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# Framing Dementia Care Practices: The Politics of Early Diagnosis in the Making of Care

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## Abstract

Dementia diagnosis is complex and hot topic. It is a public health priority, which highlights the need for early diagnosis. This is regarded as “the policy of diagnosis” and is explored and unfolded as a matter of fact in this article. The article draws on a practice theory as a research approach and shows how different modes of diagnosis frame certain care practices. Three different orderings are elaborated: the knowing, the governing, and the relational orderings. Two of these individualize and isolate the care for people with dementia, while the third ordering enacts diagnosis by connecting people, things, and places. An ethnographic approach is used drawing on interviews with 15 families of people with dementia and professional careers. The article contributes to a wider understanding of how “the policy of diagnosis” shapes some possible way to live with the disease and at the same time closes others.

## Keywords

people with dementia, policy, caring, early onset diagnosis, mode of ordering

A dementia diagnosis is complex, and not only is it a hot topic for people living with dementia but also a public health priority (World Health Organization [WHO], 2012). Within the field of dementia, there is increased attention to early and timely disclosure of the dementia diagnosis both within policy documents and research literature. “Early disclosure” refers to diagnosing dementia at an early stage, whereas “timely disclosure” refers to an increasingly person-centered approach and the readiness of the person and the family to receive the diagnosis (Dhedhi et al., 2014). Policy documents subscribe to strategic moves and actions to develop an increasingly inclusive society for people with dementia and to highlight the need for an early diagnosis (Helse-omsorgsdepartementet, 2015). In this policy document, the term “early diagnosis” refers to the early disclosure of diagnosis. Being aware of the diagnosis empowers people to make decisions regarding their lives and future care (Alzheimer’s Society, 2014). In this study, early diagnosis is regarded as “the policy of diagnosis.” A starting point for this policy is attention toward poorly mobilized efforts, and the difficulties of receiving a dementia diagnosis. Early diagnosis is closely linked to care: “Quality care for Alzheimer’s disease and other dementias starts with an early, documented diagnosis, including disclosure of the diagnosis” (Alzheimer’s Association, 2015). This indicates that disclosure of the diagnosis promotes individual and family decisions and assists care delivery. Furthermore, this increased emphasis on early diagnosis is followed by ideas regarding the possibility of proactively managing the illness (Chaufan et al., 2012). Research has primarily focused on the benefits of early diagnosis and tends to be dominated by a medical value base (Milne, 2010). Few studies have examined the advantages or risks of a timely diagnosis (Dubois et al., 2015). There is an increasing policy and practice consensus that the early identification of dementia is beneficial; this phenomenon should be examined in future studies.

In this study, I draw on the findings of a study elaborating citizenship for families living with dementia (Ursin, 2018). I conducted interviews to examine whether people living with dementia are allowed to participate as citizens in society. During interviews with families living with dementia, the diagnosis was highlighted as an important issue determining whether they live well. Simultaneously, although the diagnosis had been disclosed late for many of the families, the majority expressed mixed feelings regarding the early disclosure of the dementia diagnosis. Policy documents have indisputably described “early diagnosis” as being beneficial for both individuals and society. Therefore, in this study, I argue that early diagnosis has become a matter of fact or a black box. Blackboxing refers to the way scientific and

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technical work is made invisible by its own success. When a matter of fact is settled, the focus is only on its inputs and outcomes, and not on its internal complexity (Latour, 1987). In this study, I attempt to unfold the black box by exploring how the diagnosis is done and how these ways of doing diagnosis shape some ways of caring for families living with dementia. The aim of this study is to enhance knowledge regarding how a diagnosis is enacted. To do this, the knowledge embedded in the doing of diagnosis and how these enactments shape some ways of caring for families living with dementia will be analyzed.

