

1.

*General introduction*PART 1/2

**As long as it is not serious, it is only an inconvenience:
the story of Mrs. Steinberg**

Mrs. Steinberg is 88 years old and lives alone in a ground floor apartment. Her husband passed away a few years ago, and she has a daughter and two sons who visit her regularly. Mrs. Steinberg's youngest son suffers from Multiple Sclerosis, which is the source of a lot of her worries. Mrs. Steinberg cooks her own meals, and her housekeeping is done by her daughter-in-law and a home help.

Mrs. Steinberg cares about being active in society (a value handed down to her by her parents), which she considers self-evident and a duty. A victim of the Nazi regime, she is a volunteer for an organization that educates high school students about World War II. She is also the chairman and co-founder of a Foundation that aims to raise awareness of the history and victims of a Nazi concentration camp in Eastern Europe. As such, she is an outspoken anti-fascist, dedicated to doing everything she can to fight oppression and injustice. Her volunteer work is her passion, and it is her main drive to get up and out of the house. Despite increasing problems with her mobility, she still travels around Europe to meet other volunteers and Foundation members.

Mrs. Steinberg finds that daily life takes more effort than before. This results in her sometimes not being able to help others as much as she would like, which she regrets, but also accepts: "I have to think about myself, that is important. (...) To say 'no' once in a while". She has noticed that her short term memory is increasingly failing her, and she has problems walking. Her mobility problems are caused by spinal stenosis, for which she recently had surgery. As a result of her spine problems Mrs. Steinberg's steps are unstable and she gets tired easily. These days, she can only walk small distances with a walker and is increasingly afraid to fall. Mrs. Steinberg also complains about pain. The pain is located in various parts of her body, and is intense but tolerable. "I have gotten used to being in pain every day", she says, "which in a way is easier, since there is no point in making a big fuzz about it". More recently, Mrs. Steinberg is experiencing strange, painful sensations in her arms, legs and abdomen while urinating. After

her family physician ruled out cystitis he gave her medication, but so far, her complaints have not improved.

Aside from problems with mobility and pain, Mrs. Steinberg suffers from asthma, hypothyroidism, constipation, urinary incontinence and hypercholesterolaemia. Her conditions cause Mrs. Steinberg to feel less independent, which at times makes her feel miserable. However, she has learned to cope with this loss by making adjustments to her house (for instance by mounting assist bars in her bathroom) and by developing strategies to continue living her life the way she is used to (for instance by arranging with the greengrocer to have her groceries delivered at home).

Although she does not think of herself as lonely, Mrs. Steinberg spends many of her days in her apartment by herself. She is often anxious and quickly affected by situations she experiences as stressful or tense, which she attributes to her World War II traumas. However, Mrs. Steinberg says she does not feel she can complain about her situation: “As long as my ailments are not serious, like heart disease or diabetes, I call them inconveniences”.

I met Mrs. Steinberg (a pseudonym) in 2012, when I interviewed her as part of the process evaluation of the implementation of a comprehensive care program for frail, older people in primary care, the older Adults: Care in Transition (ACT) study. Mrs. Steinberg's personal story moved me. I was impressed by her sharp mind, her optimism and her resilience. I was enamored by her warm personality. But most of all, I was inspired by her knowledge and her dedication to fight social injustice. After the interview I found myself sad to leave, wanting to schedule another visit to learn more about her experiences, ideas and plans. It struck me that, after talking to Mrs. Steinberg for a couple of hours, I could not think of her as old and frail anymore. Having been introduced to some of the history, complexity and particularities that together formed the person Mrs. Steinberg, age and ability became variables that only marginally influenced my impression of her.

Throughout my research I interviewed more people, and apart from being old and frail, they were all very different. These differences were related to factors other than age or frailty, such as gender, social class, ethnicity and religion, living environment and professional or political identity [1]. I began to realize that age and frailty give only limited information about a person's individual and specific experiences. The interviews I did with practice nurses who carried out the home visits as part of the ACT study confirmed this. Practice nurses shared with me that a significant part of their work was based on getting to know the personal background and context of clients. In order to provide high-quality care to people of older age groups, I learned, respecting people's identities and lived experiences and knowing and understanding the uniqueness of each client and their needs is essential.

In this thesis, "frail older people" – people like Mrs. Steinberg – are often presented as a homogenous group. Although this way of describing demographics facilitates population-based research and policy making, it does not reflect the complexity and diversity of the aging population, nor does it represent a shared experience. A caveat when doing elderly care research is therefore that an essentialist approach to thinking about frail, older people can induce stereotypes about their preferences and needs, which does not only hinder adequate care giving, but also undermines the uniqueness of lived lives [2]. After all, us humans are more than our ages and ailments.

