

Summary

1.

General Introduction

While old age comes with a lot of benefits, it also comes with loss of functioning in multiple domains of life, such as physical functioning and social functioning. Loss of functioning in older people is often related to the coexistence of multiple chronic conditions, called multimorbidity. The number of older people who suffer from multimorbidity is rising: around 65 percent of people over 65 live with multiple chronic illnesses. Besides functional decline, multimorbidity is associated with disability and poor quality of life. As a result, older people with multiple chronic conditions make use of care services more frequently and more intensely. Older people with multiple chronic conditions may be or eventually become frail. The term frailty is used to indicate a stage in life where people are confronted with several health-related problems and experience a so-called 'loss of reserves'. Conceptually, frailty is defined differently by different researchers. An often-used definition is that frailty is a combination of clinical traits in the physical domain (such as slow walking speed and muscle weakness), that together determine the frail phenotype. Another definition is based on a multidimensional notion of frailty, one that assumes

that frailty includes multiple domains of functioning such as the mental and social domain. Finally, frailty is also considered to be an accumulation of deficits (i.e., illnesses, disabilities) that increases someone's susceptibility to adverse outcomes. However, independent of its conceptualisation, frailty is associated with adverse outcomes such as falls, hospitalization and mortality. In this thesis, a multidimensional conceptualisation of frailty was used to determine the study population of the ACT study.

It is widely known that the European population is rapidly aging. Consequently, the number of older people who are frail is also increasing. As frail, older people often suffer from multiple chronic conditions and disabilities, they are more likely to experience a higher need to receive long-term care, which results in a higher demand on chronic care services and subsequently in an increased pressure on European health care systems. In order to relieve this pressure, older people are favored to 'age in place', i.e., to remain living at home with some degree of independence instead of in residential care. Aging in place has led to frail, older people becoming one of the fastest growing populations in primary care and to an increased demand for in-home community care. Primary elderly care has therefore been confronted with several challenges that may hinder the delivery of high-quality care to frail, older populations. First, frail, older people's health and care needs are not always identified at an early stage. Second, health care services for frail older people are less likely to be integrated as they are often delivered by multiple care providers, which increases the risk of, for instance, unnecessary tests, conflicting medical advice and medication problems. Finally, older people experience little involvement in their own care process. These challenges imply that, in order to meet the needs of an aging and increasing primary care population, a restructuring of primary care organization and delivery is essential.

One of the way this restructuring may be achieved is by implementing comprehensive care models, which provide a framework for coordinating and delivering care services and focus on the promoting of patient self-management, improved patient outcomes and restricted health care costs. Literature shows that, compared to usual care, different kinds of comprehensive care models could potentially enhance health and care outcomes and reduce costs, and may therefore be qualified to improve the quality and delivery of care for frail, older people who live at home. The Chronic Care Model (CCM) is a comprehensive framework for chronic disease management, and is often used to guide quality improvement and care system reorganization. The model identifies six elements essential for the optimal delivery of chronic care (i.e., self-management support, delivery system design, decision support, and clini-

cal information systems, community resources and policies and health care organization). In its original design, the CCM is mostly directed at systems focussed on clinical care, and to make the principles of the CCM applicable to a wider range of settings extensions or adaptations of the CCM have been developed. Little, however, is known about the CCM's suitability to guide transitions in primary elderly care, and about its effectiveness and implementation process in this setting.

Therefore, the Geriatric Care Model, a comprehensive care model for frail, community-dwelling older people in primary care, was developed and tested for its effectiveness and cost-effectiveness by means of a randomised controlled trial (RCT). As results of complex interventions for older people who live at home are often conflicting, it is essential to gain insight in potential determinants of success or failure. This insight can be achieved by carrying out a process evaluation. Process evaluations help researchers understand more about contextual factors that could have impacted the intervention and its delivery, explore user perspectives, and distinguish between different intervention components. Frameworks for process evaluations usually consist of several theoretical constructs, whose practical operationalization depends on each individual intervention's particularities. One of these elements is fidelity, which has been defined as the level to which an intervention is delivered as planned by the program developers. Assessing fidelity helps researchers distinguish between lack of program effectiveness due to a faulty program or to a low degree of implementation, as well as providing program developers with information useful for future dissemination of research findings.

