

From home towards the nursing home in dementia : Informal caregivers' perspectives on why admission happens and what they need

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Valorisation addendum

Research on care services and care systems may have a limited “lifespan”, due to the fact that care systems are dynamic and care policies are frequently changed. However, despite the many changes in healthcare systems, certain topics remain an issue for decades. One of these topics is informal caregiving in dementia care.

The persistence of certain societal issues related to health and healthcare, such as informal care in dementia, are not the result of a lack of attention from researchers per se, considering the amount of research in existence. Looking at all the attention given by researchers to unburden and support informal caregivers of people with dementia and the many studies on predictors for care transition, one should contemplate why the issues are still in existence after decades of research. The question that should be asked is: *Why are informal caregivers of people with dementia still experiencing similar issues, despite all the scientific evidence and the recommendations by the researchers based on this evidence?* The answer lies more in the “translation” of scientific research to these healthcare issues, in this case informal care in dementia.

No one will argue the importance of informal care either in general or specifically in dementia care. Throughout this entire dissertation it is stressed how informal caregivers of people with dementia have a crucial role in the care in general, and in the transition from home-based care to care in the nursing home. It is also explained that the decision to move a beloved one to a nursing home is very difficult with many adverse effects, both prior to, and after the actual move. Informal caregivers experience, for example, feelings of guilt and betrayal towards the person with dementia. Often the decision regarding the move to a nursing home is not well prepared, with informal caregivers not thinking or not wanting to think about the care transition. This may result in the informal caregiver being “caught off guard” by the care transition process, adding to the stress and adverse effects of the decision.

This chapter aims to translate the results of this dissertation into more explicit “added value” to society and dementia care, that is to say, to valorise the results. The act of valorisation is to create value from knowledge. Valorisation can be done in many ways and depends on the type of research as well as the outcomes thereof. One form of valorisation, for example, is to make knowledge available and suitable for social exploitation. In this particular case, the research was explorative, giving a possible starting point for practice and future research. The aim is to imbed the results within the current and most recent shift in healthcare as organised within the Netherlands.

A major shift has been initiated in the Netherlands, by which municipalities are now responsible for the care of their citizens instead of the national government. The (social) care now has to be organised by and within the community. Social community teams, consisting of multiple professionals such as social workers, physical therapists and community nurses, act as a safety net to provide and stimulate care from and by

the community in order to decrease the use of more expensive specialist care. An additional aim is to offer the tools for people to be able to manage their own situation as well as possible and to empower them. These teams should also aim to provide more holistic care and prevent the fragmentation of care. The preferred approach is: "One household; one plan; one care professional". One of the target groups of these community teams are the informal caregivers. Certain aims of these community teams, such as empowerment, and the provision of holistic and defragmented care, preferably by the same main health professional (as a sort of case manager), are ideal for informal caregivers of people with dementia, as will be explained further.

Bearing in mind how hard the process of care transition from home to the nursing home is, informal caregivers deserve to be guided and coached through the care transition process, preferably by healthcare professionals. To make this guidance effective, some points of advice are provided here, by which the results of this dissertation may be used as a starting point within the new decentralisation of care in the Netherlands.

In the spirit of the holistic care aimed for in the new social community teams, care and services may be offered as a "care carousel". In a "care carousel" informal caregivers are introduced to multiple healthcare professionals and services, and then decide whether that service is required. Care professionals of the multi-disciplinary community team may visit informal caregivers at home at various stages during the dementia process, instead of informal caregivers having to seek and visit different healthcare professionals at their office. During these visits, healthcare professionals inventory, along with the informal caregiver, whether their service is required at that particular stage by that particular informal caregiver. These stages should be at moments of change within the situation of the person with dementia and his or her social environment. The results of this dissertation can be used to define or identify these stages. As seen in this dissertation, patient-related aspects are often the tipping points, initiating the move to a nursing home, according to informal caregivers. So if, for example, the person with dementia develops certain dementia related behaviour, such as wandering behaviour, or when the behaviour intensifies, the "care carousel" should be initiated again. These changes are the "red flags" for the care professionals to look out for and to use as a guideline when determining whether it is necessary to inventory the need for their services again. In this process both healthcare professionals as well as the informal caregivers inventory whether the services of a certain healthcare field are required. It is not suggested that all services should be offered "casually" to everyone but rather that they should really suit the situation. In order to make this work, the proximity and close involvement of the social community team is essential (coordinated by a single professional in the role of a case manager); otherwise these signals will not be detected in time. This approach, with healthcare professionals closely involved in the process within the