Research regarding dementia tends to be medically informed, and recently, dementia has been brought under the lens of sociology. There is an emerging body of literature exploring the diagnosis and how it constitutes a socio-political process. Jutel and Nettleton (2011) stated that diagnosis is a powerful social tool, with unique features and impacts that deserve their own specific analysis. The practice of medicine has changed and so has the interplay of social, political, technological, cultural, and economical forces, which concern diagnostic categories and processes (Blaxter, 2009). According to Trundle (2011), the term "diagnosis" is politically charged because it implies culpability; however, it can also be welcomed because the disease does not reside in the individual or in the environment, but instead exists somewhere in-between (Singh, 2011). A diagnosis shapes one's identity (Willig, 2011), and this is mediated not only by the quality of social interactions, but also by preceding pathways in the health care system (Schaepe, 2011). Hence, a diagnosis can also operate as an instrument of professional expansion and social control, thus serving to pathologize normal functions (Chaufan et al., 2012). This implies a change in the understanding of the diagnosis—from a medical issue to a socially constructed reality (Brown et al., 2011). However, over the past 10 years, diagnosis has been explored by its enactment through various practices. According to Gardner et al. (2011), diagnostic practices in cardiology are complex achievements that involve multiple players at different locations. Mol (2002) illustrated how the body becomes multiple because the body was enacted different in different medical diagnostic practices, and Moreira (2010) demonstrated how dementia is understood, managed, and experienced differently within the memory clinic. These latter contributions approach diagnosis as a fragile and performative object that changes in relation to the community it is acted upon. Furthermore, these contributions offer a symmetrical perspective on how the social and the material co-construct each other. Employing this practice theory approach allowed me to explore how different acts of diagnosis shape care practices without giving the social priority.

## Theoretical Background

This study is informed by practice theories that became prominent toward the end of the 20th century (Nicolini, 2012). In these theories, practice is understood as situated and as enacted, focusing on how humans and objects are actively engaged in knowing and being known through the community to which they belong (Mol, 2002). Mol (2002, p. 32) used the word "enact" to describe how objects are done in practice as a collective achievement. According to these theories, the conceptions of practice are rooted in a materially semiotic tradition, which emphasizes that people and objects shape each other through their mutual relations (Law, 2009). Knowledge and representations of knowledge are then constituted in and through practice, which makes practices performative because they allow certain understandings to emerge, whereas others are overshadowed (Moser, 2011).

Law (1994) introduced the concept "modes of ordering" as a set of doing actions that are done in a special way that is embodied and performed between agents. "Ordering" calls for a process and suggests that the activity of ordering involves an ongoing achievement, which is fragile (Mol, 2008). "Modes" is a plural term and invites the comparison of different ways of thinking and acting that coexist in a single situation. "Modes of orderings" offers a way to explore how self-reflexive "logics" interact to create the complex effects that we witness when looking into histories and agents (Law, 1994, p. 109). Therefore, knowledge may be seen as a product or an effect of ordering thus becoming a material matter (Law, 1992). Based on this concept, I have analyzed how social and material actors interact because they enact the diagnosis, and simultaneously shape certain ways of caring for people with dementia. This means that when a diagnosis is enacted differently, so is caring. Each practice generates its own material reality and these orderings coexist and reshape each other in multifaceted ways (Mol, 2002).

In this theorization, diagnosis becomes an effect of how social and material actors arrange themselves. This indicates that diagnosis is not something that exists by itself but rather comes into being in relation to others. Instead of analyzing what the diagnosis is, I am analyzing how the diagnosis is done in practice and what type of knowledge is embedded in these acts of diagnosis. This change in the analytical perspective makes it possible to show how different enactments of diagnosis shape different care practices. This analysis of diagnosis makes apparent that an ideal may inspire different practices, even if the overall ideal is said to be similar, "for the good of the people and society." Moreover, practice is always ethical because it involves enactments of ideals and values that develop in practice (Mol, 2008; Moser, 2010; Pols, 2008). Ethics, in this context, describes how people and things manage to coexist in a good way, by analyzing local strivings, values, and material enactments (Pols, 2008).

## Research Design

This study used ethnographic interviews, which are less rigid and provide an opportunity to explore how things happen (Fontana & Frey, 2005; Heyl, 2001). Consequently, I obtained detailed descriptions of activities, situations, connecting information, and cooperation and also stories about how the diagnosis was enacted and how these doings impacted everyday life for families living with dementia. This way I was able to follow Mol's (2002) advice that reality is not given but becomes enacted and shaped through practice.