Between 2010 and 2012, the Geriatric Care Model was implemented among 1147 frail, older people in two regions in the Netherlands. This thesis describes the outcomes of a research project with the following aims: to gain insight in the Geriatric Care Model's design and its implementation, which involves an assessment of fidelity to increase understanding of what influenced program success or failure; to explore the theoretical premises of the Geriatric Care Model by gaining insight in (aspects of) 'productive interactions' 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.

2.

*Implementing the chronic care model
for frail older adults in the Netherlands: study protocol of ACT
(frail older Adults: Care in Transition)*

This Chapter describes the study protocol of the ACT study. The aim of the ACT study was to address challenges in primary elderly care by implementing the Geriatric Care Model, a comprehensive care model for frail, older people who live at home. Chapter 2 describes how the Geriatric Care Model will be compared with usual care in a 2-year stepped-wedge cluster randomised clinical trial with 6-monthly measurements. The ACT-study trial will be carried out among 35 primary care practices in two regions in the Netherlands. Per region, practices are randomly allocated to four allocation arms designating the starting point of the intervention. Participants: approximately 1200 community-dwelling older people aged 65 or over and their primary informal caregivers. Primary care physicians identify frail individuals based on a composite definition of frailty and a polypharmacy criterion. The final inclusion criterion is scoring 3 or more on a disability case-finding tool.

The intervention entails 6-monthly in-home geriatric assessments by practice nurses. The results of the assessment are described in a tailored care plan written by the practice nurse in consultation with the primary care physician and the client. Frail, older people are encouraged to review their care plan, so that its content reflects the experienced wishes and needs of the older person. Practice nurses are managed by expert geriatric teams (consisting of an elderly care specialist and a geriatric nurse), who are in charge of quality management, organise tailored training and set up local networks of care organisations. Clients with complex care needs are discussed in multidisciplinary consultations, attended by the primary care physician, practice nurse, expert geriatric team, pharmacist, and – if relevant – other health care professionals involved in a client's care.

To gain insight in the impact of the Geriatric Care Model, an effectiveness evaluation, a cost-effectiveness evaluation and a process evaluation are performed. Primary outcome is quality of life as measured with the Short Form-12 questionnaire. Effect analyses are based on the "intention-to-treat" principle, using multilevel regression analysis. Cost measurements are administered continually during the study period. A cost-effectiveness analysis and cost-utility analysis are conducted comparing mean total costs to functional status, care needs and QALYs. The process evaluation contains an investigation of the level of implementation, barriers and facilitators to successful im-

plementation and the extent to which the intervention manages to achieve the transition necessary to overcome challenges in elderly care. The ACT study is the first study that assesses the effectiveness and cost-effectiveness as well as the implementation process of the chronic care model in a population of frail, community-dwelling older people in primary care.

3.

*From concept to content:
assessing the implementation fidelity
of a chronic care model for frail,
older people who live at home*

Chapter 3 investigates the fidelity of the implementation of the Geriatric Care Model. Assessing fidelity is important when evaluating the effect of comprehensive care interventions, as it is ubiquitously accepted that implementation fidelity can influence program impact. Fidelity was assessed by first identifying five key component of the Geriatric Care Model. These component were considered to be essential, i.e., they were expected to have the potential to cause the intervention to be effective. Subsequently, research questions were formulated in line with Carroll's framework for fidelity, which defines fidelity as 'adherence to the intervention', and distinguishes four constructs that together provide information about the degree of adherence: coverage, frequency, duration and content. These four constructs were assessed per intervention component during and at the end of the intervention period. Two moderating factors (participant responsiveness and facilitation strategies) were also assessed at the end of the intervention. In the Chapter we report that adherence to two intervention components (geriatric assessments and care plans) at a care professional level was high, but that adherence decreased over time. We also found that adherence to multidisciplinary consultations was initially poor, but increased over time. Individual differences in adherence between practice nurses and primary care physicians were moderate. Based on our experiences with assessing fidelity of the Geriatric Care Model, we recommend that a longitudinal investigation of adherence per intervention component is essential for a complete understanding of the implementation process, as well as a thorough investigation of moderating factors. We also point out that there is a risk of making a 'type 4' error: concluding that

fidelity is low and thus affects the intervention's success negatively, without taking into account the possibility that adjusting an intervention to local circumstances may lower its fidelity but increase its fit, which in fact may have a positive effect on intervention success.

