Dhr. Zoetemelk (76) “Mijn vrouw verzorgt me elke dag en dat is heel fijn. Hopelijk kan dat zo blijven.”
SUMMARY

Frailty in older adults is associated with a high vulnerability for adverse health outcomes, such as disability, dependency and mortality, resulting from age- or disease related decreased physiologic reserves. Frail older adults typically have a lower quality of life than older people who are not frail, and consume a wide range of health and social care services. With an increasing prevalence of frailty in community dwelling older adults, health care systems face an emergent challenge to adequately meet the complex, long-term and fluctuating care needs of this group. Besides concerns about the quality of care for frail older adults, there are concerns about the funding of the growing demand on health and social care. Further ageing of the population and its associated rise in health care expenditures will put additional pressure on the affordability of current health care systems.

The Dutch Ministry of Health, Welfare and Sport initiated the National Care for the Elderly Program to be able to respond to the needs of frail older adults, whilst keeping cost at a manageable level. The program funded the establishment of regional networks of relevant actors in care for older adults and research projects implemented in the context of these networks. This thesis is written within the framework of the National Care for the Elderly program, as part of one of these research projects: the ‘Frail older Adults: Care in Transition’ (ACT) study.

In the first part of this thesis we described the evaluation of an integrated care model for community-dwelling older adults: the Geriatric Care Model. This model was based on the Chronic Care Model and was designed to improve the quality of care of community-dwelling frail older adults, and subsequently improve their quality of life.

In the second part of this thesis we focused on the evaluation of quality of life measures that can be used in economic evaluations of care services for older adults.

Part 1. ‘Frail older adults: Care in Transition’ study

In Chapter 2, we presented the study protocol of ACT. This protocol included a detailed description of the Geriatric Care Model and the selection procedure of community-dwelling frail older adults, which resulted in the participation of 1147 older adults. During the intervention participants received regularly scheduled in-home comprehensive geriatric assessments by a practice nurse, followed by a tailored care plan. Geriatric expert teams managed and trained practice nurses. Participants with complex care needs were reviewed in multidisciplinary team consultations. The Geriatric Care Model was designed to target health risks and care needs at a timely
stage, to stimulate active involvement of patients in the care process and to improve the coordination between health care professionals. In the ACT study, we compared the Geriatric Care Model with usual care in a 2-year stepped wedge cluster randomised clinical trial, carried out among 35 primary care practices in two regions in the Netherlands. Practices were randomly allocated to four allocation arms designating the starting point of the intervention (at 0, 6, 12, and 18 months after baseline). Practices provided usual care until this starting point.

In Chapter 3, we assessed the implementation fidelity of the Geriatric Care Model in the ACT study. Implementation fidelity is a measure for the degree to which an intervention is implemented as intended. To assess fidelity, we identified key intervention components (e.g. geriatric assessments, care plans, multidisciplinary consultations) and formulated corresponding research questions using a well-known framework for fidelity. In line with this framework we evaluated adherence (coverage, frequency, duration, and content) and factors potentially moderating adherence. We found that adherence to the geriatric assessments and care plans was high, but decreased over time. Adherence to multidisciplinary consultations was initially poor, but increased over time. In addition, we found that the level of adherence, satisfaction and involvement varied between professionals. Nurses deviated from protocol due to contextual factors and personal work routines.

In Chapter 4, we evaluated the cost-effectiveness of the Geriatric Care model in comparison with usual care. This economic evaluation was conducted alongside the stepped wedge cluster randomised controlled trial. Outcomes were measured every 6 months and included costs from a societal perspective, health-related quality of life (SF-12 physical (PCS) and mental component (MCS) summary scales), functional limitations (Katz ADL and iADL) and quality adjusted life years (QALYs) based on the EQ-5D. Multilevel regression models adjusted for time and baseline confounders showed no significant differences in costs (€297; 95% CI: -€407 to €945) and outcomes between intervention and usual care phases. Cost-effectiveness acceptability curves showed that for the SF-12 PCS and MCS, the maximum probability of the intervention being cost-effective in comparison with usual care was around 0.80 at ceiling ratios of 20,000 €/unit of effect extra. For all other outcomes (QALY, ADL and iADL) the maximum probability of cost-effectiveness was 0.43. As the Geriatric Care Model was not cost-effective compared to usual care after 24 months of follow-up, we do not recommend widespread implementation in its current form.