community, means that informal caregivers do not have to figure out what is possible care-wise and be the ones taking the initiative to cumulate information. Within this dissertation, evidence is provided that obtaining information regarding care and services is an obstacle for informal caregivers. They claim that they are unaware about what is available care-wise, that they have to be the ones taking the initiative in gathering information, which is often difficult, and that they prefer being offered the information by healthcare professionals.

As a care carousel, these community teams can offer a gradual, continued and long-term guidance approach. This should be a "start-to-finish" process. Considering that the progress of dementia is still irreversible and incurable, care transition towards a nursing home is a realistic prospect in dementia. Therefore, it would be worth considering "introducing" informal caregivers to the idea of care transition from an early stage, despite the difficulty of the topic. In this dissertation it is stated that the care transition period starts prior to the decision and ends after the actual move. However, how long this period is and how early it starts is not set. The care transition period probably varies per situation, that is to say, per person with dementia and his or her (social) environment. Due to this variation, a gradual and structural exposure to the idea and possibilities of care transition carefully guided, coached and empowered by healthcare professionals is wise and may have multiple benefits.

First, this exposure may decrease or even eliminate informal caregivers being caught off guard regarding the impending necessity of care transition. This in turn may reduce crisis transition. That is transition due to acute reasons such as the demise of the informal caregiver or a sudden physical ailment of the person with dementia. As stated in this dissertation, informal caregivers seem quite able to realistically evaluate their own situation and express probable reasons for the care transition, and needs they experience. These evaluations then can be used by health professionals to offer appropriate care and services. For this to happen, it is important for healthcare professionals to truly listen to informal caregivers and take them seriously. An often recurring issue is that care professionals "work from experience" and fill in the needs of the informal caregiver. As shown in this dissertation, there is a big discrepancy between the views of informal caregivers and healthcare professionals. This stresses the importance of truly listening to the informal caregivers and not "assuming" the needs.

Second, the involvement of healthcare professionals will ease the process for informal caregivers. Research shows us that decisions regarding care transition in which both informal caregivers and healthcare professionals were involved facilitated the decision for informal caregivers, resulting in fewer negative effects from the decision. Due to structural, continued and holistic guidance and coaching by the social community team, the needs in this area can be met, resulting in fewer negative effects from the decision.

Finally, as stated at the beginning of this chapter, informal caregivers are one of the target groups for the social community teams. This means that, when they would like to, informal caregivers may still request some form of support from the community, even after the actual transition of the person with dementia to a nursing home. This continuation of attention for the informal caregiver after the actual care transition has not been part of regular care. This resulted in informal caregivers claiming they “fell off the radar” of the healthcare professionals, despite being in need of some sort of service. Certainly continuation of social services will not be required by all informal caregivers. However, it should be possible for those who are in need to be able to acquire certain services. These services may be simple things, such as being introduced to other informal caregivers who have been through the process or even being offered options to enhance the own social environment by (re-)introducing them to activities. These services will probably be performed by other community members and not by the healthcare professionals.

Besides all the previously mentioned options through which a translation can be made of the findings in this dissertation to be used in practice, one of the clearest ways of valorisation is to actually offer a product which is required and requested by the target group. Within this dissertation the needs of informal caregivers regarding the care transition period were inventoried. Some concrete examples of what they consider helpful were provided by the informal caregivers themselves. One such product was a “land map” or a decision tree which explains in a clear way what care services are available and where one should request these services (that is, what organisations offer particular services)