BACKGROUND

Aging comes with many benefits. The older we get, the more we understand about our self, each other and the world, and the more we are able to reflect on life and what makes it worth living. However, aging also comes with disadvantages. As we get older, we are increasingly confronted with problems such as disability and loss of autonomy [3]. Like Mrs. Steinberg, many older people suffer from multiple conditions that impact their daily functioning and make them dependent on formal and informal care. Often, such conditions are chronic. The World Health Organization (WHO) defines conditions as chronic when they are "... of long duration and generally slow progression"; the United States Centers for Disease Prevention and Control (CDC) adds that "... conditions must have been present 3 months or longer to be considered chronic". Chronic conditions with high prevalence rates in older people include, for instance, cardiovascular disease, diabetes mellitus and chronic respiratory diseases [4]. When one or more chronic conditions co-occur in one individual, it is called multimorbidity. The number of chronically ill people with multimorbidity is rising [5]: of people over 65, about 65 percent now live with multiple chronic illnesses, a percentage that increases with age [6;7]. In older people, the presence of multiple chronic conditions can lead to functional decline, disability and poor quality of life [6]. In addition, older people with multiple chronic conditions use care and support services (such as home care and rehabilitation services) more frequently, which has been associated with higher health care costs [8]. The burden of multimorbidity therefore impacts both older people's lives and society.

Frailty in older people

Older people who suffer from multimorbidity may eventually become frail [9;10]. Frailty is a concept used in gerontological and geriatric research to describe the life stage in which people encounter multiple problems and experience loss of reserves [11;12]. Although the term frailty is frequently used by clinicians and researchers to explain older people's health and functional status, no consensus exists as to how frailty should be conceptualised and operationalized. Currently, popular conceptualisations focus on frailty as a physical phenomenon ('physical frailty') [13;14]. An often-used physical frailty definition is that of Fried, who sees frailty as a combination of clinical parameters (unintentional weight loss, self-reported exhaustion, muscle weakness, slow walking

speed, and low physical activity) that together comprise the frail phenotype [11]. Based on this rules-based definition, Fried suggests to quantify the physical parameters – for instance, to investigate muscle weakness by measuring grip strength – and to use cut-off criteria to determine whether someone is frail or not. Other authors have proposed more broad, multidimensional conceptualisations of frailty [15]. Such interpretations involve more than the physical domain, but also include other domains of human functioning, such as the physical domain and the social domain. Schuurmans, for example, sees frailty as “a loss of resources in several domains of functioning, which leads to a declining reserve capacity for dealing with stressors”; following this definition, frailty can be established by assessing each of these domains (i.e. mobility, physical fitness, vision, hearing, nourishment, morbidity, cognition, psychosocial (depression, anxiety, loneliness)) [16]. Finally, authors like Rockwood consider frailty to be a continuum of changeable content [12]. According to Rockwood, frailty happens when deficits (symptoms, signs, illnesses, disabilities) accumulate, resulting in increased susceptibility to adverse outcomes. To assess the different stages of the frailty continuum, Rockwood developed the Frailty Index, an assessment instrument that gathers information on 70 deficits, including information about ability in the activities of daily living (ADL). The various conceptualisations of frailty and their methods of measurement are currently being used in clinical (e.g. to determine type and frequency of care delivery) and research practice (e.g. to determine trial eligibility).

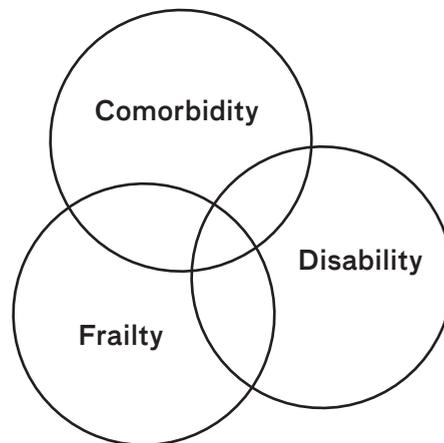
As a consequence of the different frailty conceptualisations, frailty prevalences in community-dwelling older populations differ depending on the concepts and instrument used by researchers. For instance, Collard et al. [17] found a prevalence of 9.9% using a physical definition of frailty, and a prevalence of 13.6% using a broad definition of frailty (i.e. including physical as well as psychological and social elements). However, despite the lack of consensus on how to define and measure frailty, worldwide researchers have been recognizing frailty’s impact on older people and their environment. This impact is reflected in the way frailty is associated with adverse health outcomes: people who are frail have an increased risk for falls, institutionalization, hospitalization and even death [11;14;18;19]. The risk for adverse outcomes lays bare the complex relationship between frailty and concepts such as comorbidity, multimorbidity, disability, and functional impairment. While all comprise different aspects, they are often used interchangeably and synonymously.

Several researchers have aimed to untangle the relationship between frailty, disease, functional impairment and disability. Fried uses empirical evidence to distinguish frailty from disability and comorbidity. Based on data

from large cohorts of community-dwelling older people, she considers physical frailty, disability and comorbidity three distinct, but related categories (See Figure 1) [9]. These categories may overlap, i.e., may coexist in one person; for instance, one can suffer from both disability and comorbidity, but not be frail, or can be both frail and disabled, but not have any comorbidities. Fried furthermore concludes that comorbidity is an etiologic risk factor for frailty, whereas disability is an outcome of frailty.

