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Helping Carers to Care: implementation of the 10/66 Dementia Research Group caregiver intervention in rural Benin.

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Background

In sub-Saharan Africa, the number of people living with dementia (PWD) is expected to double every 20 years, reaching 7.6 million in 2050. The shortage of trained health professionals leads family members of older people living with dementia to provide informal care. However, lack of knowledge and understanding about dementia leads to difficulties. There is therefore an urgent need to develop interventions to improve the lives of people with dementia and their families in this region.

Main objective

The objective of this study was to determine the feasibility of the Helping Carers to Care (HC2C) caregiver intervention in rural Benin.



Methods

Study design: before-and-after quasi-experimental study, January to December 2022
Setting: Djidja-Abomey-Agbangnizoun, Benin (West Africa)
Participants: two groups of 30 dyad (caregiver / person with dementia)
Intervention: three modules: 1) assessment ; 2) basic education about dementia ; and 3) training regarding problem behaviours
Outcome measures:
 – Carer: Zarit Burden Interview (ZBI) and quality of life (WHO-QoL-Bref)
 – PWD: quality of life (DEMQOL)
Evaluation: before and after intervention, 3-months and 6-months
Ethics: Approval was obtained from the Ethics Committee of the University of Parakou (0401/CLERB-UP/P/SP/R/SA)

Results

Study population : only 22 PWD + primary caregiver could be recruited.

Randomly divided into two groups (ie. 11 dyads) - control / intervention. Groups were similar regarding sex, education, marital status, dementia severity but not age (87 y.o. controls vs. 74 y.o. intervention)

Before intervention: better QoL in the intervention group, lower strain in the control group.

Participation rate: 100%

	Control - change*	Intervention - change*	p-value
Carer Quality of Life (WHO-QoL-Bref)			
Physical	0 (0-0.5)	0 (-0.5-0)	0.30
Psychological	0 (0-1)	0 (-1.5-1)	0.50
Social	-1 (-3.5-0.5)	-1 (-3-0)	0.95
Environnemental	0 (-1-2)	-1.5 (-1.5-0)	0.10
Carer's strain (ZBI)	-5 (-8-4)	3 (-2-9)	0.11
PWD Quality of Life (DEM QOL)	5 (0-8)	-4 (-21-1)	0.023

* Median (IQR)

Table 1. Differences in scores before / after intervention, Benin, 2022

Discussion

- Number of participants lower than expected -> dementia diagnosis lacking in rural areas / in the community
- Intervention provided by community workers, not health workers as in previous studies (Guerra et al., 2011, Gavrilova et al., 2009, Dias et al., 2008)
- All sessions were implemented but not always once/week due to the lack of availability of carers and community workers

Conclusion

Despite high participation rates, implementation through community relays was challenging in rural Benin, where dementia awareness is low and care structures lacking. Results on effectiveness of this caregiver intervention delivered in rural Benin will add to scarce evidence available in LMIC.