



Integrated Care for Frail Older People Suffering from Dementia and Multi-morbidity

41

Henk Nies, Mirella Minkman, and Corine van Maar

41.1 The Challenge

Due to improved living conditions and better health care, life expectancy is expanding in many countries (OECD 2019). Overall, we consider this as a blessing. But this blessing is to some extent ambiguous. Many people also extend their life with years in which they suffer from multiple chronic diseases, disabilities or frailty. One could wonder, whether quality of care has improved quality of life and whether the solution—better treatment and decreased mortality—has become a problem. It is a challenge to add life to years, instead of adding years to life.

This requires reconsideration of what we see as ‘good health’. The concept of health as defined by the World Health Organization dating from 1948—a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’—appears to be outdated (WHO 2006). According to this conceptual-

H. Nies (✉) · M. Minkman

Vilans, National Centre of Expertise for Long-Term Care, Churchilllaan 11,
P.O. Box 8228, Utrecht 3503 RE, The Netherlands
e-mail: h.nies@vilans.nl; h.l.g.r.nies@vu.nl

H. Nies

Organization Sciences, Vrije Universiteit, De Boelelaan 1105 De Boelelaan 1101,
Amsterdam 1081 HV, The Netherlands

M. Minkman

Innovation of the Organization and Governance of Integrated Long Term Care,
TIAS School for Business and Society, University of Tilburg, Postbus 90153,
Tilburg 5000 LE, The Netherlands
e-mail: m.minkman@vilans.nl; m.minkman@tias.edu

C. van Maar

Van Maar Advies, Houtwerf 14, 3451 DC Vleuten, The Netherlands
e-mail: Corine@vanmaaradvies.nl

ization, everyone who is not completely successful in life could be seen as unhealthy (Nordenfelt 2009). Also, the WHO definition is a rather static conceptualization of health, not recognizing that being healthy is an ambiguous and dynamic process.

It can be argued that this conceptualization of health contributes to an over-medicalization of society. Huber et al. (2011, 2016) proposed a new concept of health: the ‘ability to adapt and self-manage in the face of social, physical, and emotional challenges’ (Huber et al. 2011: 235). Resilience and self-management are keys to achieving as good as possible quality of life and well-being. The challenge for care professionals, organizations and to society is to support older people in living a meaningful life in dignity, in spite of the ‘social, physical, and emotional challenges’ they are faced with.

In this chapter, we will explore avenues to meeting the multiple health challenges for frail older people, in particular people suffering from dementia and multi-morbidity. We will take their needs as the point of departure for our analysis. Secondly, we will address how integrated care for these people can be organized. We will use the Dutch so-called Dementia Care Standard as an example of a framework for service integration at regional level. Then, we will address our view on future developments in integrated care by applying principles of person-centred care and personalized care. Generic standards need to be translated to individuals, as frail older people require tailored care and support. Finally, we will discuss how the organization of integrated care for frail older people suffering from dementia and/or multiple problems may be built up of similar elements. Adequate diagnostics and multiple interventions by care professionals and organizations will not suffice. A community approach combined with a holistic point of view is also required to improve healthy life styles, as well as adapting the environment.

41.2 Service Users’ Needs for Integrating Services

Before thinking about (multiple ways towards) solutions, the needs of the service users are to be explored. Frailty, dementia and multimorbidity are frequent among the older population.

Frailty is often used to describe the high vulnerability of older people. Gobbens et al. (2010, p. 175) define frailty as ‘a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, social), which is caused by the influence of a range of variables and which increases the risk of adverse outcomes’. According to these authors, the main components of frailty of older people are nutrition, mobility, physical activity, strength, endurance, balance, cognition, sensory functions, mood, coping, social relations and social support. Frailty manifests itself in adverse health outcomes such as falls leading to immobility, disability and dependency and other negative health outcomes, which may on their turn lead to increased institutionalization and mortality. It represents an imbalance of the person’s homeostatic reserve, with a weakened resistance to harmful agents (Fried et al. 2004; Puts et al. 2005; Gobbens

et al. 2011; Castell et al. 2013). It is a condition of increased risk caused by functional decline and manifested multiple ‘frailty’ elements. Traditionally elements like weakness, poor endurance, weight loss, low physical activity and slow gait speed are seen as manifestations of frailty (Fried et al. 2004). However, in addition to these physically elements, also psychological and social factors need to be considered. In other words, frailty is a multi-dimensional condition with physical, social and psychological components. It is estimated that a large proportion of the older population are frail, ranging from around 5% among people aged 65–70, to more than 15% in persons aged 80 and over, with significant differences among various sub-populations (Fried et al. 2004; Castell et al. 2013).