Figure 1

Fried's Venn diagram showing the overlap of frailty with disability (≥ 1 ADL disability*) and comorbidity (≥ 2 diseases out of the following diseases: myocardial infarction, angina, congestive heart failure, claudication, arthritis, cancer, diabetes, hypertension, COPD).



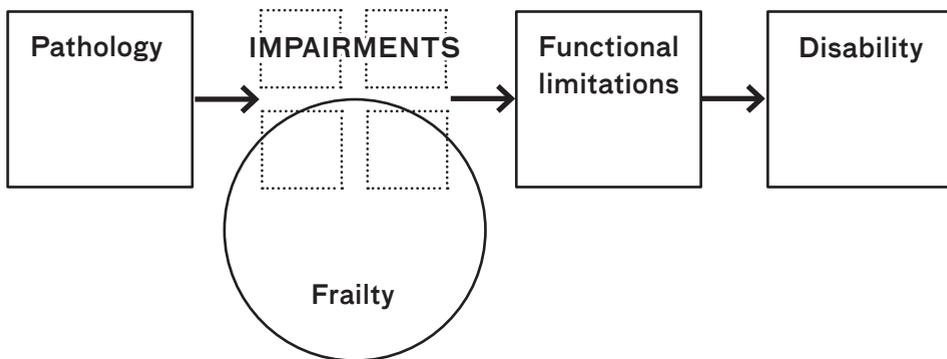
* ADL=Activities of Daily Living. Adjusted from: Fried LP, Ferrucci L, Darer J, Williamson JD, Anderson G: Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*. 2004, 59:255-263.

Verbrugge and Jette's 'disablement process' (See Figure 2), a model that presents a basic theoretical pathway from chronic and acute conditions to disability, depicts frailty as an aggregation of impairments in one or several body systems [20;21]. Frailty's location in the linear pathway suggests that it can be seen as a direct precursor to functional decline and disabilities, which

corresponds to Fried's conceptualisation of frailty and disability. Since multiple disablement pathways can coexist in one person, non-frail people with existing disability or disease may become frail throughout the aging process (for instance, by an increase in the number or severity of conditions), which in the individual may appear as a more cyclic process. The disablement model suggests that frailty could be reversed, reduced or prevented by interventions that target underlying disease and impairments. This notion of frailty as a potentially transient state has been mentioned by several other authors [14;22].

Figure 2

The disablement process, adapted from: Verbrugge LM, Jette AM:
The disablement process. *Social Science & Medicine*. 1994, 38:1-14.



Operationalisation of frailty in the ACT study

In the ACT study, we used a multidimensional conceptualisation of frailty to determine the study population. During the first step of the inclusion process, primary care physicians were asked to indicate which of their patients over 65 years old they considered frail based on Schuurman's 2004 definition of frailty as "a loss of resources in several domains of functioning". This choice corresponds with one of the central aims of the Geriatric Care Model (the comprehensive care program implemented by means of the ACT study, see Chapter 2), which is to provide care that is tailored to the care needs of older people. As such, care needs may be of physical, psychosocial or environmen-

tal nature, i.e. existing in various domains of life. Insight in these needs can be gained by a comprehensive geriatric assessment. Hence, offering care to a population that consists of older people who meet the ‘broad’ frailty definition may require both health and social care interventions.

FRAILTY COMES WITH CHALLENGES

Aging in place

The European population is aging rapidly. It has been estimated that in 2060, there will be 148 million Europeans who are aged 65 years or over [23]. Population aging is associated with a growing number of frail, older people. In European countries, estimates of the prevalence of physical frailty range from 4.1% in the middle-aged population (50-64 years old) to 17.0% in populations of 65 years and over [24]. Since frail, older people are more likely to have an increased need for longer-term care [9], the demand for chronic care services is growing, which increases the pressure on health care systems in Europe. Home care organizations and long-term care facilities are struggling to accommodate for this growing demand, while simultaneously upholding standards for high-quality care delivery; in addition, health care expenditures are growing [25].

As a result of this increased pressure on the health care system, policy makers favor having older people ‘age in place’. Aging in place has been defined as “remaining living in the community, with some level of independence, rather than in residential care” [26]. By encouraging older people to remain at home as long as possible, policy makers aim to avoid the costly option of institutional care. At the same time, research has shown that older people themselves often prefer to age in place¹ [28;29]. Growing old in a familiar environment enables them to remain autonomous and independent, and helps them preserve access to social support [28]. As a result of ‘aging in place’, frail, older people are one of the fastest growing (sub)populations in primary care [30;31], and the demand for in-home care is ever-growing [32]. In the Netherlands, this growing demand has led governing bodies to increasingly call upon older people to participate in their own care by actively engaging their social networks – e.g. family, friends and neighbours – to provide informal care services [33].