4.

*Expanding access
to tailored pain care for frail,
older people in primary care*

In this Chapter, we present and discuss the results of a study that investigated whether practice nurses identified new pain cases when carrying out comprehensive geriatric assessments (CGA's), and whether CGA results led to tailored pain action plans in care plans of frail, older people. With this study, we aimed to get a better understanding of ways in which access to tailored pain care for frail, older people can be expanded. We used cross-sectional data from care plans written by practice nurses who proactively visited older people at home and administered a CGA that included an assessment of pain. Practice nurses described pain care-related agreements and actions (pain action plans) in older people's care plans. We analyzed first-time care plans of 781 older people for the presence of pain, pain location and cause, new pain cases, and pain action plans. We found that 315 (40.3%) older people experienced any type of pain. Practice nurses identified 20 (10.6%) new pain cases, and 188 (59.7%) older people with pain formulated at least one therapeutic or non-therapeutic pain action plan together with a practice nurse. Care plans of over half of the older people whose pain had already been identified by a primary care physician featured a pain action plan. Most of these plans consisted of actions or agreements related to continuity of care. Almost one-third of all pain action plans were related to therapeutic interventions. Based on these outcomes, we concluded that practice nurses in primary care can contribute to expanding older people's access to tailored pain care.

5.

*Self-perceived met and unmet care needs of frail,
older adults in primary care*

In Chapter 5, we describe the met and unmet care needs as perceived by frail, older people, and the association between these needs and socio-demographic and health-related characteristics. We assessed self-perceived care needs of 1137 older people using the Camberwell Assessment of Need for the Elderly (CANE). Socio-demographic characteristics that were measured included age, sex, partner status and educational level, and health-related characteristics included functional capacity, hospital admissions, chronic diseases and the degree of frailty. We found that frail, older people reported on average 4.2 care needs out of 13 CANE topics, of which 0.5 needs were unmet. The highest number of needs were reported in the physical and environmental domain, but these needs were mostly met. The highest number of unmet needs were reported in the psychosocial domain. Regression analyses showed that ADL (Activities of Daily Living) limitations and a higher frailty score were the most important determinants of both met and unmet care needs. The presence of unmet care needs was associated with a younger age and a higher educational level. The majority of frail, older people reported receiving sufficient help for their physical needs, but we recommend that there should be more attention paid to people's psychosocial needs.

6.

*Together toward trust:
understanding interactions between
caregivers and receivers during home visits
for frail, older people*

Chapter 6 explores the interaction between Ann, a practice nurse, and Mrs. Peters, an older women participating in a home visit program. The aim of this study was to gain insight in the processes that underlie the caregiver-care receiver relationship, in order to understand more about what aspects of this relationship could play a role in success of comprehensive care interventions for frail, older people. In the Chapter, we describe the what took place during two consecutive home visits in Mrs. Peters' home, and the outcomes of

in-depth semi-structured interviews with Mrs. Peters and Ann. Our findings indicate that an older person's grant of authority to their caregiver plays a role in the successful implementation of home visit services. Such a grant of authority has its foundation in a trusting relationship. Ann and Mrs. Peters were able to build a trusting relationship because Ann met Mrs. Peters' needs regarding the relational aspect of the interaction. We conclude that opportunities to increase the overall impact of home visit programs may lie in securing that caregivers meet older people's relational needs.

7.

