



Fundació
La Marató de TV3
20th SYMPOSIUM
Neurodegenerative diseases



**EVALUATION OF AN INNOVATIVE INTERVENTION
(INFORMATIVE, FORMATIVE AND OF SOCIAL SUPPORT)
"INFOSA-DEM" TO INFORMAL CAREGIVERS OF PEOPLE
WITH DEMENTIA LIVING AT HOME**

Adelaida Zabalegui Yárnoz

Hospital Clínic i Provincial de Barcelona

1. Summary

Most elderly people with dementia are cared for at home by a family member, usually a spouse, partner or relative. In Spain, family members carry out most of the care voluntarily and informally. This situation can cause additional negative effects on the caregiver's health, such as deterioration of physical and mental health, financial difficulties, work problems and even loss of social relationships.

The INFOSA-DEM program was designed and implemented to respond to the needs of informal caregivers (IC) of people with dementia (PwD) by providing disease-specific information and education on home care of people with dementia, analyzing the impact on the quality of care and quality of life of the PwD and their IC, evaluating the permanence of the positive effect of the intervention three months and six months after the intervention. Likewise, specific home care scenarios have been identified, specific for patients with dementia and their informal caregivers in our population, related to the results of *Balance of Care* and the degree of satisfaction of the program participants.

For this purpose, a longitudinal study was carried out with repeated observations (pre-test, post-test I and post-test II). Almost-Experimental Design, with sampling method and intentional assignment in Intervention Group (IG) and Control Group (CG), based on the availability to attend the sessions that compose the program. The study was carried out in Barcelona, with the influence of several primary care centers and day care centers for PwD and their caregivers. We selected 160 PwD living at home and their carers who met the inclusion and exclusion criteria set from the beginning of the study. The sample was selected for convenience with consequent assignment to CG and IG.

Development of the intervention: INFOSA-DEM Program

A list of public and private community resources directed to IC was drawn up and subsequently, with the participation of a multidisciplinary group of trained experts (nurses, geriatricians, neurologists, social workers) to validate the design, the content and reliability of the intervention, the informative material for the delivery of the sessions and for the creation of the practical guide for caregivers of PwD. Four videos were created that reflect the daily life of the home care of PwD, with the participation

of an audiovisual producer and experienced actors, and under the guidance of the research group on dementia and its care they created a story that shows the family experiences from the moment a family member is diagnosed with dementia. The videos are created under the slogan of "living with dementia" and deal with topics such as:

- Wandering (<https://www.youtube.com/watch?v=2hf--uUSFEY&index=17&list=PL6JHr3EeRES4FJPytpLpkBgbGmqHxQjib>);
- Communication (<https://www.youtube.com/watch?v=J5NYAzLeCkc&list=PL6JHr3EeRES4FJPytpLpkBgbGmqHxQjib&index=15>);
- Disorientation (<https://www.youtube.com/watch?v=3634ZQV7qq0&list=PL6JHr3EeRES4FJPytpLpkBgbGmqHxQjib&index=16>);
- Selfcare (<https://www.youtube.com/watch?v=KNDo6l-LOtw&index=14&list=PL6JHr3EeRES4FJPytpLpkBgbGmqHxQjib>).

A pilot test of the intervention was conducted on six IC of PwD, a survey of 18 questions, related to the structure of the program, content, dynamics of the sessions and amount of information provided. The feedback from the participants was positive in terms of content and structure of the intervention, so the number of sessions was reduced from 8 to 5 and modifications were made to synthesize the concepts and increase the time spent in each session.

BoC approach to classify PwD and IC in vulnerable groups

Specific home care scenarios targeted at PwD and their ICs were identified, based on the results of the *Balance of Care Model* (BoC). Among those that stand out are:

- Classification of caregivers based on the phase of the disease in which the patient is (initial, moderate or severe). related to cognitive impairment.
- Classification based on the patient's level of dependence.
- Classification according to the presence of neuropsychiatric symptoms.
- Classification based on family and social support (paid caregiver, help from other family members, attendance at a day center or hospital, etc.)
- Identification of geographical areas of interest for the study.

Posters and informative sheets were prepared, with information of the program and contact data. National public television TV2 (<http://www.rtve.es/alcanta/videos/tips/tips-vida-sana-acordarse-memoria/3863705/>) and local (<https://www.youtube.com/watch?v=eZPiuNAFdU>) collaborated in the promotion of the project in a single broadcast.