Dementia occurs relatively often in old age. The term ‘dementia’ refers to a syndrome and describes a wide range of symptoms associated with a decline in memory. According to the World Health Organization (2015), ‘It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.’ Alzheimer’s disease is the most prevalent and best known form of dementia. It accounts for 60–70% of all cases of people with dementia (WHO 2015). The second most common type of dementia is vascular dementia, accounting for about 10%. Other types are dementia with Lewy bodies, mixed dementias, dementia as a manifestation of Parkinson’s disease, frontotemporal dementia and Creutzfeldt-Jacob disease. There are also reversible conditions that can cause symptoms of dementia, such as thyroid problems and vitamin deficiencies (Alzheimer’s Association 2015).

Dementia primarily occurs in the ‘oldest old’. After the age of 80, the prevalence increases rapidly from around 15% in the age group 80–84 to almost 50% among the 95+ population (OECD 2015). It is expected that worldwide the number of people suffering from dementia will rise from 47.5 million at present to 75.6 million in 2030 and 135.5 million in 2050 (WHO 2015). In the Netherlands, dementia is in the top five of diseases with the highest mortality among women, and it accounts for 10.3% of total health spending in the Netherlands, being the most expensive disease (RIVM 2020a).

Comorbidity can be conceived as the presence of additional diseases in relation to an index disease in one individual, when the nature of conditions, the time span and sequence of conditions are considered (Valderas et al. 2009). This assumes one disease taking a central place (for instance Alzheimer’s disease), in terms of being dominant in terms of the care and well-being of the individual. *Multimorbidity* is defined as the ‘co-existence of two or more chronic conditions, where one is not necessarily more central than the others’ (Boyd and Fortin 2010: 453). This implies that differentiating the nature of conditions is critical to the conceptualization of comorbidity (Valderas et al. 2009).

Data on incidence and prevalence of multimorbidity are complex to aggregate. Studies vary in the populations being studied, sources of data, data collection methods, age groups and diagnoses that are included (Boyd and Fortin 2010). Data from The Netherlands suggests that around two thirds of the Dutch seniors (65+)

have more than one chronic condition. In the 85+ population, this is around 85% (Van Oostrom et al. 2011). However, multimorbidity is not only a phenomenon in the older population. An Australian cohort study found more than 40% of the people with multimorbidity are younger than 60 years of age (Boyd and Fortin 2010). The bad news is that prevalence of multimorbidity is rapidly increasing; the good news is that most older people with multimorbidity remain independent and self-supporting, and most people do not feel limited in daily functioning. However, this is different in the oldest age group. In 2018, 31% of the general population on the Netherlands suffered from multimorbidity, and of the 70 + population, more than 70% had three or more chronic conditions (RIVM 2020b).

Studies into the comorbidities of dementia are scarce. From the few studies that exist, it is known that people with dementia have on average two to eight additional chronic diseases or comorbidities. One of the larger studies among nearly 73,000 people aged 65 and over in Spanish primary care centres showed that 12% of the people suffering from dementia had dementia as the only diagnosis, almost 70% had at least two comorbidities, nearly 50% had three or more. These figures are around 50% higher than in the total older population. Like in the general population, hypertension and diabetes were most often observed among people with dementia. However, the conditions that were most strongly associated with dementia are Parkinson's disease, congestive heart failure, cerebrovascular disease, anaemia, cardiac arrhythmia, chronic skin ulcers, osteoporosis, thyroid disease, retinal disorders, prostatic hypertrophy, insomnia and anxiety and neurosis. Some of these can be considered as risk factors, others as complications and others just as comorbidities (Poblador-Plou et al. 2014). What these studies show is that dementia often does not come 'alone' and that, also related to ageing, more health challenges have to be faced. Further, there is some evidence of a 'lack of continuity in healthcare systems and structures for people with dementia and comorbidity, with little integration or communication between different teams and specialties' (Bunn et al. 2014, p. 11).

