

Patterns and pathways. Indicators for potential improvements of dementia care

Citation for published version (APA):

Janssen, N. (2019). *Patterns and pathways. Indicators for potential improvements of dementia care*. Gildeprint Drukkerijen. <https://doi.org/10.26481/dis.20191115nj>

Document status and date:

Published: 15/11/2019

DOI:

[10.26481/dis.20191115nj](https://doi.org/10.26481/dis.20191115nj)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
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Knowledge valorization

Currently, between 254.000 and 270.000 people in the Netherlands have dementia, and of which the majority is living at home (1, 2). As a consequence of the aging population, it is expected that the number of people with dementia will increase in the upcoming years (3). At present, there is no cure that can alter the course of dementia, and developing Disease Modifying Treatments comprises a long process (4). The burden of disease, i.e. the loss of health due to disease or condition, attributed to dementia is substantial and expected to be the highest contributor compared to other diseases (e.g. coronary heart disease) in 2040 (1). Furthermore, costs attributable to dementia, so called cost-of-illness, were estimated 6.6 billion Euros in 2015, comprising 7% of total costs of Dutch healthcare and expected to increase to 15.6 billion Euros in 2040 (1).

The first step towards improving dementia care is by identification of factors associated to quality of life, access and care use that could be targeted. Such research, as demonstrated in this thesis, could already be performed in people without dementia to examine what would be possible the gains in terms of care(costs) and quality of life if a Disease Modifying Treatments would come available.

This Chapter will discuss how findings from this thesis could be of use for science, healthcare and society. Moreover, the studies presented in this thesis are mostly explorative and can be considered *innovative* as 1) they address fundamental questions on pathways of care use and quality of life, 2) the studies cover a large part of the cognitive continuum and 3) the use of statistical methods like latent class analysis to address the research questions in Chapter 2 and 4 can be considered original.

ACTIVITIES, POTENTIAL APPLICATIONS AND STAKEHOLDERS

Below, activities and potential applications resulting from this thesis are described. The research presented throughout this thesis was largely explorative and therefore the activities described are mainly targeted at the *researcher*. The potential applications that result from the current findings and future activities could be of interest for the *policy- and decision maker, healthcare professionals, and the person with the cognitive disorder and their proxy*.

Potential application: Development of a theoretical framework to prioritize interventions

Various factors are associated with (HR)QoL. As shown in this thesis, cognition in people not having dementia was not associated with HRQoL when adjusted for other factors (e.g. depressive symptoms). This leads to the discussion on the development of a theoretical framework to study (HR)QoL drivers and validate this framework in populations throughout the cognitive continuum. The development of such theoretical framework should be executed by *researchers*. Ideally, such framework should be 1) built upon scientific knowledge on determinants already known (e.g. depressive symptoms), and 2) explore other determinants in a sequentially manner to construct a framework as complete as possible. It is thereby not only important to examine the direct effects of e.g. factor A on (HR)QoL, but also study the interplay between factors and its relation on (HR)QoL. This will provide an in-depth understanding of the complex mechanisms that drive (HR)QoL. Besides development of such framework, validation in different populations is needed by making use of various datasets. Validation could furthermore show in which population certain factors will have more impact. Therefore, once such theoretical framework is thoroughly tested, this knowledge could be useful for *policy- and decision makers*. As improving or retaining (HR)QoL is an important outcome, it is important to know what factors should be targeted that have the highest impact in terms of benefiting (HR)QoL, furthermore important for research agenda setting

Potential application: Need-based interventions

Care needs of people with dementia increase over time, and measurement and identification of needs is important to provide timely care and interventions. As was demonstrated in Chapter 2, profiles of care needs and associated determinants can be identified. As the research approach (Chapter 2) was quite innovative, *researchers* should therefore further explore and validate need profiles in different stages of dementia and over time; i.e. to examine whether and how profiles develop.

Furthermore, besides examination of determinants associated with these profiles, distal outcomes should be explored i.e. what are possible consequences of 'belonging' to a certain need profile. This will lead to two possible scenarios in which the acquired current (from this thesis)- and future knowledge can be translated and applied in clinical practice by *care professionals*.

Scenario 1: addressing need profiles by using an already existing intervention.

Multiple interventions exist that could potentially address several needs.

A hypothetical example. Need profile 'A', characterized by multiple unmet needs in the social domains, is associated with an increased risk of person with dementia being admitted to a nursing home. By targeting this specific profile with an already existing intervention 'B' that addresses these multiple social needs, admission to a nursing home can be postponed.

Scenario 2: developing a new intervention based on specific need profiles.