*Measurement properties
of the Client-centred Care Questionnaire (CCCQ):
Factor structure, reliability and validity of a questionnaire
to assess self-reported client-centeredness
of home care services in a population of frail, older people*

In Chapter 7, we describe the results of a study that investigated the factor structure, reliability, content validity and acceptability of the Client-centred Care Questionnaire (CCCQ), an existing instrument that aims to measure client-centeredness from the client's perspective. We tested the CCCQ's measurements properties in a population of frail, older people in the Netherlands using data from the ACT-study. We first performed confirmatory factor analysis, then investigated reliability and validity parameters and assessed acceptability. The factor analysis yielded a bifactor model with essential unidimensionality. Internal consistency was high (omega total: .88). We found a test-retest reliability of total test scores of .81; the standard error of measurement was 2.61 (total score range 15-75) and the limits of agreement were -7.03 and 7.86. We rejected three out of four hypotheses for construct validity. In Chapter 7, we recommend calculating total test scores, reliability values were acceptable, and results on construct validity were inconclusive. Respondents found the CCCQ questions challenging to answer, which could be indicative of a high respondent burden. We conclude Chapter 7 with the recommendation that future instruments that measure client-centeredness of home care from the frail, older client's perspective should therefore be tailored to the specific circumstances of this population.

8.

General Discussion

This final chapter contains a summary of the main findings described in this thesis and implications for research and practice, as well as an elaboration on methodological aspects of the studies, a reflection on study strengths, limitations and outcomes.

Methodological considerations

Chapter 8 describes that when designing a process evaluation, we chose the approach proposed by Saunders et al. This choice was reconsidered and replaced with Carroll's framework for implementation fidelity. We assessed the various components of Carroll's framework over time, which provided insight in the way in which fidelity developed throughout the intervention period. Assessing all aspects of implementation fidelity over time and including all moderating factors proved to be unfeasible, which may have limited our overall understanding of the degree of fidelity. Furthermore, to investigate fidelity of the intervention, data was used that was collected or generated by care professionals. Due to challenges inherent to using such data, we recommend that future investigations of fidelity explore the feasibility of collecting such data prior to the start of the intervention and developed data collection methods together with the care professionals. In this section of Chapter 8, referral is made to a "type 4 error". Type 4 errors may occur when the method used to evaluate the level of implementation is based on a fixed idea of the imagined nature and delivery of intervention components, while in practice the intervention is adapted to local circumstances. As a result, the possibly incorrect conclusion may be drawn that the intervention is not fully implemented as intended. Finally, evaluating at the client's level is important when evaluating a care program, but that this comes with challenges. During the ACT study, these involved challenges related to data reliability, such as issues related to older people's comprehension of quantitative interview questions or problems recalling the practice nurse's visit. We evaluated at the health care professional's level by carrying out qualitative interviews with practice nurses, primary care physicians and geriatric nurses; in Chapter 8, we recommend that in future research, interviews with individual health care professionals should be carried out at multiple stages throughout the intervention period.

Reflections on study outcomes

In Chapter 8, we reflect on the client-care giver relationship, one of the concepts central to two studies in this Thesis. We mention that, in order to understand what makes older people comply to care professionals' advice, understanding what causes an older person to reject or accept care is essential. Several explanations are addressed: the advice is not tailored to an older person's needs, there is a lack of a trusting relationship with the health professional, or older people may not always experience a need for care. Meeting the relational needs of an older person and building trust may ask for a time investment, but may eventually motivate an older person to comply with professional advice. Furthermore, we discuss measuring client-centeredness. The respondent burden that we found when we tested the CCCQ may likely be due to items being too abstract, or to norms that underlie certain questions not always corresponding to norms and expectation of respondents. When developing a measurement instrument to assess self-perceived client-centeredness of in-home care services among frail, older people, it is therefore necessary to consider values, norms and expectations of the study population regarding autonomy in the care process and the client-caregiver relationship. In addition, future developers should take into account the specific circumstances of frail, older people (i.e., multiple care givers and multiple chronic conditions) and the tendency of people to give socially desirable answers.