Frailty, dementia, co- and multimorbidity are multi-faceted conditions, which require multi-faceted interventions. These multiple, mental and physical problems are often associated with (psycho-) social problems, such as limited participation in society, loneliness or weak social relations, restricted mobility, feelings of meaninglessness or uselessness, anxiety, depression and loss of dignity. From a traditional point of view of health care—being compartmentalized and organized according to medical, paramedical, psychosocial and social disciplines and organizational entities—these needs cannot be met by simply adding up single interventions. On the contrary, coherent multiple interventions are required from professionals, but also from non-professional carers, such as next of kin and neighbours, as well as by the community at large (Nies 2014). In our view, the perspective should be oriented to the new—above depicted—concept of health, in strengthening self-management and resilience. Thus, an integrated approach for these groups of people is needed which goes beyond connecting medical and social care. The new paradigm of health needs focuses on domains such as bodily functions, mental functions, perception, spiritual/existential issues, quality of life,

social and societal participation and daily functioning (Huber et al. 2016). To put it in simple wordings: it is about ‘living your day-to-day life in a satisfactory way’.

In practice of care delivery, this means that while drafting an individual care/support plan with a person suffering from dementia, one needs first to discuss what matters for this person. Before thinking in solutions for care and support, a deeper insight into what is important for a satisfactory, meaningful way of living is necessary to guide interventions that do not only address the physical and mental condition. It is about how the household can be run, how social contacts can be maintained, what the person can do or mean for his or her relatives, what role intimacy and sexuality plays, whether membership of activities such as a choir or a lunch club, whether spiritual needs are being met and so on. It requires professionals to have attention beyond traditional professional domains. It requires care providing organizations to operate in collaboration in networks of relevant professional and non-professional organizations (volunteers, citizens’ initiatives). It requires dementia friendly communities, in which public (police, clubs, public transport, etc.) and private services (shops, restaurants, museums, etc.) and infrastructure (signage, ramps, housing, etc.) are attuned to people with dementia (Davis et al. 2009; Nies 2016).

41.3 Inter-organizational Collaboration by Care Standards

In order to organize care and support for older people with complex needs, new coherent inter-professional and inter-organizational arrangements are required. As in many countries, in the Netherlands, care and support for people with dementia could and can be improved. Although GP services, diagnostic clinics and home care are available for all persons in the Netherlands, the quality of dementia care is still subject to shortcomings and inter-regional differences. Areas for improvement include early detection of the disease, support after medical diagnosis and under-diagnosis of patient and caregiver depression. Lack of care coordination, timely referrals and information flows between health professionals and informal carers are other improvement areas (Minkman et al. 2009).

To improve dementia care, a number of incentives were initiated over the last fifteen years. At this moment, there are about 85 dementia care networks in the Netherlands. In these networks, professionals and managers of different organizations (e.g. mental health care, home care, long-term care, municipalities) and local Alzheimer users’ organizations work together for more coherent dementia care. The needs as defined by users and their informal carers, formulated in their language, were taken as the point of departure for the regional plans (Nies et al. 2009; Minkman et al. 2009).

To prevent that every region had to figure out their own way of setting up inter-organizational arrangements, for this purpose, a so-called care standard can be helpful. A care standard is a document developed multidisciplinary, which describes what the important ingredients are for dementia care and support, based on the most state-of-the-art (evidence based) knowledge and guidelines. Based on

this national standard, solutions can be contextualized to adapt to the specific needs of the local communities (Nies 2016).

The emergence of the dementia care networks and the needed collaboration between a wide range of professionals showed that for providing the best care and support guidelines from one perspective or profession were not sufficient. Therefore, in 2013, the first national care standard for dementia was developed, led by Alzheimer Nederland, supported by Vilans (Alzheimer Nederland, Vilans 2013). The instrument resembles to a certain extent the NICE guideline on *dementia, disability and frailty in old age* (NICE 2015) but is more specific in term of what in these services should be organized. In 2020, an updated version of this standard was published.

The process of developing a care standard, as it is presently carried out in the Netherlands, is time consuming, as all relevant professionals and stakeholders need to be involved. Professionals, providers, service users and healthcare insurers need to agree on the standard and authorize it. This is a requirement for being acknowledged by the National Health Care Institute, which gives a legal status to the standard.