I started by interviewing 15 families living with dementia and 27 professionals participating in shaping the everyday lives of these families. Then, I re-interviewed 12 of the families after 6 to 9 months to elaborate changes and the progression of how the diagnosis was enacted. Through this method, I was able to trace the different doings of diagnosis and how they shape certain ways of caring. A total of 54 interviews were conducted. These interviews made it possible to bring out understandings of how the diagnosis is shaped by culture and materially located (Mol, 2002).

The interviews with families were based on a semistructured guideline focusing on the work to be done (Nicolini, 2012; Westby, 1990). Interviews with the family explored everyday life by asking questions (such as "what," "who," "how," and "when") about everyday situations, and paying special interest to their contact and experience with health care services. On the contrary, the interviews with other carers (health professionals and health care professionals) directed attention toward activities, work organization and performance, and cooperation. Generally, the work of people and things are placed at the forefront to follow actions (Nicolini, 2012). The guideline became a document-in-progress based on three axes: individual follow-up because of their unique situation, horizontal inquiry based on phenomena enlightened by previous interviews, and trying out understandings in progress. The data gathering process became an ongoing inquiry wherein new spaces and places were explored.

The interviews were conducted in person, with the exception of one re-interview and a telephonic interview with an executive officer. The time and place for conducting the interview was adjusted based on the interviewees' schedule. The interviews were conducted at various places, such as homes, institutions, workplaces, cafés, and rented locations. However, interviews with professionals were primarily conducted at their workplaces. Instead of turning spouses, persons with dementia, and professionals into subjects of my study, I drew on their skills as co-researchers as they offered knowledge about care and living with a diagnosis. The knowledge expressed in this study was, therefore, produced by the researcher, interviewees, and questions (Hilden, 2002).

## Participants

To articulate the enactments of diagnosis, I examined the case of families of younger persons with dementia. "Younger persons with dementia" is a term used to address people receiving diagnoses before the age of 65. This case was particularly selected because younger people with dementia interact within society in different ways, compared to others with dementia; some younger people with dementia have work relationships, children living at home, are physically fit, and lead an active lifestyle (Alzheimer's Society, 2014). Not only do they actively participate in society, but so do their families and friends. Their spouses are often people in various career paths and interact with society in a variety of ways. In addition, they are exposed to care burden, depression, and stress (Brodaty & Donkin, 2009; Svanberg et al., 2011; van Vliet et al., 2010). Simultaneously, they are perceived as an important resource assisting the person with dementia (Hong & Coogle, 2014; Ulstein, 2009). Families of younger persons with dementia as a case represent variants of caring and living with dementia.

## Recruitment and Sampling

In collaboration with three community health care services and one memory clinic, I recruited families living with dementia. A total of 15 families volunteered, some initiated direct contact, whereas others were referred through professionals. These families received various levels and volumes of health care services: living at home with only day-care services ($N = 4$), living at home with extended care services ($N = 6$), and living at institutions ($N = 5$). The carers interviewed were daughters ($N = 2$), memory clinic workers ($N = 3$), homecare and occupational therapists ($N = 3$), day-care service providers ($N = 4$), auxiliary and institutional care providers ($N = 4$), community dementia coordinators ($N = 3$), a primary nurse ($N = 1$), and a personnel from the National Association for Public Health ($N = 1$). The family members were all married to the person with dementia, except for one case, where a daughter was the only relative. Among the spouses I interviewed, seven were men and eight were women. In one case, the diagnosis was disclosed 12 years ago. In four cases, the families had lived with the diagnosis for a duration of 1 to 2 years, whereas the remaining families had lived with the dementia diagnosis for a duration of 4 to 9 years.

After the first interview with the family, I contacted professionals and two daughters to further elaborate and explore the enactments of diagnosis and care practices. The professionals included had daily work at auxiliary care, respite care, homecare, nursing homes, day-care centers, and provider offices.

## Ethical Considerations

This study is part of a larger study that was approved by the Norwegian Center for Research Data. The study data were anonymized. In general, all interviews started by explaining the anonymization process, the voluntary nature of research, and the possibility of withdrawing. The spouses consented to contact with carers. When the person with dementia participated, their spouse had preconsented. Nevertheless, these interviews started by ensuring that the person with dementia understood the purpose of the talk, and on both occasions, the person with dementia consented verbally and by signature. The interview questions were designed to be easy for respondents, and awareness of discomfort guided these interviews (Robertson, 2014; Tranvåg et al., 2014).