1 Not all older people want to age in place. The anticipation of future needs causes some older people to prefer to relocate to a long-term care facility. Reasons for relocation are, among others, a desire for continued care, freedom from household upkeep and maintenance, and the wish not to depend on or burden others [27].

Challenges for primary elderly care

The increasing number of frail, older patients in primary care is confronting primary elderly care with several challenges. In Europe, three major barriers to high-quality care for home-dwelling older people have been identified [34]. First, due to the predominantly reactive nature of the primary care system, frail older people's health and care needs are not always identified at a timely stage. Late identification of needs may arrest the successful halting or prevention of adverse outcomes: it is expected that early intervention improves older people's quality of life and reduces costs [14]. Second, health care services for frail older people are often delivered by various care providers and therefore less likely to be integrated – their care is prone to be inadequately coordinated, incomplete and inefficient, which may lead to unnecessary tests, conflicting medical advice, medication problems and avoidable hospitalizations [5;8;35;36]. Finally, older people have been reporting that they experience little involvement in their own care process. Client involvement in care can result in fewer limitations in physical and role-related activities, and in increased preference for involvement in the decision making process [37]. Although encouraging patients to participate in all levels of the care process is central to contemporary health care practice, research has shown that caregivers do not always successfully explore patients' ideas concerning their preferred level of participation [38-40]. These three challenges are an indication that, in order to better equip health care systems to meet the needs of frail older people, a restructuring of primary care organization and delivery is necessary.

Comprehensive care models

In the last decade, health care systems all over the world have seen the implementation of a type of care model characterized as integrated, or comprehensive [5;41;42]. Comprehensive care models provide a framework for the coordination and delivery of patient-centered services that aim to promote patient self-management, improve patient outcomes and restrict health care costs. The programs based on these models involve multiple healthcare providers that provide patient-centered care to a population with chronic care needs, often in a primary or chronic care setting [41]. Since a large share of this population consists of frail older people, comprehensive care programs are likely to be implemented among older people who live at home [41]. Rec-

ognizing the importance of comprehensive care models, the European Commission is setting short term and long term goals to increase the availability of comprehensive programmes for older European citizens with the aim to reduce avoidable hospital admissions [43].

Two often-used versions of comprehensive care models for older people in a primary care setting are models based on collaboration between disciplines (interdisciplinary primary care models), and models that aim to enhance traditional primary care by providing supplementary services (i.e. case management, disease management, preventive home visits, comprehensive geriatric assessments, pharmaceutical care, chronic disease self-management, proactive rehabilitation and caregiver education and support) [41]. In their 2009 review article, Boult and others report evidence on the success of models of comprehensive chronic care for older people, defining a model as ‘successful’ when “at least one high-quality study reported that at least one version of the model is capable of improving the quality, outcomes or efficiency of care” [41]. The authors found that, compared to usual care, both interdisciplinary care models and supplementary care models have the potential to improve quality of care, quality of life, functional autonomy and survival; in addition, implementing these models may lead to cost reduction. Comprehensive care models, both interdisciplinary and supplementary or a mix of both, may therefore be particularly suited to improve the quality and delivery of care for frail older people who live at home.

The Chronic Care Model

A comprehensive care model often used to guide quality improvement and care system reorganization is the Chronic Care Model (CCM). The CCM is a framework to guide quality improvement and disease management activities in the care for patients with a chronic disease [44]. It is based on the premise that a restructuring of the care system will result in a satisfying interaction between an informed, activated patient and a prepared, proactive practice team, which provides a basis for high-quality care delivery and eventually leads to improved health outcomes and reduced health care expenditures [44]. While evaluations of the CCM have produced mixed results, previous studies have demonstrated that the CCM has the potential to achieve its goals [45;46].

The CCM developers envision chronic care to take place in a tridimensional space, shaped by the aggregation of the community domain, the health care system domain, and the provider organization domain. Within this space,