The most recent standard focusses on general conditions for adequate dementia care as well as good care and support in the four phases of dementia:

General conditions for quality dementia care	
<ol style="list-style-type: none"> 1. Advance care planning 2. One care/life plan 3. Case management 4. Coordinated network of services 	
Phase of uncertainty	Diagnostic phase
<ol style="list-style-type: none"> 5. Regional information structure 6. Signalizing 7. Signalizing (specific target groups) 	<ol style="list-style-type: none"> 8. Diagnostics: physical, mental, functional and social
Living with dementia	Dying and aftercare
<ol style="list-style-type: none"> 9. Palliative support: from life extension to maintaining functions to comforting 10. Discussing with person and informal carers how to deal with consequences 11. Daily support in personal and domestic tasks 12. Supporting meaningful activities 13. Balancing between safety, autonomy and privacy 14. Medical and non-medical treatment 15. Use of medicines 16. Emergency services/crisis intervention 17. Polyclinical hospital care 18. Intermediate admission in (mental) hospital 19. Respite care 20–24 Nursing home care (information, ownership and homeliness, environmental aspects, diversity, informal carers) 	<ol style="list-style-type: none"> 25. Care for loss and mourning of informal carers

The recommendations describe what ‘good’ care should be, based on—for as far as possible—established guidelines and consensus, and how it should be organized. The standard does not define *which* professional (group) is eligible for providing care, this is held to the professional organizations and the local context.

A large number of dementia networks will implement this renewed care standard. There is a gap between the national (total) standard and the actual delivery of individual person-centred dementia care. To bridge this gap, region-specific or local standards or pathways need to be elaborated, to translate the ‘national standard’ into a regional version. This is a necessary step, because the standard gives a functional description of what should be considered or arranged, not whose task this is or how it looks like in practice. Translating the national standard into a regional version facilitates implementation and guides the steps that can be taken.

41.4 Implementation

In order to further and optimize regional dementia care according to the care standard, a number of quality indicators are proposed. The regional dementia care networks can choose which indicators they prefer to use, in accordance with their regional priorities for improvement.

However, organizing regional networks is not an easy task. Issues that are frequently encountered are (Van Maar et al. 2014):

1. Significant differences between regional networks, also with respect to the collaboration with municipalities (which have a role in social support and prevention);
2. Commitments on quality, diagnostics and follow-up activities exist, but are not always followed in day-to-day practice;
3. No structural funding for case management;
4. Inter-organizational collaboration not fully implemented;
5. Structural funding of the networks;
6. Client perspective is not always in focus.

The regional networks are expected to work according to the principles of the care standard, but this is not a stand-alone endeavour. The coordinators are often connected to other networks in the region, in particular generic networks for care for frail older people and networks for palliative care. Some of the networks are focusing on one of the domains of dementia care, such as case management, others are focusing on the full range of services.

The care standard provides an external framework for inter-organizational collaboration. It is also used as a basis for commissioning services by healthcare insurers, although not very strictly.

The example demonstrates that a care standard provides a national framework based on (inter)nationally agreed evidence and consensus which is to be translated at regional level as a basis for—in the terminology of Valentijn et al. (2013)—normative and functional integration of services. It needs regional or local contextualization to make collaboration work.

41.5 Personalization

The term ‘Care Standard’ suggests that care is standardized and that personalized care is not feasible. However, the instrument of a care standard does recognize individual needs and requires tailoring services to needs. There are two ways of tailoring service provision to needs: one is to apply methodical principles of person-centred care in interacting with the service user and his or her informal carers and that are applicable across various groups of service users. The other is to develop more evidence on which interventions work for particular groups of users and—more specifically—for which persons and under which conditions.

For person-centred care, a number of main ingredients can be defined. The key is putting the person and the family at the heart of every decision and empowering them to be genuine partners in their care. The focus shifts to new models of care that change the conversation from ‘What’s the matter?’ to ‘What matters to you?’ A starting point of person-centred care is that people’s care preferences are understood and honoured, including at the end of life. In providing care, collaborating with partners on programs designed to improve engagement, shared decision-making and compassionate, empathic care is important (Barry and Edgman-Levitan 2012). In this scope, it is not only about care, but a much broader perspective on daily living is captured, in line with the aforementioned new paradigm of health (Huber et al. 2011, 2016). Working with partners to ensure that communities are supported to stay healthy and to provide care for their loved ones closer to home is the leading societal perspective.

On a more detailed level, personalized care requires evidence on ‘what works for whom?’ Most studies on interventions in frail older people and people with dementia are generic. They do not make distinctions between the characteristics of the subgroups, the circumstances in which they are effective and the specific outcomes. However, effects of interventions, also in multi-problem target groups, can be enhanced by tailoring services to the idiosyncrasies of the person and his or her social network (see: Van Mierlo et al. 2010; 2012).

