



Access to Timely Formal Care (Actifcare) Newsletter

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Website: www.actifcare.eu

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Editorial

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We welcome feedback on this newsletter and questions about the Actifcare project. If you would like to contact us, please email the editor:

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Or use the 'Contact Us' page of the Actifcare website

Welcome to the third newsletter of our European dementia research project Actifcare (ACcess to Timely Formal Care), of which the ultimate goal is to optimize the care for Europeans with dementia in the middle phase, by identifying best practices and finding the best fit between needs and appropriate access and use of care services. In this newsletter you can find some results of the study, an interview with a researcher, some experiences of a study participant and much more.

The end of the Actifcare study is approaching quickly. We look back at a busy but fruitful year. A lot of work has been performed during the past year. All measurements are finished, the data have been entered in MACRO and this dataset has been cleaned. The protocol paper has been published in BMC Health Services Research. Although there is a slight study delay, we have done a great job so far!

Recently the Portuguese team hosted an excellent meeting in Nova Medical School Lisbon. Besides the interactive and enthusiastic discussions, we enjoyed the delicious authentic Portuguese cuisine and experienced their great hospitality! All work packages presented their work there. The German team have already finished their Work Package 2, and gave a clear overview of their results. Work Package 3 and 4 are currently very busy analysing the data. Preliminary results were presented and discussed in Lisbon. In Work



Package 3 we are interested in the different needs people have, and their relation with Quality of Life. We are also going to study the factors that are associated with the use or non-use of formal care. In the Lisbon meeting we agreed on the methodology, so in the coming months we hope to find definite answers to our questions. The members of Work Package 4 already have two papers in progress, which means we can expect more scientific output very soon. Now the most important part of the Actifcare study is taking place; the Norwegian researchers involved with Work Package 5 will eventually provide insight into the best practices and are now coordinating a Delphi process. As ever, the Irish team (Work Package 6) have done a great job disseminating the Actifcare study. We will keep up this hard work! The final results of the Actifcare study will be presented to you in our next (and final) spring newsletter.

Although the end of Actifcare is coming near, we are already thinking about the continuation of the consortium. All Actifcare members agree that it has been a positive and successful collaboration so far. Ideas for further research will be discussed at our next meeting in March of next year. Meanwhile, we wish you all an active, happy and healthy 2017!

Professor Frans Verhey, Dr. Marjolein de Vugt & Dr. Claire Wolfs

A Comparison of Actifcare Participant Demographics from Italy with those from other Actifcare Countries and National Italian Figures

In Italy, the cohort study conducted as part of Work Package 3 ended up with the enrollment of 53 dyads at baseline. The descriptive features of the sample are summarized in Tables 1 & 2 below.

Table 1: Demographic information of PwD

Participant type	Demographic		Mean	Number (N)	Frequency (%)
PwD	Sex	Male		16	30.2
		Female		37	69.8
	Age		78.77		
	Education		7.21		
	Mini mental state exam (MMSE) score		16.91		
	Marital status	Single (never married)		1	1.9
		Married		31	58.5
		Widowed		21	39.6
	Occupation	Retired		40	75.5
		Homemaker		13	24.5
	Living situation	Own home		48	90.6
Other			5	9.4	

Table 2: Demographic information of carer

Participant type	Demographic		Mean	Number (N)	Frequency (%)
Carer	Sex	Male		15	28.3
		Female		38	71.7
	Age (years)		59.96		
	Education (years)		10.85		
	Relationship to PwD	Spouse (wife/husband)		20	37.7
		Son/daughter		29	54.7
		Son-in-law/daughter-in-law		1	1.9
		Sibling		1	1.9
		Other relative		2	3.8
	Marital status	Single (never married)		6	11.3
		Married		44	83
		Co-habiting		1	1.9
		Separated		1	1.9
		Divorced		1	1.9
	Occupation	Retired		24	45.3
		Employed		23	43.4
		Homemaker		3	5.7
		Unemployed/unable to work		2	3.8
		Other		1	1.9

Having been presented with the demographic data for the whole Actifcare cohort, it is clear that while some of the Italian data are consistent with it, other figures stand out as different. First of all, Italian caregivers' mean age (60 years) is lower. This can probably be explained by looking at caregivers' relationship to the person with dementia (PwD); while 55% of the Italian caregiver sample is represented by children, 64% of the whole Actifcare caregiver sample is represented by spouses. This difference in carers' relationship to the PwD is perhaps partly explained by the fact that 39% of Italian PwD are widowed, compared to 24% of the total Actifcare sample.