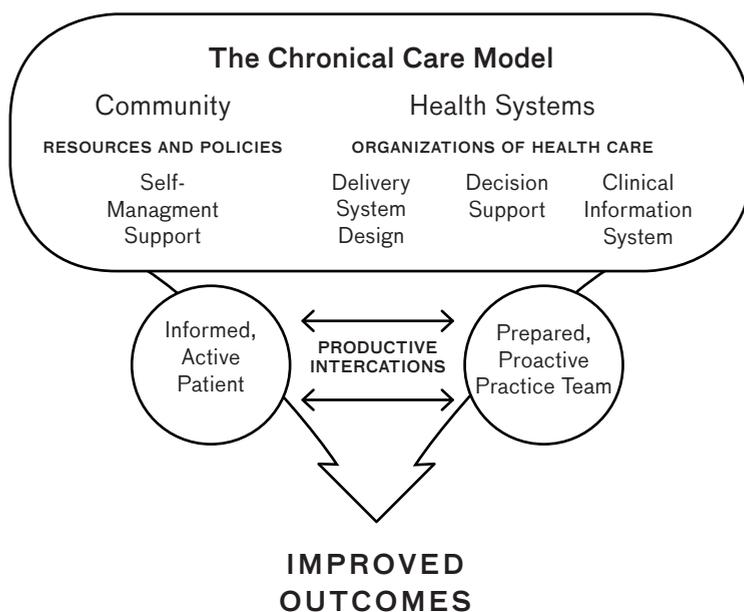
the CCM identifies 6 essential elements that play a role in the optimal delivery of chronic care (See Figure 3). Four elements refer to the delivery of care by healthcare providers (i.e., self-management support, delivery system design, decision support, and clinical information systems) and two to the context of care delivery (i.e., community resources and policies and health care organization). These ‘pillars’ provide a foundation upon which providers and provider organizations can build their chronic care services². The CCM as envisioned by Bodenheimer et al. [44] is directed mostly at systems with an emphasis on clinical care. Therefore, extensions or adaptations of the CCM have been developed in order to make the principles of the CCM applicable to community settings, for instance by integrating aspects of social care and prevention [47]. Since the development of the CCM, the model has been implemented in several health care settings and for several chronic conditions, such as diabetes, HIV, respiratory disorders, depression and heart failure [46;48-52]. Furthermore, components of the CCM have been used to guide transitions of care (when patients move between professionals and settings during the disease trajectory) [53]. However, since CCM principles have only marginally been applied to primary elderly care settings, little is known about the CCM’s usefulness in restructuring and improving care for older people who live at home, and data on its effectiveness and implementation process in this setting is scarce [54-57].

In order to assess whether the CCM’s principles could be used to meet European elderly care’s challenges, we developed the Geriatric Care Model (GCM), a comprehensive care model based on the CCM [58]. The GCM envisions a multilevel, structural transition of primary elderly care. Similar to the CCM, the GCM is based on the idea that productive interactions between prepared, proactive caregivers and informed, activated care receivers result in improved quality of care and client outcomes. The GCM is aimed at providing integrated, client-centered care to frail older people who live at home, and incorporates CCM elements by synthesizing components of interdisciplinary primary care models and supplementary care models, which are

2 Linkages with *community-based resources*, for instance home care organizations, senior centers or self-help programs, help care providers expand their network and knowledge about available community services. The CCM emphasizes that characteristics of *health care organizations* have a major influence on the way chronic care is delivered: the structure, goals and values of an organization determine the position of chronic care quality and innovation on the organization’s priority list. Since people live with chronic illness for many years, *self-management support* can improve patient’s agency by giving them more control over their condition. Helping patients manage their chronic disease(s)/illness involves teaching them and their family self-management techniques and skills, and regularly assessing patients’ progress and problems. In order to improve chronic care, the CCM requires a change in the way *delivery systems* are designed. A system optimal for the delivery of chronic care is structured in such a way that acute care management and chronic care management are separated, and consists of practice teams optimally trained to tailor their care to the demands of long-term chronic patients. In addition, practice team *decision making* is supported by guidelines for evidence-based practice, education and specialist expertise. Finally, the CCM features *clinical information systems* that serve as a reminder for compliance with guidelines, facilitate monitoring of patients’ chronic illness measures, and help practice teams plan care [44].

implemented at a client level, at a professional level and at an organizational level. Central to the GCM are routine home visits, during which practice nurses carry out a comprehensive geriatric assessment to identify health and care needs. Geriatric expert teams manage practice nurses in the field and organize educational activities based on practice nurses' learning needs. In order to facilitate coordination and access to resources on a community level, geriatric expert team members build networks of local care providers and health care professionals. Older people with complex needs are discussed in multidisciplinary team consultations (MTCs), attended by a practice nurse, the geriatric expert team, a primary care physician, a pharmacist and, if indicated, other care professional involved

Figure 3
The Chronic Care Model (CCM)
Retrieved and adjusted from www.improvingchroniccare.org



PRODUCTIVE INTERACTIONS WITH FRAIL, OLDER PEOPLE AT HOME

Caregiver-receiver interactions: a platform for care delivery

Modelled after the CCM, the GCM credits the caregiver-care receiver interaction with a central role: it is a key step toward improving quality of care and client outcomes. While organisational, logistical and financial aspects of providing care are important contributors to overall quality of services, the caregiver-care receiver interaction is the most concrete, visible stage of the care process, providing a platform for fundamental processes such as needs communication, negotiation of care, and implementation of practices. Furthermore, it provides care professionals with a communicative space to carry out strategies and approaches – such as client involvement, client participation and shared decision making – that have the potential to positively impact client satisfaction and success of health promotion practices³ [38;44;59-63].