### *Analysis*

There is a dialogic relationship between data and theory (Coffey & Atkinson, 1996). Theoretical understandings used to make sense of data, and data may create new understandings. Being aware that most of the doing diagnosis is invisible, I drew on theoretical resources that allowed me to interpret the implicit doings as they are enacted in everyday situations. The chosen theoretical lenses also imply that things and humans are given the status as actors as long as they contribute to action (Law, 2009).

The analysis has been an ongoing process that started during data collection among families living with dementia and extended throughout the further data collecting process. The following research questions helped to guide my analysis: What impact does the diagnosis have on the everyday lives of families living with dementia? What diagnosis is done at various locations and how? Which material and social actors interact and how do they interact? My initial interest developed as I collected data, but the formal analysis started after the data collection was completed.

All interviews, except one, were taped and transcribed. One interview was analyzed based on ongoing notes and the postwritten text. I coded the material with empirical codes and grouped them into categories based on themes. As part of the work of making sense of the data, I used the analytical strategy outlined by Nicolini (2012) called "zooming in and out." "Zooming in" refers to watching something from a close view, such as what families do to disclose diagnosis and why. Second, this is combined with another activity, "zooming out," which allowed me to follow relations and enabled me to overview the practices that are studied. These strategies assisted me to understand what was happening in the data and establishing meaning. This was a creative process as I tried to sort the main ideas and developed key findings with reference to how the diagnosis was enacted differently. As part of the process of writing up the results, I followed Latour's (1987) advice to be sensitive to controversy. Doing so, I will in the next sections, elaborate two orderings that are based on experiences from families living with dementia and how care-managers and medical professionals conduct their work. The third ordering contracts the first two ordering because it highlights how the diagnosis can be conducted in a manner that ensures the well-being of the entire family. These orderings enact the diagnosis differently, but they also illustrate how care has been framed as an effect of how a diagnosis is enacted.

## Results: Doing Diagnosis

### *"We Don't Have Any Secrets"—A Knowing Ordering of Diagnosis*

The memory clinic is, most often, where young people are diagnosed. Professionals use tools and tests that are accepted in the field, which includes different types of neuropsychological tests and in-depth history from family and relatives. These are important because they allow medical professionals to exclude other diseases: ". . . that something can be done with" (HK 02). This statement proclaims that there is less to do in terms of dementia because the medical riddle of how to cure dementia has yet to be solved. A cure for dementia that either prohibits or halts the progression of brain damage does not exist. In the medical context, this indicates that one's chances to live well are endangered (Moreira, 2012).

In this practice, "early diagnosis" is beneficial because medical treatment and technical devices can be offered. Antidementia treatment implies an early or moderate stage of dementia. Simultaneously, the antidementia medicine and its effect are debatable: "Half of those that receive this medicine don't experience any effect, and 20% of those with an effect will have a small improvement, meanwhile, 30% adhere uniformly or don't get new symptoms the next half year" (HK 01). Medical treatment is a way of giving hope for less rapid progression of the disease (Moreira, 2010). A side-effect is controlling appointments every 6 months to evaluate the effects of the medicine and examine the disease progression. A daughter who regularly follows her mother to these appointments reveals how these consultations evoke emotional reactions: "For her, it becomes a half year reminder of her tragic situation, that's the effect these consultations have on her" (Ph 2.4 daughter). Nevertheless, these appointments point out where in the trajectory the patient is and what help they require. "If their dementia is in a moderate phase of dementia, then they need help from others to be able to manage their everyday life, that's the definition" (HK 01). Medical knowledge about their brain function is then linked to their everyday activity and an indicator of care needs. Technology is seen as a partial solution to living well and offers assistance to resist the effects of disease and to overcome the limitations of biology. For this to happen, new knowledge must be introduced at an early stage: "If a person with dementia doesn't learn how a technical device works at an early stage, then it will be difficult later" (HK 02).