There are more female Italian caregivers than male, and most caregivers are married, which is consistent with the whole Actifcare sample. The mean years of education for carers are also similar, to the overall European data. Italian PwD had slightly less years of education than the other Actifcare participants. They are mostly females, which is consistent with the European sample, even if the percentage is higher (70% vs 64%), and the mean scoring on the MMSE is a little lower too (17 vs 19). The mean age is consistent with the whole sample.

The Italian Actifcare sample can be also compared with the most recent National data presented in February, 2016 by Censis and AIMA (Associazione Italiana Malattia di Alzheimer – Alzheimer's Disease Italian Association)¹. The national mean age of Italian PwD is 79 years, and they are mostly retired (72%); this is consistent with our Actifcare sample (mean age 79 years; 75.5% retired). In 2015, 34% of Italian PwD lived alone (or with a carer) in their own homes, while the Actifcare Italian sample shows that 91% of PwD are living at home. This is likely due to the fact that the National data took into account all dementia patients while the Actifcare study specifically searched for people whom were not receiving formal care at baseline.

The national mean age of Italian caregivers is 60 years, which is representative of the Actifcare Italian caregivers. Carers' relationship to the PwD is consistent with national data, too, as only 37% of them are a husband/wife (this is true for male persons with dementia, in particular). This allows us to say that the demographics of Italian caregivers may indeed be different to European carers, and it cannot be assumed that this is solely due to the Actifcare Italian sample being biased towards children caregivers. Nevertheless, the number of spousal carers has been growing in Italy in the last few years, so it would be interesting to see if National Italian data could come close to the Actifcare figures in the years to come.

Overall, we can say that National and Actifcare Italian samples show more demographic similarities than differences, suggesting that the Actifcare sample is representative of the National situation.

¹Spadin & Vaccaro (2016). *Cittadini come gli altri? La condizione dei malati di Alzheimer e dei loro caregiver.*

Recruitment/Interviews in Portugal

The Portuguese participation in Actifcare has been highly stimulating and fruitful, despite initial recruitment challenges due to Actifcare's narrow inclusion criteria. On the one hand, our challenging recruitment process illustrated how mild dementia is not regularly diagnosed in primary care (referrals to specialized care mostly occur when disability befalls). On the other, some cases signalled by hospitals or Alzheimer Portugal were too severe and had to be excluded. We adopted two main strategies to overcome these challenges: a) experienced clinicians acted as local facilitators for recruitment; b) we multiplied efforts to include different regions and services (primary care, public and private hospitals and clinics, non-profit institutions – including Private Institutions of Social Solidarity, *Misericórdias*, etc.), alongside a key partnership with Alzheimer Portugal, to whom we are most grateful. Through these efforts we were successful in recruiting 66 Portuguese dyads at baseline.

Interviews proved lengthy, especially given low literacy levels of some elderly participants, and the final follow-up assessments were quite challenging due to the worsening of cognitive dysfunction in most persons with dementia. Home visits were made in most cases. To prevent losses and maximize retention, we maintained regular phone contact with the dyads in-between assessments. Sometimes, clinicians in charge were most helpful motivating participants for the follow-up assessments. Considerable attention was given to ways in which interviews were conducted. Some dyads did not spontaneously talk about 'dementia', but of 'memory/cognitive problems' instead. Care was taken to ensure a relaxed atmosphere throughout assessments, field researchers looked for signs of fatigue or potential stress and split evaluations into 2 sessions whenever needed. They also always tried to find a positive subject on which to conclude, leaving the dyad with some sense of achievement and avoiding 'hit and run' approaches.

Conversations after the more structured, initial part of the interview represented - for carers and persons with dementia – an opportunity to share and validate their feelings and experiences. At the end, feedback was systematically required from participants: these inputs were most valuable while preparing subsequent evaluations. We are strongly convinced that assessments and interviews provided valid, reliable data for the research project, while constituting a valuable life experience for most participants and researchers alike.