In order to understand how caregiver-care receiver interactions impact the care process, researchers have aimed to categorize the different shapes and forms interactions in health care settings can take. Conceptually, the interaction process permits a myriad of possible paradigms for classification, and a variety of frameworks have been proposed. For instance, in their landmark article about interactions between physicians and patients, Emanuel and Emanuel propose four models of relationships (i.e. the paternalistic model, the informative model, the interpretive model, and the deliberative model), using patients' and physicians' value systems regarding medical decision making as the denominator for classification [64]. When Schoot et al. [62] observed chronically ill clients' responses and attitudes toward their caregivers, they identified six patterns of interaction⁴, each directly related to a client's desired or attainable participation in care and a caregiver's allowed participation in care. Several authors have aimed to categorize the nature of interactions between care professionals (primarily nurses) and older people in the home setting. Their analyses resulted in classifications based on, for instance, the level of client involvement, the method of care negotiation, the level of client autonomy or the nature of the interpersonal relationship [65;66].

3 Health promotion is defined by the World Health Organisation (WHO) as 'the process of enabling people to increase control over, and to improve, their health' (http://www.who.int/topics/health_promotion/en/)

4 The authors identified the following patterns: obedience, reluctance, willingness to engage in a dialogue, consumption and fighting.

While in all settings, the flow in an encounter between older people and nurses is – as the word ‘interaction’ suggests – influenced by actions and characteristics of both actors, in the private setting these actions and characteristics may be complicated by the specificities of the home context. As opposed to intramural settings, where institutionalized power dynamics and the hegemony of clinical, disease-centric thought processes cause older care receivers to be prone to passivity and acquiescence, the home environment provides older people with opportunities to actively influence or control the care process. Receiving care at home, for instance, allows older people to decide in what atmosphere to receive caregivers [66]. At the same time, nurses may experience less control when providing services to clients at home. Interactions in the home setting is therefore a dynamic process that is intrinsically paradoxical [63;67]. Spiers [63] describes this paradox as follows: “...nurses are empowered by their expert knowledge and skills, but the counterweight to this authority and legitimacy is the need to work respectfully in the patient’s home environment. Being in their own environment might be a source of strength for patients, but their illness and need to negotiate care counter this”. Furthermore, aspects of the home setting may either impede or facilitate successful interactions. The privacy of the home space may initiate ‘mutual knowing’ and connection through an exchange of personal information; on the other hand, the continuity of a care relationship may be disturbed by the scheduling of different care providers [66].

Although several authors argue that the interaction process may play a central role in achieving successful health and care programs [59;68;69], it is yet not clear which interaction elements mediate intervention effectiveness in in-home geriatric settings, and how. Research findings suggest an association with the method of care delivery, indicating that certain approaches – such as collaborative approaches and empowerment approaches – can positively influence intervention impact and effectiveness in in-home geriatric settings [70;71]. There are, for instance, some indications that a client-centered approach to the caregiver-care receiver interaction may improve client outcomes and reduce health care expenditures [72-74]. Highly valued by policy makers and health care professionals, the approach is generally assumed to be inherent to quality of care [72;73;75;76]. Caregivers who practice client-centered care aim to gain a holistic insight in a person’s problems and preferences, and take into account clients’ personal complexities, values and experiences when guiding a person in managing their illness [77;78]. During a client-centered interaction, caregiver and care receiver actively build the foundation for a relationship that is based on a shared understanding of how care can be tailored

to the care receivers' needs. The client-centered paradigm has been incorporated into various domains of care giving, involving practices that range from emotional support of clients and customization of meals, to support of client decision making [76;77]. However, despite its popularity, so far no clear definition of the term 'client-centeredness' exists [72;74;77-79]. This ambiguity in conceptualization hinders the identification of fundamental characteristics of client-centered care, which in turn challenges the implementation of client-centered activities and the optimal measurement of outcomes of these activities. The latter may especially be of importance in primary elderly care settings, where frail, older people's complex needs and frequent encounters with care providers necessitate the evaluation of the client-centeredness of services delivered. So far, a valid and reliable instrument to measure the client-centeredness of home care for frail, older people does not exist.

Self-perceived care needs of frail, older people

Frail, older people are characterized by the complexity of their care needs. It has been suggested that a thorough and tailored assessment of care needs in primary care has the potential to delay or prevent the onset of adverse outcomes in frail demographics; it may prevent nursing home admissions, decrease frequency and duration of hospital stays and reduce mortality [80;81]. Two types of needs assessment methods have been developed. One method involves a comprehensive geriatric assessment and is used by caregivers to evaluate older people's capacities and needs in the medical, physical and environmental domain [82]. Another often-used approach centers on the assessment of self-perceived care needs, i.e. needs as they are experienced by the older person themselves [83]. However, despite the availability of these assessment methods, health and care needs are not always adequately identified [70;84]. As a result, older people who live at home often have to deal with care needs that are unmet⁵. Prevalence estimates of self-perceived unmet needs range from 2 percent to 35 percent [84;85]. Frequently occurring unmet needs involve needs regarding problems with eyesight and hearing, psychological distress and urinary incontinence [83].