I have decided to call this ordering the "knowing ordering." The diagnosis is enacted based on biomedical scientific knowledge and cannot exist without symbolic representation, such as brain scans, biomarkers or blood prints, and analyses of brain activity through validated memory tests (e.g., the Mini-Mental State Examination, Clock-Drawing Test, and the Questionnaire on Cognitive Decline in the Elderly). These scientific mappings of brain function assist professionals to detect deficiencies and determine care needs.

The earlier the diagnosis is recognized, the more readily it can be acted upon, for instance, through technology but also decisions about how to live with dementia. Thus, diagnosis is enacted as an individual issue located in the brain. In addition, people with dementia are perceived as people with limited individual capacities. This implies the need for highly educated professionals, and the care is related to knowledge and information. In this practice, medical knowledge speaks the truth: "We do not have any secrets, and we are more than likely to share our knowledge with people with dementia if we believe they need it for a good living" (HK 01). Simultaneously, family members are less likely to share this view. Mike: "I'm also questioning how expedient it is to get a diagnosis too early; it's a matter of life quality. Not all knowledge is beneficial, in a way" (Ph 2.4). Mike lives with Linda, a 63-year-old woman in her second year with dementia. According to him, the diagnosis is not only a medical term but it also affects the quality of their life, which implies that ". . . the less it is discussed, that she is demented, the better she feels."

In this practice, professionals become the knowers; they seek, detect, and determine whether or not it is dementia. They are knowledgeable about biomedical understandings that enable them to analyze tests and scores. Dementia is reduced to a disordered biochemical process and "doings" are linked to the regeneration of chemical normality. Normality is how tests, biomarkers, or blood prints can be placed in the predefined statistical area for normality. In contrast, families and people with cognitive deficit hold the position of the known, an object of biomedical inquiry. Care, in this practice, is based on information and knowledge transference from medically schooled professionals to families and people with dementia.

## *"It Opens Doors, But It Also Closes Doors"—A Governing Ordering of Diagnosis*

In this section, I will pay attention to another way the diagnosis shapes everyday life. In this ordering, the diagnosis becomes a social performance and organizes everyday life. Kari is married to Kim, who is 59 years old and used to be a successful businessperson with his own factory and several employers. Kari claims that receiving a dementia diagnosis was important: "It opens doors, but it also closes doors" (Ph 1.1). The diagnosis enabled her to close down her husband's business and take control of the factory, which was a messy place at that time. Legally, the diagnosis allowed her to shut down the factory and dismiss the employees. In this case, the diagnosis became an actor that protected the family from an economically bad situation.

The diagnosis is also important in the practice of service construction because it opens doors. The case illustrating this is a complex case due to the fact that the dementia diagnosis was not disclosed because it was a rare form of dementia. Moreover, the family had to deal with the challenges of the undefined disease. Magne is 57 years old, unable to work, and needs assistance day and night. Sissel, his wife, has obligations at work and wishes to follow her career path; for her to do so, they need care services. In the absence of the diagnosis, it became difficult for them to access services. She contacted a general practitioner and questioned the power a diagnosis gives:

> Sissel: I had to ask her (GP), whether the dementia diagnosis was a real diagnosis or whether it was a strategic diagnosis. And then she asked me, "If he (Sissel's husband, Magne) needs a dementia diagnosis, then I can help you with it, so it can help you get some help?" (Pi 1.1)

A diagnosis labels symptoms, and it also provides families living with dementia the right to access services. The information the diagnosis provides about someone's health can lead to some prospective implications and actions. Professionals at the provider office negotiate symptoms in accordance with the law and local standards for the written decision to be legal: "It is always a judgment about who is meeting a demand and who is fulfilling the conditions. . ." (Ph 3.1 Ttk).

I have titled this ordering the "governing ordering." In this practice, there is a close relationship between diagnosis and service construction. Within the practice of service construction, different actors interact and discuss issues, such as needs, symptoms, professionals, people with dementia, family members, services, and written decisions. There is an ongoing negotiation between nature (biological changes) and the social (interaction with others). The diagnosis assumes a privileged position in this practice, due to the power to make services available, and also to exclude certain services and activities (Callon, 1984). There is a risk that care implied by this ordering becomes instrumental by its occupancy of needs classification. This is exemplified by the experience of Trine, who newly accepted a nursing home for her husband, Fredrik. In this case, Fredrik's social needs were not recognized, only his biomedical malfunction. When Fredrik moved to the nursing home, he was physically fit, played squash, and went hiking every day. They applied for a support person, but were rejected.