Work Package 5: Scoping Review

Work Package 5 conducted a scoping review to examine the effect of interventions to improve access to community care services, and to map policies and recommendations from governmental and non-governmental bodies about how to improve access. A comprehensive literature search was conducted in international databases as well as in international and national grey literature.

The review showed that the research in this area is limited. Only fifteen studies were found that fulfilled the inclusion criteria. Most of them used a randomized controlled trial or a pretest-posttest design. The variation in sample size and duration was great. Nine of the fifteen papers were from the United States. The studies were classified into five types. Six of the fifteen studies were "*Care management interventions*", the others were "*Monetary support interventions*", "*Referral enhancing interventions*", "*Awareness and information focused interventions*" or "*Inpatient focused interventions*". Most of the studies tested the effect of the intervention on use of respite and day care, and reported positive effect on the use of these services.

Thirty-two documents describing policies and recommendations that mentioned access to community care services were included. Twenty-eight of these were issued by national governmental or non-governmental agencies (NGOs), four were from international NGOs like the World Health Organisation and Alzheimer Europe. Seventeen of the national documents were issued at federal/national level. Care coordination in different forms was recommended by both international and national NGOs as a means to facilitate better access to care at various points in the care journey. The governmental documents provided more recommendations of practical procedures than the NGOs. Several of the documents issued at federal/national level recommended the provision of information about how to access community services, including services from the voluntary sector, as a means to eliminate barriers to access. The evidence base for the policies and recommendation was characterized by research that did not concern access directly, like studies with outcomes regarding prevalence of dementia, need for services, barriers for access, effect and quality of services. The review concluded that there is a gap in the research regarding interventions to improve access to and use of community care services.

Work Package 2 Expert Interviews: Shaping Access to Formal Dementia Care

As part of the Actifcare Work Package 2, we conducted expert interviews with policy and political decision makers to determine their perspective on access to formal care for people with dementia and their carers, and their innovative ideas, strategies or suggestions concerning how to structure and shape dementia care. The work built on previous research in the Actifcare project including literature analyses and focus group interviews with people with dementia, their carers, and health care professionals in all eight Actifcare countries. Each country conducted semi-structured interviews with between 4-7 experts (N=38) between September 2015 and January 2016. The interview guide addressed three broad topics found to be important barriers and facilitators to dementia care across the Actifcare countries; “Complexity and continuity of care”, “Formal services”, and “Public awareness”. Interview transcripts were analysed in each country by applying an inductive qualitative content analysis. The findings were then synthesised across countries, focussing on similarities in themes across the Actifcare countries.

A summary of the themes identified for each topic is depicted in the Figure opposite. The common themes across countries revealed keywords such as “Coordination”, “Information”, “Networking” and “Person-centred, proactive, multidisciplinary services”. These keywords are not novel, but are well established within the literature. Thus, policy and political decision makers seem to be well aware of barriers and facilitators in their current dementia care systems, and are familiar with current discussions among both researchers and practitioners of possible approaches to improve dementia care.

Although experts did not produce remarkably new or innovative ideas, they did produce practical, realistic strategies, such as creating a coordinating role to help people navigate the system, providing websites and databases to inform people about available services, or involving celebrities to help raise public awareness about dementia. Such ideas are preferable when looking for reasonable, feasible options to improve dementia care. The experts’ perspectives on access to formal dementia care will contribute to the core Actifcare aim of developing best-practice strategies to improve the effectiveness and efficiency of access to European dementia care systems. Ultimately, knowledge gained in these expert interviews may enable national decision makers to make evidence-based decisions when they consider reshaping the organisation of dementia care.