Several researchers have investigated which factors and circumstances are associated with the presence of unmet needs. For instance, Casado et al. [86] identified factors on a client level (greater care needs, less informal support, lack of awareness of own needs and reluctance to accept care) and on a

5 An unmet need is the lack of care or help to reduce a problem [85].

health system level (unavailability and affordability of services). Walters et al. found that people with unmet needs resigned from or disengaged with their illness, or had low expectations of the health care system [87]. Despite this previous research, there still is a lack of insight in the health and social care needs of older people in primary care, and in the socio-demographic and health-related factors associated with these needs. Even less information exists about the care needs of older people in primary care who are frail.

IMPLEMENTING A CHRONIC CARE MODEL FOR FRAIL, OLDER PEOPLE

At the outset of this chapter, we introduced Mrs. Steinberg, an older woman who lives at home. Mrs. Steinberg's story reveals she experiences limitations in several domains of functioning: she suffers from multiple conditions and disabilities that affect her daily life, and she experiences a loss of independence. When we apply a broad definition of frailty to Mrs. Steinberg's situation, we see that she could be labelled as frail, indicating that she is part of a demographic that might benefit from a comprehensive, primary care-based geriatric intervention such as the abovementioned Geriatric Care Model [88].

Evaluating the Geriatric Care Model

When in 2008 we planned to carry out the GCM in the Netherlands, Mrs. Steinberg was eligible to participate in the ACT study, the research project that aimed to implement the GCM in a population of community-dwelling, frail older people. Mrs. Steinberg was considered frail according to her family physician based on a multidimensional definition of frailty and the PRISMA-7, a seven-item questionnaire that comprises risk factors for functional decline [89]. Since it was the first time the GCM was implemented in a frail population, it was essential to gain insight in the extent to which the model could improve the situation of people like Mrs. Steinberg; i.e., whether it could identify people's health and care needs at a timely stage, increase people's control over and involvement in their own care, and improve coordination between people's care providers. The GCM's effectiveness was therefore investigated by means of a randomised controlled trial (RCT), the gold standard for assessing the effectiveness of interventions, including complex,

community-based interventions for older people⁶. So far, outcomes of evaluations of such programs have been mixed: systematic reviews show that some studies find positive effects on outcomes such as functional status, nursing home and hospital admissions and perceived social support, while others find no results at all [91-95]. These conflicting findings urge a deeper understanding of determinants of program success or failure, and indicate that insight in the true nature of the intervention and its delivery is essential [90;96;97]. Gaining this insight, sometimes referred to as 'opening the black box', can be achieved by performing a process evaluation parallel to or following an effectiveness RCT [98]. The word 'black box' refers to the actual content and context of program delivery. For a long time, a 'black box evaluation' (the evaluation of program outcomes without an examination of the issues that underlie changes in outcomes), was the accepted approach to investigate effectiveness of health care programs and innovations [99-101]. However, when researchers began to recognize the value of understanding the mechanisms through which the results of their programs got established, an increasing number of RCT-based intervention studies began to feature process evaluations.

Process evaluations aim to explain study outcomes by exploring how and how well an intervention is implemented and received: they allow researchers to gain insight in contextual factors that could have influenced the intervention, explore views of participants and implementers, and distinguish between different intervention components [98]. Different conceptual frameworks for process evaluations exist for different program types and settings. Since such frameworks consist of similar, but differently interpreted or arranged elements, that often partially overlap. Often-used frameworks are the RE-AIM⁷ framework and the TICD framework⁸ [102;103]. Saunders et al. proposed a framework based on the assessment of six components [104], while the recently published Medical Research Council (MRC) guidance for conducting and reporting process evaluation studies suggests three key elements of a process evaluation (context, implementation, and mechanisms of impact), each consisting of separate components that correspond to research questions about, for instance, the frequency and quality of delivery [105]. Although the different frameworks propose different components as indicators for the degree to which an intervention is implemented, the frameworks

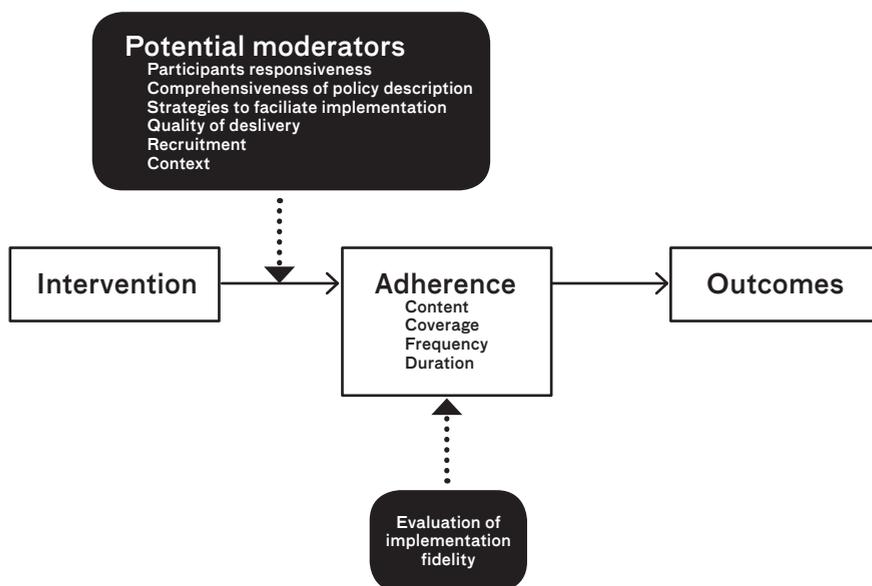
6 Complex interventions are interventions that consist of multiple interrelated 'active' components, i.e. components envisioned by the intervention developers to contribute to the desired intervention effect. Due to this multifaceted design, they are notoriously challenging to implement into practice [90].