> Trine: He got a "no," because he was living at the care home, and there he did not need a support person according to the provider office. . . . It was like when you receive a dementia diagnosis and move to a nursing home then you should be satisfied. Why is it that when you get a dementia diagnosis then you are not entitled to demand other things? (Pi 3.2)

In this ordering, legal knowledge is combined with a biomedical understanding of dementia. The biomedical understanding of dementia makes it easier to group the challenges into needs and design services. Rights are formulated in written decisions, which demand that the family be active and request services. Living well with dementia depends on how well families spell out dementia symptoms and act as active citizens by applying for services. On the contrary, for professionals, the diagnosis is an important tool that allows them to quantify and manage the care service. Medical knowledge is important; it makes it possible to classify, calculate, and group challenges on a societal level. Based on this knowledge, different classification systems outline the disease trajectory and draw correlations between the lack of cognitive functions and need for services and care (Rose & Lopez, 2012). Care, in this practice, is based on how well the disease assessments are done by professionals and accessing services based on a universal principle, judged equally by the law. Then, care is not only a matter of quality in life, but how to prioritize needs for younger people with dementia and other citizens needs.

### *"Relational Knowledge Must Be Important"—A Relational Ordering of Diagnosis*

Previously, two ways of managing diagnosis have been elaborated. They illustrate how the diagnosis is managed on an individual basis, which separates people with dementia from others and from places. In contrast, the diagnosis can be done differently when the biomedical and legal knowledge is doubted. I have called this practice "relational ordering" to illuminate the relational knowledge in play. To illustrate this, I will start by using a case from a smaller Norwegian community that faces economic struggles.

The leader of the nursing institution, whom I have named Lill, explains the challenge faced by the community because of the estimated increased numbers of people with dementia. This is a worldwide challenge, according to statistical accounts (WHO, 2012). Lill, an administrator, is preparing a report about how to organize good services for people with dementia; this report is being prepared for the purpose of presenting it to politicians. More precisely, the question was about outsourcing institutional care. This case aroused Lill's interest, and she problematized the case as follows:

> Lill: When a community wants to outsource a service, they have to know the quality criteria. Furthermore, people with dementia in a way are a forgotten group and currently are given increased attention politically. However, often the person disappears and the diagnosis becomes important. (pda 2.1 TK)

The political decision ended not to outsource institutional care but rather to reorganize the existing services. According to Lill, people with dementia are similar to other people because they need to be seen, to be someone, and to be part of society. Lill started to reorganize long-time institutional care according to this principle. The building construction was divided naturally into five wards. One of these became a short-term ward, which had two functions: first, to affirm the person with dementia, and second, to find others who shared some common interests and matched their personality. This way of organizing made it possible to find "a neighborhood where the person felt at home" (Lill, Pda 2.1 hj). The term "neighborhood" refers to an acknowledgment that different wards have different qualities, depending on other patients, staff, and room facilities. Finding a suitable ward by matching staff and patients is how this institution organizes their care services. Nina is one of the patients who profited from this way of organizing care. Nina is a 61-year-old woman; she is highly educated and well-known in her community. Recently, it became troublesome for her to stay at home; therefore, she alternates between her home and an institution. During her stay at the short-term ward, they found a "neighborhood" where she felt comfortable.

> When she comes for her stay, she immediately seeks her "new" best friend. They do everything together; they even go to the bathroom together. They have a good dialogue together even though they are on different levels of cognition. Neither of them would be a lighthouse for others, but they became that for each other. (Lill, Pda 2.1 hj)

In this case, the diagnosis and level of need became less prominent, compared with the relationships and how the relations were connected to herself and others. It is difficult to proclaim that this is the best way of organizing services, but it simultaneously shows another way to organize care. Truls, who is married to Nina, is confident that the institution takes care of Nina, and it is important that Nina is satisfied:

> Truls: When we drive to the institution, she immediately settles. Then, when she arrives back home, she recognizes that she is home too. She is more cooperative. She is more tender and gives me many hugs. I interpret that she misses me . . . . However, I am happy as long as she is happy. (Pda, 2.1)