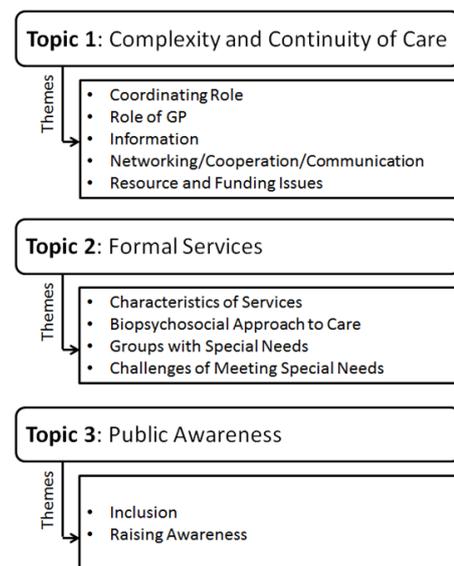


Figure: Themes for the three topics of the expert interviews in ActifCare

Actifcare in the News— Interview with Marjolein de Vugt

The work of the Alzheimer Center Limburg – including their participation in the Actifcare project –has contributed to the evidence that individualized psychosocial treatment programs have a positive effect on the well-being and quality of life of family caregivers of people with dementia. An interview with Marjolein de Vugt, speaking about this work can be found at the link below;

<https://www.youtube.com/watch?v=BJcpDeoeuJE>



Recent Actifcare Publications & Presentations

Journal articles and conference presentations/posters are available on our website on the **Publications — Actifcare Publications** page. Recent highlights include:

- Kerpershoek, L., de Vugt, M., Wolfs, C., Jelley, H., Orrell, M., Woods, R., Stephan, A., Bieber, A., Meyer, G., Engedal, K., Selbaeck, G., Handels, R., Wimo, A., Hopper, L., Irving, K., Marques, M., Gonçalves Pereira, M., Portolani, E., Zanetti, O., Verhey, F., and the Actifcare Consortium. (2016). Access to timely formal dementia care in Europe: Protocol of the Actifcare (ACcess to Timely Formal Care) Study. *BMC Health Services Research*, 16(1), 423.
- Janssen, E.P.C.J., de Vugt, M., Köhler, S., Wolfs, C., Kerpershoek, L., Handels, R.L.H., Orrell, M., Woods, B., Jelley, H., Stephan, A., Bieber, A., Meyer, G., Engedal, K., Selbaeck, G., Wimo, A., Irving, K., Hopper, L., Marques, M., Gonçalves-Pereira, M., Portolani, E., Zanetti, O., & Verhey, F.R. (2016). Special issue on Social Health in dementia: Caregiver profiles in dementia related to quality of life, depression and perseverance time in the European Actifcare study: the importance of social health, *Aging & Mental Health*, 1-9.
- Verhey, F.R.J., de Vugt, M., Wolfs, C., Handels, R., & Kerpershoek, L., on behalf of the Actifcare Study Group (2016, November 2nd). Actifcare, Plenary presentation, 26th Alzheimer Europe Conference, Copenhagen, Denmark.
- Stephan, A., Bieber, A., Bartoszek, G., Broda, A. & Meyer, G., on behalf of the Actifcare Study Group (2016, October 7th). Access to formal care for people with dementia and carers. A focus group study in eight countries, Oral presentation, 5th European Nursing Conference, Rotterdam, Netherlands.
- Hopper, L., Joyce, R., Bieber, A., Broda, A., Irving, K., & Verhey, F.R.J., on behalf of the Actifcare Study Group (2016, September 30th). Experiences of Providing Formal Home and Community Dementia Care in Ireland: Advocating for a Holistic Systemic Approach. 64th Irish Gerontological Society Conference, Killarney, Ireland.

Forthcoming Events

- The next Actifcare Plenary Meeting will be held from 30-31 March 2017 in Brescia, Italy.
- Abstract calls are currently open for the Integrated Care International Conference to be held in Dublin in May 2017 and the Alzheimer Association International Conference to be held in London in July 2017.

In the Next Issue (Spring 2017)

- Key care, policy and economic results from the 1-year cohort study.
- Plans for the Best Practice Policy Seminar to be held during summer 2017.
- Other news items from around the project.

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- Germany, Bundesministerium für Bildung und Forschung (BMBF)
- Ireland, Health Research Board (HRB)
- Italy, Italian Ministry of Health
- Netherlands, The Netherlands Organisation for Health Research and Development (ZonMW)
- Norway, The Research Council of Norway
- Portugal, Fundação para a Ciência e a Tecnologia (FCT)
- Sweden, Swedish Research Council (SRC)
- United Kingdom, Economic and Social Research Council (ESRC)

Actifcare Partners