Most people with dementia show one or more behavioural and psychological symptoms such as psychological pain: depressive, anxious, apathetic, psychotic and aggressive behaviour (Bakker 2010). Both people with dementia and their informal caregivers experience these symptoms as burdensome, whether they reside at home or in a residential setting. The Dutch Healthcare Inspectorate (2015, 2020) concluded that healthcare professionals often respond tardily or inadequately to these behavioural and psychological symptoms of dementia. Exemplary for this is that

so-called ‘calming’ medication is prescribed, on a non-targeted manner. It would be more appropriate to apply a stepwise approach, involving person-centred and more effective solutions. To be able to do this, it is essential to know the causes of the behavioural and psychological symptoms. In other words: first get to know and understand the person with dementia well. Only then will one be able to offer good personalized care to the person and the informal carers. For this, it is essential that both are in a central position and actively participate in finding the best solutions. It is also vital that all involved healthcare professionals discuss and coordinate everything with each other in an integrated way. A personalized, integral approach can prevent unnecessary stress and escalation in people with dementia, their informal caregivers and the healthcare professionals.

An integrated approach has been developed in the Netherlands based on the Dutch Guideline on behavioural and psychological symptoms of dementia (BPSD) (Verenso/NIP 2018). This led to the *personalized integrated stepped care approach to BPSD (STIP method)*. This approach is built on two elements: (1) Five phases of integrated methodical clinical reasoning and (2) Four ‘Stepped Care’ interventions.

The **STIP** method follows these principles:

Phase A Detection: Early detection of BPSD with the Neuropsychiatric Inventory (NPI; Cummings et al. 1994) provides insight into the type and severity of the problems, including the degree of burden experienced by the informal caregiver. Next to that, the biography provides substantive information about the person’s life course and the person’s most important positive and negative experiences.

Phase B Diagnosis and Broad Analysis: Identifying basic needs, pain, physical, psychological and social needs.

• **Step 1 Basic Approach:** Based on the NPI, biography and the broad analysis, describing the approach to the client. It is important that the nurse is able to be really present, can show empathy for the person as now known from the broad analysis and can show respect for the client.

• **Step 2 Personalized Day Program:** Applying a personalized balance between rest, cleanliness and regularity, again based on the NPI, biography and broad analysis.

Phase C Integrated Treatment Plan: Including achievable goals based on Phase A and B.

• **Step 3 Emotion-Oriented Care:** Applying, e.g. reality orientation, validation, snoezelen, reminiscence to necessary extent

• **Step 4 Pain Medication/Psychotherapy/Psychopharmacology:** Applying, e.g. life review, cognitive behavioural therapy, system therapy and targeted medication to necessary extent.

Phase D Multidisciplinary evaluation of interventions: Assessing progress based on shared decision-making and interdisciplinary consultation.

Phase E Reanalysis: Applying new NPI and broad analysis, checking implementation of stepped care interventions based on new information, adjusting interventions to necessary extent. The **STIP** method is supported by a Web application that is specifically designed to support this integrated methodical clinical reasoning approach. In this Web application—which is also used in Sweden and Japan, among other countries—care professionals can keep track of the BPSD of clients. Such a tool supports the implementation of an integrated, methodical manner of working, thereby facilitating a stepwise approach with person-centred and effective interventions.

41.6 Future Perspectives

The current state of play is that dementia is a syndrome that with some exceptions cannot be cured, is multi-faceted and asks for person-centred integrated care. The same holds for frailty and to a large extent for the accompanying complex multi-morbidities. The symptoms can be alleviated, and people can be supported in their self-management and resilience. At macro-level, the best strategy is prevention of diseases and disability. Recent research shows that the prevalence of dementia is substantially decreasing in some countries if corrected for age, sex, area and deprivation status. Although there are various factors that could have increased dementia prevalence at specific ages, associated with diabetes, survival after stroke and vascular incidents, it appears that other factors such as improved prevention of vascular disease and higher levels of education appear to have a greater effect (Matthews et al. 2013; Larson et al. 2013). This implies that preventive measures, improvements in treatment and care and disease modifying interventions combined will be the most effective strategy for the future (Prince et al. 2013).

The OECD (2015) describes the key elements of such a strategy. Generic life-styles recommendations such as non-smoking, physical activity, healthy diets, cognitive training and formal education are linked to reduced risk of dementia. Treatment of medical conditions such as brain injury, diabetes, mid-life obesity, mid-life hypertension and depression is a second line of reducing the risk of dementia. What at present cannot be influenced are hereditary factors and age.