In this practice, the relational knowledge is and ordering the doings. The diagnosis remains part of the practice; it is the interplay between diagnosis, people, and place that makes it possible for families to live well with dementia. To be connected with others is an important aspect that defines a person (Pols, 2016). In this ordering, care becomes a relational activity. According to Per, who is married to Ester, a practice based on relational knowledge represents a quality of care. Ester is 60 years old, attends a day-care activity, and has previously attempted other different activities. During the interview, Per questioned the quality of previous services and presumed that professionals require special knowledge: "I guess relational knowledge must be important . . . but it seems that there is a lot more to do according to this." Per is satisfied with the day-care activity Ester attends but is afraid that moving to another institution, when her needs increase, will lead to discontinuity in care.

In this ordering, relational knowledge is a way of doing and managing care. This has implications for how the diagnosis is done, which are different than the previous orderings. Biomedical knowledge is less prominent and needs are not detected by legal knowledge, but instead through assisting people with dementia to stay connected to others and places that are familiar to them. Care, in this ordering, is about being held in relation to others. The relational knowledge is not only social but also material due to the location and culture, which the people and location establish together. In this practice, the person becomes the subject of knowledge, and people with dementia are constituted in and through relations to (social and material) others. Moreover, families are constituted in and through these relations. In this practice, normality is practiced by being held in relations that matter for the person with dementia, instead of through scores and numbers that provide certain rights to services.

## Discussion

This study was developed as a response to the observation that early diagnosis in policy documents is presupposed for the benefit of people living with dementia and of society. However, families living with dementia have expressed mixed feelings about early diagnosis during interviews about how to live well with dementia. This contradiction aroused interest in exploring how the diagnosis is enacted and how it influences the everyday life of families living with dementia. Instead of focusing on the impact that early diagnosis has on people living with dementia, my aim was to make the work done by the diagnosis visible, to enhance the understanding of how the diagnosis may shape good living. Using practice theory as an approach enabled me to describe different doings of diagnosis. I have demonstrated how the diagnosis is known, defined, enacted, and acted upon in three various ways followed by different care practices.

I have shown that there is a complex tension between forms of practice that individualize and those that collectivize people living with dementia. The "knowing" and the "governing" orderings individualize care for people with dementia. In the "knowing ordering," biomedical knowledge is privileged and guides people regarding how to live well with a dementia diagnosis. In the second practice, the "governing ordering," legal knowledge defines and guides how people with dementia can live well because they need assistance to manage their everyday life. This practice relies on the legal rights people have to services and works in a reductionist way to detect the needs and deficiencies. These two orderings enact diagnosis in an individualistic approach, wherein individual needs and lack of capabilities become the primary objectives for living and caring with a dementia diagnosis. Even though they rest on different knowledge practices, they work by separating, disconnecting, and isolating the person with dementia from others or other places. There is an understanding that their mission is, to be honest with biology, rather than to humans, which they individually have to bear, face, and deal with (Moreira, 2010). In the last ordering, the diagnosis is enacted somewhat differently. This practice is neither underpinned by the progression of cognitive decline, or promising therapeutic solutions, nor is it bound by legal rights. Instead, it is a matter of handling daily life and being a part of a community. Care then becomes an effect of a collective achievement, which involves not only professionals, but also people with dementia, new acquaintances, families, and localization. The collectivization is more difficult to do and to sustain because dementia is managed as a singular and individual phenomenon by politicians who decide the systems of care.

According to Pols (2006, 2016), patients need to be individuals to become citizens. The knowing and the governing orderings divide the experience of being a person and having a dementia disease. Simultaneously, these care practices empower families living with dementia by attempting to understand what is wrong, how to handle new situations, and the ability to apply for professional assistance. Meanwhile, in the relational ordering, people with dementia become individuals in relation to others. Care practices guided by relational knowledge should, therefore, move away from the value of doing over being (Power, 2014). To build a care practice on being-in-a-relationship with someone or something requires a commitment to help people with dementia to be held in relations that produce well-being. Care, then, gives attention toward assisting people to handle daily life by being held in relations that matter. Hence, we should discuss the person's capacities rather than the sole biological aspects of the disease (Kenigsberg et al., 2015).

