



The Journey Towards Community-Based Dementia Care: The Destination, Roadmap, Guide, Tour Group and the Conditions



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Abstract

In their paper, Morton-Chang et al. (2016) discuss how aging societies are struggling and trying to cope with the rapidly increasing numbers of persons living with dementia (PLWD). In that sense, the Canadian case is not unique. On the contrary, it is very similar to other developing countries. Therefore, it is worthwhile to reflect from another country's perspective on this unprecedented societal development.

In this paper, I will consider the challenge of dealing with increasing numbers of PLWD from the European and, in particular, Dutch perspectives. Whereas, MortonChang et al. pose the question: "How do we get there from here?" I will address the issues of what the "there" should be and how we get there from my European/Dutch perspective. I will provide my view on how the roadmap can be drawn, who needs to be on the tour, who might be the guide and what conditions need to be in place to arrive at the desired destination.



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The Destination

Before I discuss the destination – the “there,” in terms of Morton-Chang et al. (2016) – I will first briefly depict my “here,” The Netherlands. Geographically, The Netherlands is a small country, with a population of 17 million, of whom ~260,000 people suffer from dementia (RIVM 2016). The Dutch spend ~5.3% of their health budget on dementia (RIVM 2014). As in other countries, there are some signs that the prevalence is decreasing, probably because of improved prevention of vascular disease and higher levels of education (Larson et al. 2013; Matthews et al. 2013). Because of the sheer aging of the population, however, predictions are that in 2050, the number of PLWD will be ~500,000 in The Netherlands (Alzheimer Nederland 2013). Or, to give an impression of how it will affect society, in every street, there will be, on average, two PLWD. No doubt, dementia will affect the Dutch society to a large extent, as it will affect the Canadian society.

Acknowledging that there will be no cure for dementia in the short term, society has to deal with this reality. It needs to take up the hazardous journey into developing communities that can accommodate PLWD. One argument for this journey is guided by normative principles: it is a human right that PLWD find a place in society and can participate without any discrimination, irrespective of disease or disability, as stated in the UN Convention on the Rights of Persons with Disabilities (UN 2006). Communities, therefore, should be accessible to all citizens, irrespective of the kinds of disabilities or impairments. Therefore, according to these principles, we need to develop dementia-friendly communities, that will be beneficial to other groups of people with disabilities as well.

The second argument is an economic one. Calculated over a person’s life, dementia is – after learning disabilities – the second most

expensive disease or disability (RIVM 2014). The OECD (2015) recently estimated the worldwide cost of dementia was US \$645 billion in 2010. This is more than the GDP of Switzerland. As the number of PLWD is expected to double the next 30 years, expenses will increase enormously, in high-income countries, but even more in middle- and low-income countries (OECD 2015).

The third, and maybe the most appealing argument, is the enormous challenge to support PLWD and their relatives to live a life with dignity and that it is worthwhile to live. On average, they live eight years with their disease, i.e., approximately, one-tenth of their lives. These should be years with as high as possible quality of life. The same holds for their relatives, neighbors and their neighborhoods in which they live. The pressure on informal carers is large: European data suggest that in the early stages of Alzheimer’s disease, more than half of informal carers spend more than 28 hours per week providing care. As Alzheimer’s disease progresses, the burden increases, with half of the carers spending more than 70 hours per week providing care (Glendinning et al. 2009). So, the quality of life is surely a good case for working on communities that can deal with dementia.

Thus, whatever argument is taken first, the destination is clear: we need a dementia-friendly society, with dementia-friendly communities.

The Roadmap

If a dementia-friendly community is the joint destination, what should be the roadmap? As outlined above, dementia has huge consequences for society. In my view, it is not merely a healthcare issue. Not surprisingly, a traditionally economy-oriented organization such as the OECD has recently extensively addressed the issue on how to deal with dementia in society at large (OECD 2015). Along with other more

healthcare-oriented policies, the OECD calls for a wide variety of measures to be taken in and by society: healthy aging strategies for PLWD, safer communities, more acceptance, awareness raising, dementia education at schools, training of people who get in contact with PLWD, promoting independence and self-determination through user-directed support and care coordination, support of relatives and friends who take up care tasks, peer-to-peer support networks, safe and appropriate environments including alternatives to institutional care for living with dementia in dignity, guidance and financial support to help people to make their homes suitable for living with dementia and the use of effective technologies. One can hardly disagree!