Following this analysis of risk factors, the OECD defines ten elements of dementia policy:

1. Risk reduction by healthy ageing strategies targeting generic risk factors;
2. Selective early diagnostics (standardized needs assessment) for people who are concerned about symptoms and post-diagnostic support to people;
3. Safer communities for and more acceptance of people with dementia by awareness raising, dementia education at schools, training of people who get in contact with people with dementia in the community;
4. Support of relatives and friends who care for people with dementia respite services, peer to peer support networks, training to informal carers, etc.;
5. Safe and appropriate environments including alternatives to institutional care for living with dementia in dignity, making houses suitable for living with dementia and communities safer and more accessible for people with dementia (dementia friendly communities);
6. Access to safe and high quality long-term care services by recruiting and training a dementia care workforce, systematic attention to behavioural symptoms, including the use of antipsychotics and physical restraints and promoting independence and self-determination through user-directed support;
7. Health services recognizing and dealing with people with dementia effectively, supported by registries or electronic health records, trained, dedicated and specialized staff in hospitals;

8. Increasing opportunities for dying in dignity in the place of people's choosing, trained home care staff in palliative care;
9. Coordinated, proactive and closer to home delivered primary care, multidisciplinary management of comorbidities;
10. Applying the potential of technology to support dementia care.

The OECD translates user-directed support also in financial terms for users and informal carers. It signals that financial systems should support independence and give control to service users and their families. This can be strengthened by appropriate benefits in the form of cash benefits, vouchers or personal care budgets, instead of services in kind. This allows people with dementia to choose the type of services they prefer, which may go well beyond traditional care and across financial, legislative and professional barriers.

Changes in funding and legislation, in roles between stakeholders and in collaboration also have consequences for governance. Governance of (traditional) organizations needs reframing, because inter-organizational collaboration becomes more important and asks for new dynamics and governance which is linked to the community (Nies and Minkman 2015).

Lastly, it can be argued that most of the above-mentioned elements for dementia policy are also relevant for frail older people and people with multi-morbidities. Hence, one of the key elements is safe and supportive living at home, be it in the community or in a care facility supported by—when useful—technology and by informal caregivers and people in the community. These elements relate to the earlier described new concept of health of Huber (Huber et al. 2016) in which 'whole person thinking' is key.

41.7 Conclusions

The challenges of care for frail older people with dementia and multimorbidity are increasing, partly due to our improved healthcare services and increased life expectancy. This challenge is not an easy one. It requires innovative approaches in order to face these challenges and to reduce current and future burden of service users, their families and society. It is a challenge that requires new care paradigms and new organizational paradigms. Working towards the principles of a new concept of health, working towards personalized and person-centred care in networks, based on shared normative and functional frameworks, needs full attention of policy makers and care providing organizations. But the challenge of an ageing population is not merely a professional task in the field of health, long-term and social care. The solution also lies in the community. It has to get tuned to a changing demography, supporting people with limited functioning and supporting healthy behaviour at all ages. Communities need to get acquainted with a changing population, where people sometimes behave 'differently'. Therefore, health and long-term care professionals and services should not limit their focus of integrated

care to their peers or care partners; it is a challenge to society and to local communities.

New questions need to be addressed such as how to create adoptive and resilient communities and organizations? What are effective approaches and which pre-conditions are necessary? How do we improve collaboration between the public sector in a broad sense such as schools, clubs, welfare services, public transport, police on the one hand and the private sector and private life of citizens, such as housing, shops, banks, neighbours' support, volunteers and the dementia care sector? Examples such as dementia friends (see: <https://www.dementiafriends.org.uk/>) and dementia friendly communities (see: <https://www.alzheimers.net/2013-12-12/building-dementia-friendly-communities/>) (Scharlach and Lehning 2013) are promising, but ambitious. Turning population ageing into a blessing requires high ambition on a wide variety of societal actors, integrating their strengths to meet the challenging social and individual needs of frail older people suffering from dementia and accompanying problems.