The three doings of diagnosis illuminate that diagnosis is not a singular thing, it is multiple (Mol, 2002). While exploring how the diagnosis is done in practice, the reality changes from singular to multiple. My analysis reveals that the diagnosis is enacted differently at various locations and creates different opportunities regarding subjectivity, normality, and care. If there are various ways to enact a diagnosis, it may seem that there is, or should be, a choice between them (Mol, 1999). Simultaneously, policy documents seem to choose a certain way to act upon diagnosis. In my reading of policy documents, the controversy of dementia is closed and defined by some set of understandings that rely on a reductionist approach and biomedical knowledge. Therefore, the diagnosis is singular, thus enabling policymakers to manage and make political strategies. Policy documents frame dementia as an individual disease that requires individual needs and services (Callon, 1998). Subsequently, dementia diagnosis becomes an actor with a particular arrangement attached to it (Callon & Law, 1995), a particular arrangement of people and things, such as stages of illness, medical tests, and measurements, need assessment, cognitive deficits, and needs for individual care. This enables the diagnosis to be quantified, compared with other diseases, but also calculated as an economic issue (Brookmeyer et al., 2007).

Although "the policy of diagnosis" is designed to protect, nurture, and care for people with dementia, both individually and on behalf of society, it privileges medical knowledge in medical research (Fox, 1989). This is intentionally for the good, to presume legal rights and attention toward needs. In the case of families living with dementia, it gives them the right to access services and to gain knowledge, but at the same time they are isolated, divided, and disconnected from things, acts, and people that may make their everyday meaningful and manageable. It seems that this individual enactment of diagnosis proceeds very well in our society and has become part of a durable way of doing diagnosis because biomedical knowledge allows for calculating and quantifying the diagnosis, whereas legal knowledge makes it is possible to estimate care costs. I do not argue that biomedical or legal knowledge is less useful to shape good living for families with dementia; rather, my argument is that it is problematic when some way of enacting diagnosis is given priority, and thereby, overshadows others. Therefore, I am concerned that policy in the field of dementia is not careful enough and neglects things that are most needed, such as "care" relying on relational knowledge, which may shape the well-being of the entire family. This is in line with Roach's (2016) claim that it is time to change the way we react to a diagnosis of dementia and strive to maintain active engagement in the community. Furthermore, there is a need for more research on how to protect the quality of life as long as possible, especially concerning how the diagnosis is enacted as a "knowing" object.

### *Limitations and Methodological Considerations*

The findings I have presented in this study only reflect the enactments of diagnosis in the Norwegian context. The Norwegian health care system is based on a liberal welfare model that is funded by the state budget, and the overall intention is to ensure just allocation and equal access to services. Furthermore, the use of practice studies as a research approach does not lead to universal conclusions. Instead, the lessons learned are quite specific. Therefore, I do not claim that the three orderings described are the only ones possible, but they are the ones at work in my material. However, the study analysis points to new ways of thinking about diagnosis and care practices, which can be brought beyond single cases, and potentially have a far-reaching impact on people living with dementia, namely, that practice enacts diagnosis in various ways and shapes care practices, which may be good for families but could also be the opposite.

## Conclusion

The study findings show the black box concerning early diagnosis as being for the good of people living with dementia and of society. The use of practice theory enabled me to describe how different doings of diagnosis shape different care practices. I have described the knowing, the governing, and the relational orderings, which call for different opportunities to live well with a diagnosis. The first two individualize living with dementia and create attention toward malfunction and illness needs, whereas the latter gives attention to resources and assists the person with dementia and the family to be related to others and places that shape one's well-being. The way diagnosis is translated from policy documents can potentially have unintended impacts on how it is enacted in practice because it highlights the diagnosis as an individual object of concern. An increasing attention toward early diagnosis may be important, especially for care professionals to understand and label symptoms, and for health care planners to estimate care and service needs. For some families, early diagnosis will enable them to plan everyday life. However, for others, early diagnosis will cause more prolonged emotional distress. This alerts us to develop understandings and care practices that are not merely occupied with diagnosis in an individual way of living but instead encourage practices that enable people living with dementia to stay in relationships with others, socially and materially.

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