Dementia care standard

The issue is how to take this further. In The Netherlands, we have developed some strategies, which may also work for other countries. One is the instrument of the so-called Care Standards. A Care Standard is a document that describes what the important ingredients are for optimum dementia care and support in a region, based on the most state-of-the-art (evidence based) multidisciplinary knowledge and guidelines for a particular disease or category of health-related problems. It is developed by all relevant national stakeholders and experts (Nies et al. in press). The national Care Standard is translated to the regional and local communities by care programs. The Dutch Care Standard for Dementia resembles the NICE guideline on *Dementia, Disability and Frailty in Old Age* (NICE 2015). It specifies what should be organized in functional terms without exactly saying *who* is responsible for what.

The present standard, however, is pretty much health-, long-term- and social care-oriented. It more or less follows the process in the disease of the PLWD. It describes how to organize early recognition and prevention,

diagnostics, case management (or care coordination), treatment, counselling and support, delivery of care and services, and organization of integrated services/care. The regional translation and implementation is a responsibility of dementia care networks. These are networks of professional organizations and/or professionals (e.g., general practitioners) in dementia care, as well as representatives of local or regional Alzheimer's associations, representing the voices of the users. To make dementia care work at the regional level, the Dutch Government has issued a large implementation program to encourage the development of regional collaborative networks (Nies et al. 2009), and will do so again from 2017 on. Between regions, differences can exist in how dementia care is organized and how far it is implemented (Nies et al. in press).

However, the present approach is not yet a success in all respects. The present Care Standard is signed by a great number of stakeholders, but not by healthcare insurers and municipalities, two important categories of stakeholders. The national council of municipalities did not sign the Standard because of the political autonomy of local governments. The healthcare insurers were reluctant because of financial implications. At the time the standard was approved, it was not an obligation to get them on board and committed. The standard as a quality instrument was at that time merely seen as a professional standard, but tested from a user perspective. A final limitation is that the current standard is yet a *care* standard, not a *community* standard.

Dementia-friendly communities

A second strategy is that of "dementia-friendly municipalities." As in other countries, at present, a number of municipalities are profiling themselves as such. The Dutch Alzheimer Association supports this development by encouraging municipalities to join the aforementioned care networks, to

commission and to develop dementia-friendly services (Alzheimer Nederland 2012). The movement towards dementia-friendly communities (municipalities, neighborhoods, companies, citizens) is at its beginning stage. There are quite a number of good examples, for instance, in encouraging arts work among PLWD, teaching on how to interact with PLWD at schools, enabling police officers to be more aware of dementia, providing information to citizens, organizing informal carers' support and so on.

Innovation

A third strategy is innovation. A number of services that fit in the concept of "dementia friendly" are well-developed and grounded on scientific evidence. For instance, the dementia meeting centres are – as the name suggests – a place where the PLWD meet. A small team of professionals and volunteers provides support and a social environment to a group of mildly to moderately impaired PLWD in a lowthreshold setting. Meeting centres integrate different types of support and offer a wide range of activities. Informal carers are invited to join for information meetings and discussion groups. The centres are also open for assistance in practical, emotional and social problems (Dröes et al. 2004, 2006). At this moment, ~150 meeting centres exist.

Another type of service, and to some extent similar, are the Alzheimer Cafés (Jones 2010; Jones and Miesen 2011; Miesen and Jones 2004). These cafés provide, usually on a monthly basis, opportunities for meeting and sharing information for PLWD, their informal carers and professionals. The meetings are often accompanied by music performances and themes on dementia are discussed and usually inspired by presentations of one or more experts. The Alzheimer Cafés are widely spread across the country and are often run by volunteers or professionals, or professionals in their leisure time.