7 The RE-AIM acronym stands for Reach , Efficacy, Adoption , Implementation and Maintenance [101].

8 The TICD acronym stands for Tailored Implementation for Chronic Diseases [103]. The framework provides a structured method to investigate barriers and facilitators to program implementation by means of seven factors: guideline factors, individual health professional factors, patient factors, professional interactions, incentives and recourses, capacity for organisational change, and social, political and legal factors [103].

of Saunders and the MRC have in common that both include the component 'fidelity' (Saunders uses the term 'quality of the implementation'). Fidelity is generally considered an important component of a process evaluation, and has been defined as the level to which an intervention is delivered as planned by the program developers [106]. Fidelity impacts the relationship between intervention content, context and intended outcomes: an increase in fidelity is known to correspond with an increase in program success [107;108]. Assessing fidelity helps researchers understand whether a lack of program effect should be explained by problems inherent to the program itself, or by inadequacies regarding program delivery (a 'type III error'); in addition, a fidelity assessment provides developers with information that can be used to tailor the intervention to local contexts, and to facilitate the dissemination of research findings into practice [106].

Figure 4
Conceptual framework for implementation fidelity. Originally from Carroll et al. (2007), adjusted from Hasson (2010).



The last decade has seen a rise in the number of studies that have chosen to perform an investigation of implementation fidelity alongside their RCT, which has revived interest in the theoretical aspects of fidelity assessments [109-111]. Currently, it is generally considered that the most complete way to investigate the degree of fidelity is by assessing the construct 'intervention adherence', that consists of the subconstructs content, frequency, duration and coverage, and several potential moderating factors, i.e. factors that may influence the relationship between the intervention and adherence⁹ [96;112]. This conceptual framework is presented in Figure 4. While the implementation process of the Chronic Care Model has been evaluated in different settings, so far no studies have assessed fidelity of a chronic care model for frail, older people who live at home.

AIMS AND OUTLINE OF THIS THESIS

Between 2010 and 2012, the GCM was implemented among 1147 frail, older people in two regions in the Netherlands and evaluated by means of effectiveness and cost-effectiveness studies. This thesis describes the outcomes of a research project with the following aims: (1) to gain insight in the way in which the GCM was designed and implemented during the 2-year intervention period, which involves opening the 'black box' of the GCM to increase understanding of what influenced program success or failure; (2) to explore theoretical underpinnings of the GCM, i.e. to gain insight in the particularities of (aspects of) 'productive interactions' that take place between a client and a care professional in the home environment, both at an intervention level and at a measurement level, and in the care needs at stake during these interactions.

The thesis is divided in two parts, each consisting of three research articles. PART 1 consists of articles that describe the GCM's implementation process. *Chapter 2* describes the study protocol of the implementation and evaluation of the GCM, and gives insight in its planned delivery, implementation strategies, and evaluation methods. *Chapter 3* aims to demonstrate to what extent the Geriatric Care Model was implemented as intended by presenting outcomes of a fidelity assessment. *Chapter 4* investigates the preva-

⁹ Carroll proposed 5 moderating factors: participant responsiveness, comprehensiveness of policy description, strategies to facilitate implementation and quality of delivery [96]. Hasson added two more factors: recruitment and context [112].

lence of pain and pain management plans in care plans, with the aim to provide insight in the way in which comprehensive geriatric assessments (CGA's) can improve access to tailored pain management for frail, older people who live at home. PART 2 consists of articles that explore the GCM's theoretical background. *Chapter 5* explores the self-perceived met and unmet care needs of frail older adults in primary care. *Chapter 6* aims to demonstrate how the interaction might play a role in success of such home visits by providing insight in the caregiver- receiver interaction during proactive home visits for older people. *Chapter 7* describes the evaluation of the measurement properties of a questionnaire to assess self-reported client-centeredness of home care in a population of frail older people. Finally, in *Chapter 8*, design, methodology and main findings of the research presented in this thesis are discussed, and their implications for practice, policy and research in the field of primary elderly care are addressed.

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