References

- Alzheimer Nederland, Vilans. (2013). *Zorgstandaard Dementie*. Utrecht: Alzheimer Nederland, Vilans.
- Alzheimer's Association. (2015). *What is dementia?* Accessed October 14, 2015, from www.alz.org/what-is-dementia.asp
- Bakker, T. J. E. M. (2010). *Integrative reactivation and rehabilitation to reduce multiple psychiatric symptoms of psychogeriatric patients and caregiver burden*. Dissertation, VU University Amsterdam, Amsterdam
- Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making—The pinnacle of patient-centered care. *New England Journal of Medicine*, *366*, 780–781.
- Boyd, C. M., & Fortin, M. (2010). Future of multimorbidity research: How should understanding of multimorbidity inform health system design? *Public Health Reviews*, *32*(2), 451–474
- Bunn, F., Burn, A.M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J., & Brayne, C. (2014). Comorbidity and dementia: A scoping review of the literature. *BMC Medicine*, *12*, 192. <https://doi.org/10.1186/s12916-014-0192-4>
- Castell, M.-V., Sánchez, M., Julia'n, R., Queipo, R., Mart'ın, S., & Otero, A. (2013). Frailty prevalence and slow walking speed in persons age 65 and older: Implications for primary care. *BMC Family Practice*, *14*, 86. <https://doi.org/10.1186/1471-2296-14-86>
- Cummings, J., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994). The neuropsychiatric inventory: Comprehensive assessment of psychopathology in dementia. *Neurology*, *44*, 2308–2314.
- Davis, S., Byers, S., Nay, R., & Koch, S. (2009). Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia*, *8*(2), 185–203. <https://doi.org/10.1177/1471301209103250>.
- Fried, L. P., Ferrucci, L., Darer, J., Williamson, J. D., & Anderson, G. (2004). Untangling the concepts of disability, frailty, and comorbidity: Implications for improved targeting and care. *Journal of Gerontology: Medical Sciences*, *59*(3), 255–263.
- Gobbens, R. J. J., Luijckx, K. G., Wijnen-Sponselee, M. T., Schols, J. M.G. A. (2010). Towards an Integral Conceptual Model of Frailty. *The Journal of Nutrition, Health & Aging*, *14*(3), 175–181.

- Gobbens, R., Luijckx, K., Wijnen-Sponselee, R., Assen, M. v., & Schols, J. (2011). Wetenschappelijke definities en metingen van kwetsbaarheid. In C. v. Campen (Ed.), *Kwetsbare ouderen* (pp. 39–50). Den Haag: Sociaal en Cultureel Planbureau.
- Huber, M., Knotnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., et al. (2011). How should we define health? *British Medical Journal, BMJ*, *343*, d4163.
- Huber, M., van Vliet, M., Giezenberg, M., Winkens, B., Heerkens, Y., Dagnelie, P. C., & Knotnerus, J. A. (2016). Towards a ‘patient-centred’ operationalisation of the new dynamic concept of health: A mixed methods study. *British Medical Journal Open*, *6*, e010091. <https://doi.org/10.1136/bmjopen-2015-010091>.
- Inspectie Gezondheidszorg en Jeugd. (2015). Kijken met andere ogen naar de zorg voor mensen met dementie en onbegrepen gedrag. 29–6–2015, Utrecht.
- Inspectie Gezondheidszorg en Jeugd (2020). Verbetering nodig in zorg voor cliënten met zeer ernstig probleemgedrag bij dementie, 13-1-2020, Utrecht.
- Larson, E. B., Kristine Yaffe, M. P. H., & Langa, K. M. (2013). New insights into the dementia epidemic. *New England Journal of Medicine*, *369*, 2275–2277. <https://doi.org/10.1056/NEJMp1311405>
- Matthews, F. E., Arthur, A., Barnes, L. A., Bond, J., Jagger, C., Robinson, L., & Brayne, C. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: Results of the cognitive function and ageing study I and II. *The Lancet*, *382*(9902), 1405–1412.
- Minkman, M. M. N., Ligthart, S. A., & Huijsman, R. (2009). Integrated dementia care in the Netherlands: A multiple case study of case management programmes. *Health and Social Care in the Community*, *17*(5), 485–494.
- NICE. (2015). Dementia, disability and frailty in later life—Mid-life approaches to delay or prevent onset. *NICE Guidelines [NG16]*. Accessed January 7, 2016, from <https://www.nice.org.uk/guidance/ng16>
- Nies, H. (2014). Communities as co-producers in integrated care. *International Journal of Integrated Care*. ISSN 1568-4156.
- Nies, H. (2016). The journey towards community-based dementia care: The destination, roadmap, guide, tour group and the conditions. *Healthcare Papers*, *16*(2), 57–63. <https://doi.org/10.12927/hcpap.2017.25001>.
- Nies, H., Meerveld, J., & Denis, R. (2009). Dementia care: Linear links and networks. *Healthcare Papers*, *10*(1), 34–43.
- Nies, H., & Minkman, M. (2015). Innovatie in governance. Eigenaarschap van het publieke belang in een participatiesamenleving. In H. Den Uyl, T. van Zonneveld (red.), *Zorg voor toezicht. De maatschappelijke betekenis van governance in de zorg* (pp. 74–82). Amsterdam: Mediawerf.
- Nordenfelt, L. (2009). Health, autonomy and quality of life: Some basic concepts in the theory of health care and the care of older people. In L. Nordenfelt (Ed.), *Dignity in care for older people* (pp. 3–25). Chichester: Wiley.
- OECD. (2015). *Addressing dementia: The OECD response*. Paris: OECD Health Policy Studies, OECD Publishing.
- OECD. (2019). Health at a glance 2019: OECD Indicators. *OECD Publishing, Paris*. <https://doi.org/10.1787/4dd50c09-en>.
- Poblador-Plou, B., Calderón-Larrañaga, A., Marta-Moreno, J., Hanco-Saavedra, J., Sicras-Mainar, A., Soljak, M., & Prados-Torres, A. (2014). Comorbidity of dementia: A cross-sectional study of primary care older patients. *BMC Psychiatry*, *14*, 84. <https://doi.org/10.1186/1471-244X-14-84>
- Prince, M., Bryce, R., Albanese, E., Wome, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and meta-analysis. *Alzheimer's and Dementia*, *9* (1), 63–75.
- Puts, M. T. E., Lips, P., & Deeg, D. H. J. (2005). Static and dynamic measures of frailty predicted decline in performance-based and self-reported physical functioning. *Journal of Clinical Epidemiology*, *58*, 1188–1198.