Reflections on GCM implementation

We discuss the implementation process and its results. First, we discuss adherence to GCM components (care plan delivery, MTC delivery and community networks) that were envisioned to enhance coordination of care and factors that influenced adherence. It is explained that factors that influence care coordination exist at a micro, meso and macro level, and that some of these, such as use of health information technology (HIT), are associated with better care coordination. We therefore suggest to explore the possibility to develop digital, user-friendly care plans. We also suggest that if barriers to implementation of MTCs can be overcome, widespread implementation may be successful in achieving optimal care coordination in primary elderly care. Finally, as care coordination has been shown to improve through community support, it is essential that current barriers to implementation of community-level collaboration are targeted at a provider and organisation level.

Insight in the opinions and experiences of care professionals who implemented the GCM is necessary to increase understanding of how their satisfaction and involvement influenced implementation. Individual experiences may play a role in the way in which health professionals interact with an intervention, adopted its methodology and implement its components. We recommend that future fidelity researchers measure participant responsiveness at multiple times during the intervention period, collect quantitative and qualitative data simultaneously so that ratings can be explained, and explore the relationship between participant responsiveness and quality of intervention delivery. Moreover, they should include an investigation of health professional characteristics, including preferences and opinions regarding elderly care structure and delivery, and the relation of these factors to experiences of satisfaction and involvement.

Reflections on effectiveness outcomes

Effectiveness and cost-effectiveness evaluations suggest that the GCM is not cost-effective compared to usual care. Chapter 8 addresses several factors at a methodological, program and implementation level that could explain these outcomes. The outcome measures used in the ACT study may not have been able to capture the effects of the various types of care interventions, or the intervention period may not always give a practice nurse enough time to build a trusting relationship with an older person, and an older person enough time to adopt the intervention. Furthermore, there may have been bias in the selection of the study population, the GCM or one or more of its individual components may not have been inherently effective, or the GCM had limited added value as compared to usual care. The fact that adherence to most intervention components was adequate does not automatically imply that implementation issues did not play a role in the establishment of the outcomes, as the relationship between implementation and outcome may not be linear and we did not investigate several moderating factors. We conclude that whether the absence of intervention effect can be attributed to factors related to study design and methodology, to program weaknesses or to implementation issues is uncertain.

Reflections on GCM objectives

Chapter 8 discuss whether the three main objectives of the GCM (to identify health and care needs at a timely stage, to improve older people's involvement in their own care process, and to increase coordination between health care professionals) were achieved, and briefly address implications for future implementation. We argue based on study outcomes that that indeed, proactive home visits and CGAs administered by practice nurses have the potential to lead to more timely identification of new or changed care needs and expand access to tailored pain care. We therefore suggest that proactive home visits, CGAs and regular follow ups may be more widely implemented into practice, but that this implementation should be accompanied by a re-evaluation of the way in which the individual intervention components are delivered. Furthermore, we write that drawing an overall conclusion about the GCM's ability to improve older people's involvement in their own care is not possible; however, there are indications that actual involvement can only be achieved in a subgroup of motivated people whose mental or physical state allows for it. Finally, we argue that in order for care plans to improve coordination of care, a third objective of the GCM, all potential users should be involved in the care plan' development process and trained to use it adequately. MTC's – including ones that involve clients and/or their family members – have the potential to contribute to better care coordination, providing current barriers to its implementation are targeted, and building local networks takes time and skills, but is essential to make optimal use of structures that facilitate integrated community care.

Implications for practise and research

At the end of Chapter 8, we make several more recommendations for practice and further research. We address why primary elderly care needs to change to prepare for the future, and discuss several characteristics of the GCM that could facilitate this change. We argue that one of these characteristics is a central role for practice nurses, by virtue of the increased level of patient satisfaction following contact with nurses and the emerging evidence that skill mix can maintain access to primary care, improve quality of care and client outcomes, and potentially lower costs. This shift would require advanced training programs for practice nurses. We furthermore recommend that future implementors of the GCM increase their focus on facilitating users' learning

processes regarding the different intervention components in order to ensure rapid implementation of the model, that the level of implementation should be investigated over time and for each intervention component separately, and that evaluators should be deliberate about which framework or concepts to use for the operationalization of their process evaluation study.

