

Access to formal dementia care

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Knowledge Valorization

Societal relevance

Currently, 47 million people worldwide live with dementia. Due to the fact that the population is aging these numbers are expected to double within the next 30 years. This will have great economic consequences as public health care costs will increase accordingly. In a response, the World Health Organization has recently highlighted dementia as a global public health priority.

In absence of a cure for dementia, the optimization of care is crucial. In this context, an early diagnosis is important as it opens the door to care and treatment, and as such can help people with dementia and their informal caregivers to take control of their lives. Many countries in Europe have adopted strategies to foster timely recognition of dementia. Besides timely recognition, timely access to dementia care services is important. Despite these strategies, people with dementia and their informal caregivers are often not satisfied with the type, quality and timing of care that is offered. The majority of people with dementia live at home with the support of informal care. When the dementia progresses and needs increase, this might need to be complemented with formal care at home.

Living at home with the use of informal and formal care is encouraged because of the economic advantages: institutionalization is the main health care cost-driver for elderly, and for people with dementia in particular. With the postponement of nursing home placement, health care costs could be reduced to a great extent. In addition, crisis situations can be prevented as people are monitored more closely at home. Therefore, it is of crucial importance that people can easily find their way to formal care.

Target groups

The findings presented in this thesis are relevant for people with dementia and their informal carers as well as for health care professionals and (inter)national policy makers.

Many countries are adopting strategies to ensure that people with dementia can live at home as long as possible with the right type of care. In this way, they can maintain their integrity and independence at home, and enjoy a higher quality of life. Within the Actifcare project, best practice recommendations have been developed based on all study outcomes. These best practice recommendations are of importance for policy makers and national decision makers who are in the process of reforming their health and social systems. There would not only be societal but also economic benefits if access to formal care would be optimized, and if people are enabled to live in their homes longer with a higher quality of life.

The findings of the Actifcare study are also important for people with dementia and their informal caregivers. They have been involved to a large extent in the cohort study and the in-depth interviews, and have shared their experiences and attitudes with us. Based on these, we described the optimal access to care. Moreover people with dementia and their informal caregivers would benefit from the implementation of the developed best practice recommendations. If recommendations concerned with for example a specific dementia training for health care personnel or better psychoeducation after a diagnosis would be implemented, this would have a direct positive effect for care users.

Lastly, our findings are of interest to health care professionals. In the list of best practice recommendations, there are very specific recommendations for the training and education of dementia health care professionals. There is for example a detailed description of the competences and skills that a key contact person should be enabled with. In addition, we provide advice for creating the optimal circumstances for overall access to dementia care, which is useful for professionals to ensure that they can provide care which is easy accessible, personal and tailored to needs.

Activities and products

Next to the cohort study presented in this thesis, a multitude of other research methods have been used. Literature reviews have been conducted and expert interviews were carried out with policy makers, health care professionals, health care insurers and clinicians. Besides, focus groups were organized with people with dementia, informal caregivers and health care professionals. Based on all Actifcare findings, 23 best practice recommendations have been developed by means of a Delphi consensus panel. The recommendations are concerned with enhancing access to care, enhancing the use of care, and with factors that facilitate access or use indirectly. To enhance access, it is recommended that each person with dementia is appointed a contact person with defined competencies and tasks. The contact person should establish contact proactively as soon possible in the disease process, provide individualized information about available services, assess needs regularly and facilitates access to services. To enhance use, measures are described as to how services can be made attractive so people would want to use them. Recommended enabling factors that can facilitate access or use indirectly are for instance training of health care personnel, including the general practitioner, and raising awareness about dementia through the educational system and mass media.

Each Actifcare country hosted a national meeting to present and discuss these best practice recommendations. Attendees for this meeting were government agencies, policy makers, researchers, healthcare providers and insurers, primary care organizations, dementia organizations (e.g. Alzheimer societies), and experts by experience (i.e. people with dementia and their family carers). The aims were to discuss the implementation, to propose a prioritized list of the recommendations that have not already been implemented and to describe action points that should be executed to implement them. Each country was free to design the meeting according to its own views, for example, a World Café Method was used in the Netherlands. In all countries the discussion was semi-structured and the facilitators aimed to address questions regarding the importance of the best practice recommendations in each country. They can be integrated in existing European health and social care systems in order to enable national decision makers to base their decisions on the best knowledge available when they reform the organization of dementia care.

Innovation

Actifcare was the first large European longitudinal cohort study to investigate access to formal dementia care for community-dwelling people with mild to moderate dementia. The variety of research methods enabled us to cover a wide range of opinions and experiences. The Actifcare Best Practice Recommendations represent a step forward from describing barriers to access by suggesting practical measures to overcome the barriers, based on the existing knowledge. The key recommendation was to have one appointed proactive contact person, whom they can contact when they are in need or when they need specific information. This was not only firmly expressed by the dyads in our cohort study, but also resulted clearly from the Actifcare expert interviews and focus groups. People with dementia and their informal caregivers indicated that it is confusing to have so many different people to turn to, and the abundance of different health care professionals with different specializations has the undesired effect that dyads did not know who to address.

We are aware that this recommendation has been suggested before, but the availability of a key contact person has varied to a great extent in the last years. This could be due to economic motives, but also due to policy-related motives. Across European countries there is a large variation in the way the role of the contact person was operationalized, and there is an urgent need to empower their skills and competencies. In contrast to general beliefs dyads also experience the lack of a key contact person in the Netherlands, where some of these tasks are embodied by the casemanager. In Norway some of these tasks are carried out by a so-called dementia advisor, but in the majority of European countries this function, and in particular the continuity of this function is lacking.

Implementation

Participants of the Actifcare study were updated about the study progress and the results through newsletters. Newspaper articles were published in several countries as well, not only to recruit participants but also to inform about the results. Besides, updates and publications were placed on the website (www.actifcare.eu). Once the results were available, a motion graphic was developed with a voice over for each Actifcare country to summarize the project and the results in a captivating way. In addition, results have been presented at a variety of national and international congresses and symposia with poster and oral presentations. The best practice recommendations generated through this project were presented on national meetings to facilitate implementation. Finally, national institutions, such as Alzheimer Nederland in the Netherlands, will be used to disseminate our scientific findings and accompanying clinical implications.