Contents of the INFOSA-DEM Program

The INFOSA-DEM program consists of five information/training sessions given consecutively during one week, with an approximate duration of 90 min/session/day. It has been developed for small groups of 8 to 10 caregivers. Topics include: basic concepts of dementia and care in specific topics such as nutrition, rest, medication, physical and cognitive alterations and management of behavioral symptoms, affective problems of PwD and in IC, verbal and non-verbal communication techniques, caregiver self-care, as well as information on available community resources and services. At the end, a practical guide for caregivers was handed out, summarizing the topics covered in the program.

2. Results

A total of 160 ICs took part in the study. They were recruited from the participating centers and 74 and 86 caregivers were subsequently assigned to CG/IG respectively. Morning or afternoon groups were offered, depending on the availability of caregiver with a total of 7 groups of 10 caregivers and 2 groups of 8 caregivers. After the follow-up period, three more groups of 10 CG caregivers were run. At three months, the follow-up was done for 115 caregivers and at six months of the study, 112 participants went through the follow-up phase. Seventeen out of 86 IG participants dropped out or refused to continue to follow up the study (19%) and 28 out of 74 CG participants (39%) also dropped out, responding that they did not benefit from the study and/or were not available for further evaluation, or because of death or admission to a residential unit of the person with dementia. In relation to satisfaction with participation in the program, all caregivers stated that they were satisfied with the INFOSA-DEM program, as they were able to describe their particular experiences and meet other people in the same situation. All caregivers expressed feeling better about

sharing their experience as a caregiver. In terms of duration, 94% fully agreed with the length and number of sessions.

The mean age of the participating ICs was 63.7 years. 76.2% of the caregivers were women and more than 50% shared the bond of wife with the PwD, 38% of the caregivers were children. Almost 80% of the caregivers lived with the PwD. With regard to PwD, the average age of the patients was 79 years. More than 50% were women. 70% had a diagnosis of dementia and had been diagnosed for more than five years. 39% of the PwD had a partial dependence for the realization of the activities of daily living and 43% had a moderate cognitive deficit in relation to the general deterioration state (GDS). 49% had a disease added to their diagnosis of dementia and an average of 6.7% PwD had neuropsychiatric symptoms, which causes some distress in the caregiver. However, an average of 67.3% of caregivers in the baseline interview self-described good health and 68% reported normal psychological well-being, considering that 32% had a low level of psychological well-being. In relation to social support and overload, 79% of caregivers reported having a good social support network, 45% reported mild to moderate overload and 49% a high level of overload. In terms of preparation for the role of caregiver, 51% of caregivers were moderately prepared and 46% said they needed preparation.

25% of the caregivers have paid work but lose an average of 11.2 hours/week to care for their family member, because most PwD (98%) need to attend follow-up medical visits, among others. An improvement in psychological well-being (Figure 1) and in overload (Figure 2) was observed in the IC of the IG compared with a slight worsening in the CG three months after participating in the program. Regarding the positive or negative aspects of care, a statistically significant worsening in CG is observed in the interferences in daily activities and an improvement is observed in the health dimension for IG with its worsening in CG. At six months, the improvement in overload and psychological state is maintained in the IG although the differences are not statistically significant. Likewise, self-esteem and interferences in daily activities worsen in both groups but only the latter is statistically significant in the control group.

3. Relevance and possible future implications

This project allowed the development, implementation and analysis of the impact of an educational, informative and social support intervention on the quality of life and on the quality of care of people with dementia and their informal caregivers, exploring its incidence and effect on variables such as overload, depression, anxiety and others related to the health status and quality of life of caregivers and the duration of this effect over time. The program meets one of the needs expressed by caregivers for professional guidance on specific issues in their role as carer, in order to develop skills and effectively address certain strategies for the resolution of disease-related problems at home. The study serves as a reference and bibliographic support for the implementation of non-pharmacological, educational interventions aimed at a specific population group with particular needs, and being able to analyze whether the information provided, the time and number of sessions used in the intervention is adapted to the needs and availability of caregivers, and to know the main reasons for compliance or non-compliance of participants. It also serves to produce clinical guidelines and to improve the quality of life and the quality of care of informal caregivers. This program and its results allow the INFOSA-DEM intervention to be implemented in primary care centers and in the Catalan and national context.