- RIVM. (2020a). Volksgezondheidszorg.info. <https://www.volksgezondheidszorg.info/onderwerp/dementie/kosten/zorguitgaven#node-zorguitgaven-dementie-naar-sector>
- RIVM. (2020b). Volksgezondheidszorg.info. <https://www.volksgezondheidszorg.info/onderwerp/chronische-ziekten-en-multimorbiditeit/cijfers-context/huidige-situatie>
- Scharlach, A. E., & Lehning, A. J. (2013). Age-friendly communities and social inclusion in the United States of America. *Ageing and Society*, 33, 110–136. <https://doi.org/10.1017/S0144686X12000578>.
- Valderas, J. M., Starfield, B., Sibbald, B., Salisbury, C., & Roland, M. (2009). Defining comorbidity: Implications for understanding health and health services. *The Annals of Family Medicine*, 7(4), 357–363.
- Valentijn, P., Schepman, S., Opheij, W., & Bruijnzeels, M. (2013). Understanding integrated care: A comprehensive conceptual framework based on the integrative function of primary care. *International Journal of Integrated Care*, 13 (Jan–Mar), URN:NBN:NL:UI:10-1-114415.
- Van Mierlo, L. D., Van der Roest, H. G., Meiland, F. J. M., & Drfoes, R. M. . (2010). Personalized dementia care: Proven effectiveness of psychosocial interventions in subgroups (review). *Ageing Research Reviews*, 9, 163–183.
- Van Mierlo, L. D., Meiland, F. J. M., Van der Roest, H. G., & Drfoes, R. M. (2012). Personalized caregiver support: Effectiveness of psychosocial interventions in subgroups of caregivers of people with dementia (Review). *International Journal of Geriatric Psychiatry*, 27, 1–14.
- Van Maar, C. E., Wijenberg, E., Stapersma, E., & Siegerink, E. (2014). *Ketens dementie goed op koers met de Zorgstandaard Dementie als kompas*. Utrecht: Vilans.
- Van Oostrom, S. H., Picavet, H. S. J., van Gelder, B. M., Lemmens, L. C., Hoeymans, N., Verheij, R. A., Schellevis, F. G., & Baan, C. A. (2011). Multimorbiditeit en comorbiditeit in de Nederlandse bevolking—gegevens van huisartsenpraktijken. *Nederlands Tijdschrift voor Geneeskunde*, 155, A3193.
- WHO. (2006). Constitution of the World Health Organization. www.who.int/governance/eb/who_constitution_en.pdf
- World Health Organization. (2015, March). Dementia (Fact sheet No362).
- Zuidema, S. U., Smalbrugge, M., Bil, W. M. E., Geelen, R., Kok, R. M., Luijendijk, H. J., van der Stelt, I., van Strien, A. M., Vink, M. T., & Vreeken, H. L. (2018). *Multidisciplinary guideline problem behaviour in dementia*. Verenso, NIP. Utrecht 2018.