%)
Age (Years): Mean $\pm$ SD (range)	Male	4	40.8 $\pm$ 13.9 (24-58) *
	Female	17	51.9 $\pm$ 15.9 (24-71) *
Gender	Male	4	19
	Female	17	81
Occupation	Baker	1	4.8
	Caregiver	5	23.8
	Court Process Server	1	4.8
	Housewife	3	14.3
	Pensioner	1	4.8
	Petty Trader	1	4.8
	Trader	1	4.8
	Retired Teacher	4	19
	Retired Nurse	1	4.8
Marital Status	Retired Caterer	1	4.8
	Father	1	4.8
	Divorced	2	9.5
	Married	13	61.9
Relationship to Patient	Single	5	23.8
	Widow	1	4.8
	Child	2	9.5
Duration of Caregiving	Family Member	5	23.8
	Paid Caregiver	5	23.8
	Spouse	9	42.9
Time Spent in a Week Caregiving	<12 Months	5	23.8
	$\geq$ 12 Months	16	76.2
SD: Standard Deviation. *These were represented in years.	From 21-36 Hours Per Week	17	81
	>36 Hours Per Week	4	19

## References

1. Bhimani, R. (2014). Understanding the burden on caregivers of people with Parkinson's: A scoping review of the literature. *Rehabilitation Research and Practice*, 2014, 1-4.
2. Martinez-Martin, P., Rodriguez-Blazquez, C., & Forjaz, M. J. (2012). Quality of life and burden in caregivers for patients with Parkinson's disease: Concepts, assessment and related factors. *Expert Rev. Pharmacoecon. Outcomes Res*, 12(2), 221-230.



## Conclusion

- There is joy and satisfaction in caregiving, keep that focus.
  - Accept help when needed.
- Don't feel bad about taking a break. It is good for your quality of life.
- Thank you for all you do and continue to do as a caregiver.
  - Your efforts are much appreciated.





➤ **THANK YOU FOR YOUR ATTENTION**

➤ **ANY QUESTIONS**



## References

- Berg D, Postuma RB, Bloem B, Chan P, Dubois B, Gasser T, et al. Time to redefine PD? Introductory statement of the MDS Task Force on the definition of Parkinson's disease. *Mov Disord*. 2014;29(4):454–62.
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- Bhimani, R. (2014). Understanding the burden on caregivers of people with Parkinson's: A scoping review of the literature. *Rehabilitation Research and Practice*, 2014, 1-4.



# Thank you!

For more information and resources visit: [www.parkinsonsafrica.org](http://www.parkinsonsafrica.org)

Get in touch if you have a query: [tania@parkinsonsafrica.org](mailto:tania@parkinsonsafrica.org)

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