Further, the so-called green care farms fit within the model of dementia-friendly communities. These are often a form of collaboration between healthcare and social care and agriculture. People with dementia or learning disabilities; those with psychosocial, psychiatric or (formerly) addiction issues, and those with burn-out issues and other problems that make it difficult for them to participate in society, are working under guidance at a farm for a given number of days a week. Hereby, people engage in meaningful activities and meet other people. Participants sometimes also have the option of staying overnight. The mixture of target groups is diverse, and sometimes, the farms only focus on people of one of these groups (De Bruin et al. 2010a, 2010b). The number of care farms has mushroomed from 214 in 2000 to 1,088 in 2009 (no recent data available) (Federatie Landbouw en Zorg n.d.). At present, the continuation of these green care farms has become critical in some cases because of recent changes and cutbacks in public long-term care funding.

The Guide, the Tour Group and the Conditions

These examples demonstrate that optimum dementia care and dementia-friendly communities can be encouraged and guided by governments; for instance, by establishing an instrument like the Care Standard, by using a label such as "dementia-friendly community" or by issuing a significant implementation program. In our – Dutch – view, it is a system-responsibility of our government to ensure healthcare for all citizens. However, its needs to be taken up by service users and their representatives, citizens (including volunteers), service providers, professionals and authorities. They need to be actively involved in designing these communities. They constitute the "tour group" that is heading for the jointly agreed destination. And if the tour doesn't

take place, our government can be held accountable for not upholding its system-responsibility.

The examples also show that creative entrepreneurship and initiatives of citizens are helpful. The green care farms, to some extent, developed because of the difficult times in agriculture and a number of farmers had to find new ways to continue their business. On the other hand, new paradigms of participation, inclusion and normalization were adopted by the dementia care providers. Pioneers are to explore new pathways!

Thirdly, the examples show, that supportive conditions need to be in place. It is not always big money that makes the difference, but some money is necessary. Skillful people are also needed to develop and run the right services, which are attuned to the needs of PLWD. Moreover, infrastructure is necessary: building homes suitable for PLWD, running buses to transport people and constructing local information structures.

The challenge

The journey from “here” to “there” is a challenge. The destination is clear: a supportive society that is receptive to PLWD and enables them to live as full a life as possible. But what do we mean by saying this? “A life in good health” could be the obvious answer. However, “health” has become a concept that is heavily medicalized. The definition of the World Health Organization (WHO 1948) – “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” – declares the majority of people, particularly older people with multiple conditions, as unhealthy. This easily contributes to over-medicalization. Huber et al. (2011: p. 235) introduced the concept of “positive health,” which is the “ability to adapt and self-manage in the face of social, physical and emotional challenges.” Resilience and selfmanagement are key

to experiencing quality of life, well-being and dignity, although impairments, frailty and/or multiple conditions exist, which is the case in PLWD. This concept of “positive health” implies living a normal life for as much as possible. It also implies a paradigm shift away from the traditional disease-oriented healthcare, which is often dominant in care for PLWD. PLWD are more than their disease, although their conditions are limited. Huber et al. (2016) identified the following six main dimensions within the concept of “positive health”: bodily functions, mental functions and perception; the spiritual/existential dimension; quality of life; social and societal participation; and daily functioning. These dimensions are made up of in sum 32 aspects.

It was established that citizens and patients value all these dimensions, but the values of professional carers differ from those of citizens and patients. However, according to Huber et al.’s (2016) research, policy makers, healthcare insurers and researchers deviate most from the values of citizens and patients.

The real challenge will be to support positive health for PLWD. The on-average eight years are too long to live a life that is “unhealthy” and dominated by the disease. Optimizing life alongside the six dimensions by supporting self-management and resilience is the real challenge; sometimes by counseling, nursing and treatment, but most of the time by supporting what makes life worthwhile. And often that can be done by providing support to the social and physical environment. And, in the end, people constitute their own lives, for good or for bad.

From a community point of view, conditions need to be created to enable positive health for PLWD. This community journey needs a well-designed roadmap. Many barriers exist that we ourselves have created,

such as legislation, funding, organizations, professions, which create their own boundaries, whereas the PLWD deserve fully integrated support. This calls for a guide who knows how to navigate around these barriers and to cross the boundaries. It also requires a tour group that is destined to reach the “there” and to establish supportive conditions and investments, in terms of money and infrastructure. Each local itinerary and each journey can be different and should be different, be it in Canada or in The Netherlands. But there needs to be a common view: supporting people with dementia and their dearest to make life worthwhile and dignified!

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