However, it may be the case that by applying a similar method as in Chapter 2 in different populations, other need profiles are identified for which currently no potential intervention exists. In this case, the need profiles as identified could serve as a basis for new interventions to be developed, or existing interventions to be adapted.

Potential application: Improving timely access to care

Untimely access to care may lead to a loss of HRQoL utilities (Chapter 3), highlighting the importance of addressing these care needs in a timely way. There are several barriers that limit the access to appropriate care, such as a lack of knowledge about available services. The overarching aim of the European Actifcare study was to examine access to formal care in people with dementia and their caregiver, and developing best practices. One of the major facilitators for access to formal care showed to be having a casemanager or other key contact person (5, 6). This finding may not be surprising. However, although it is recommended in the Dutch '*Zorgstandaard*' (7) that every person with dementia should have a casemanager, it is not always the case, and many motives exist. **Policy- and decision makers** could highlight the importance- and help stimulate the use and provision of casemanagement.

Potential application: Care planning tool

As people with dementia do have increasing care needs, planning of such care is important. As was shown in Chapter 5, people with MCI started using (in)formal care over two years. This finding indicates a potential in plannable care. However, more evidence is needed in terms of what (socio)demographic and neuropsychological determinants are related with these care

transitions. Here lies a role for the *researcher*. Current results from Chapter 5 resulted in a crude estimate. To allow for individualized prediction, it is essential to use large datasets and possibly data registries, and develop an algorithm that makes individual prediction possible. Once such algorithm is developed, it is possible to start developing a care planning application, being a tool or provision of information in general. It is essential to conduct focus-group interviews with the person with the cognitive disorder (e.g. person with MCI) and their proxy, to make sure the application is user-centered and built around the needs and wishes. As mentioned, one of the main usages of such application could be individualized care prediction i.e. providing information on what care can be expected with the next (e.g.) 2 years. The person with the cognitive disorder may want to know what care he or she can expect within the next years. This could therefore prepare both the **person with the cognitive disorder and their proxy** for the future. Furthermore, this could be of use for **healthcare professionals** and e.g. to coordinate future care and **policy- and decision makers** to indicate whether and which care is needed.

IMPLEMENTATION

Dissemination

First of all, results of the presented studies were submitted to international peer-reviewed journals. Two of them, which included implications and recommendations targeted at the main stakeholders, were already published (8, 9). Second of all, results were also presented at both national (i.e. LolaHESG conference) and international conferences (i.e. Alzheimer Europe annual conference and EuHEA conference), for an audience including researchers as well as policy makers and people with dementia and their caregivers. Besides conferences, results were also presented at a meeting at the Ministry of Volksgezondheid, Welzijn en Sport (VWS; The Hague), for an audience including researchers, policy makers, and people working for a healthcare insurance company. Not only the implication of these results was discussed, but also a discussion was held on how to increase implementation and communicate results to policy makers by e.g. making sure that recommendations described in articles are specified ('who should do what') One other point of interest concerns the national agenda setting. To increase the likelihood that results are useful for policy- and decision making, it is important for researchers to understand the current National political agenda setting.

Last of all, within the Actifcare project final results and recommendations were presented to policy- and decision makers, researchers and healthcare professionals during a one-day meeting which was held for each participating country separately. During the Dutch national meeting, held at Alzheimer Nederland (Amersfoort, The Netherlands), the World Café Method was applied in which a subset of recommendations were discussed during several rounds. At the end of the day, a summary of each discussion was presented describing which recommendations would be most impactful and ways to address these.

Possible future steps

In sum, before potential products and activities (as described above) can be implemented into practice, more empirical evidence needs to be acquired. Evidence could then be used to e.g. advice policy- and decision makers(*see above*), and to ultimately be of benefit for the person with the cognitive disorder (e.g. dementia or MCI) and their informal caregiver.

Including stakeholders from an early stage onwards could improve implementation (10, 11). This could be done by means of e.g. an advisory board, focus-groups or meetings to make sure there is no communication gap. When developing new- or adapting existing interventions, focusing on i.e. need profiles, these should first be pilot tested (11). Furthermore, when developing a care planning tool, it is necessary to interview the primary stakeholder (i.e. person with MCI or dementia and their caregiver) whether such tool is perceived as beneficial, what should be included and how it should look like (e.g. an application or more general information). Also, other parties should be involved and a systematic search should be performed on existing care planning strategies. During the whole process, results should be presented at (inter)national conferences and meetings, and also to for instance a client panel to discuss findings.

Last, developing these products requires financial investment and will take several years to develop, but in the end could potentially improve HRQoL and save care costs by making sure the person with dementia can live longer at home, and the informal caregiver can get the maximum perceived benefits of receiving care and support.