4. Generated literature

No.	Title	Author	Magazine	Year of publication	IF
1	Costs and burden associated with loss of productivity in informal caregivers of people with dementia: Results from Spain	M. Farré; E. Risco; Zabalegui A, et al.	Journal of Occupational and Environmental Medicine	2018	1.355
2	Caring for a person with dementia on	Zabalegui A	J Am Med Dir Assoc	2017	5.325

the margins of long-term care: A perspective on burden from 8 European countries

3	Application of the balance of care model in decision-making regarding the best care of people with dementia	Risco E; Zabalegui A, Farré M, et al.	Gac Sanit	2017	1.581
4	Direct and indirect costs and resource use in dementia care: A cross-sectional study in patients living at home	Farré M; Risco E; Cabrera E; Zabalegui A, et al.	Int J Nurs Stud	2016	3.656
5	Perspective about health care provision in dementia care in Spain: A qualitative study using Focus-Group methodology	Risco E; Cabrera E; Farré M; Zabalegui A, et al.	Am J Alzheimers Dis Other Demen	2016	1.602
6	Inter-country exploration of factors associated with admission to long-term institutional dementia care: evidence from the RightTimePlaceCare	Zabalegui A, et al.	J Adv Nurs	2015	2.267

	Study				
7	The association between physical dependency and the presence of neuropsychiatric symptoms, with the admission of people with dementia to a long-term care institution: prospective observational cohort study	Risco E; Cabrera E; Zabalegui A, et al.	Int J Nurs Stud	2015	3.656
8	Dementia care in European countries, from the perspective of people with dementia and their caregivers	Zabalegui A, et al.	J Adv Nurs	2015	2.267
9	Change in quality of life of people with dementia recently admitted to long-term care facilities	Zabalegui A, et al.	J Adv Nurs	2015	2.267
10	Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European	Zabalegui A, et al.	J Adv Nurs	2015	2.267

RightTimePlaceCare

prospective cohort
study

11	Most appropriate placement for people with dementia: individual experts' vs. expert groups' decisions in eight European countries	Zabalegui A, et al.	J Adv Nurs	2015	2.267
12	The association between positive-negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: a cross-sectional study	Risco E; Cabrera E; Farré M; Zabalegui A, et al.	J Adv Nurs	2015	2.267
13	Older persons with dementia at risk for institutionalization in eight European countries: a cross-sectional study on the perceptions of informal caregivers and healthcare professionals	Risco E, et al.	J Adv Nurs	2015	2.267
14	Predicting institutional long-term care admission in dementia: a	Zabalegui A, et al.	J Adv Nurs	2015	2.267

