

ACTIFCare

Introduction: Many individuals are often not receiving services of the type, quality and timing that they need. The international Actifcare study aimed to better understand the reasons for inequalities in access to healthcare. At the macro level, we assessed and compared health care systems giving access to formal home care across Europe using literature review, expert consultation and focus groups. At the individual level, performed a cohort study in 8 EU countries in order to examine the predisposing and enabling factors for access to formal care, needs and quality of life in community dwelling dementia patients and their carers. This was combined with a cost–consequences analysis, based on the clinical and economic data. Based on these empirical findings, we formulated recommendations to improve access to formal care across Europe.

Results: Facilitators for formal care use were a lower score on instrumental- and daily activities of life, the person with dementia living alone, having a higher educated informal carer, and the informal carer visiting a support group. Older and higher educated people with dementia and younger carers found access to home personal care easier, and lower educated carers were more likely to be admitted sooner. These findings indicate inequity in access to care. Qualitative results showed that there was a lack of information about available services, and that having a key contact person was regarded as crucial. The number of unmet needs was associated to a lower quality of life, but not to costs. Thus, untimely access to care does not impact short-term costs but reduces quality of life. Future research should assess the longer-term effects as well as focus on strategies to prevent unmet needs as this could potentially increase the quality of life of persons with dementia.