mixed-methods
study of informal
caregivers' reports

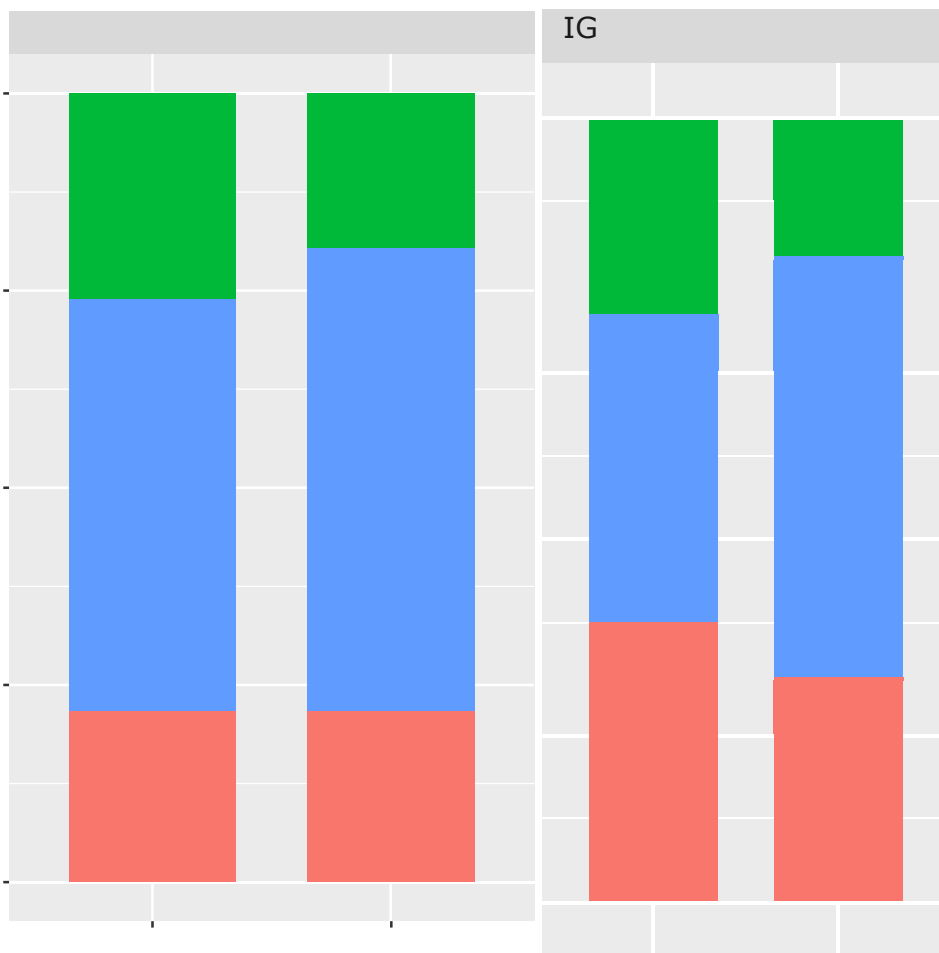


Figure 1. Difference in overload between baseline and follow-up of caregivers participating in CG/IG

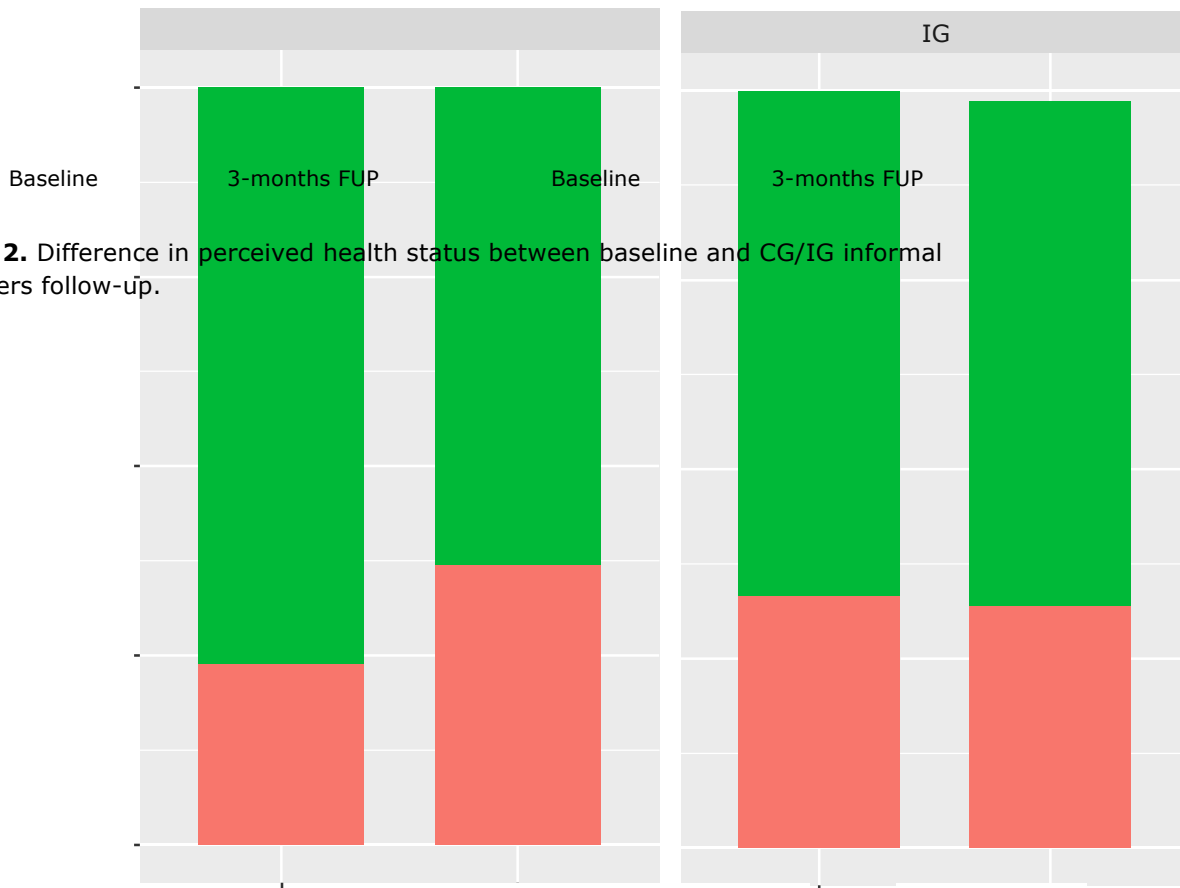


Figure 2. Difference in perceived health status between baseline and CG/IG informal caregivers follow-up.