**Part 2. Measuring quality of life in older adults**

The value for money that competing interventions provide can be measured with generic outcomes such as quality adjusted life years (QALYs). QALYs reflect both length and health-related
quality of life. The EQ-5D is the most well-known and widely used instrument to measure and value this health-related quality of life. It is increasingly recognised, however, that although health is an important determinant of quality of life, consequences and objectives of many care services include aspects of quality of life beyond health, particularly in areas such as public health, mental health and care for the elderly. Recently, two new measures were developed for the purpose of evaluating care services for older adults/social care service users from a broader perspective, the Adult Social Care Outcomes Toolkit (ASCOT) and the ICEpop CAPability measure for Older people (ICECAP-O). In Chapter 5, 6 and 7 we used data from the ACT study to evaluate the ASCOT and ICECAP-O.

In Chapter 5, we described the translation process of the ASCOT into Dutch, in which we followed international translation guidelines. The procedure included the development of two forward and back translations, and several reviews from an expert committee. Part of the translation procedure was an assessment of the cross-cultural validity; the prefinal version was pilot tested in frail older adults using think-aloud interviews, test-retest reliability and a comparison of the response distributions and construct validity in England and the Netherlands. The pilot tests showed that translated items were in general understood as intended, that most items were reliable, and that the response distributions of the Dutch translation and associations with other measures were comparable to the original English version. Based on the results of the pilot tests, some small modifications and a revision of the Dignity items were proposed for the final translation, which were approved by the ASCOT development team.

In Chapter 6, we compared the test-retest reliability, construct validity and responsiveness of the total index scores of the ASCOT, ICECAP-O and EQ-5D. The test-retest reliability (i.e., the extent to which scores for patients who have not changed are the same for repeated measurement over time) was considered good for all three instruments as indicated by two reliability parameters. In addition, the differences in the values of these reliability parameters between the ASCOT, ICECAP-O and EQ-5D were small. We formulated hypotheses about correlations with other measures and tested these to assess construct validity and responsiveness; most hypotheses were accepted. Compared to the EQ-5D, the ASCOT and ICECAP-O were more strongly correlated to other instruments that measure aspects of quality of life beyond physical health. We found that change in self-perceived quality of life, change in mastery and change in client-centeredness were stronger correlated to changes in the ASCOT score than to the changes in ICECAP-O and EQ-5D scores. Change in mental health was most strongly associated with change in ICECAP-O.

In Chapter 7, we reported the content validity and feasibility of the ASCOT, ICECAP-O and EQ-5D from the perspective of older adults, by identifying response issues and participants’ opinions about the comprehensibility of items and coverage of quality of life domains. Think- aloud
interviews among older adults revealed response issues for various items in all three instruments, mainly related to the mapping of the responses on predefined response categories and to the interpretation of abstract or double-barrelled items. Often, the older adults’ responses to the quality of life items were more positive than would be expected from the point of view of an outsider. Furthermore, the respondents in this study stated that their responses to the items of the instruments did not give such a comprehensive picture of their quality of life as a proper personal conversation would. Of the three instruments, the older adults preferred, both in terms of coverage and comprehensibility of the domains, the instrument and more specifically the items that most closely reflected their daily life. This differed from person to person.

In Chapter 8, we used data from the English national Adult Social Care Survey to examine associations between the ASCOT and three potential policy targets for local authorities: (1) accessibility of information and advice, (2) design of the home and (3) accessibility of the local area. After adjusting for physical and mental health factors and other confounders our findings indicated that the quality of life as measured with the ASCOT is significantly lower for older adults who find it more difficult to find information and advice, for those who report that their home design is inappropriate for their needs and for those who find it more difficult to get around in their local area. These three variables were as strongly associated with the ASCOT as physical and mental health factors. Furthermore, this association was particularly strong for older adults with higher needs and less assistance from informal carers, and among older adults with lower ASCOT scores; suggesting that older adults that are most vulnerable may profit most from interventions in these areas.

Finally, Chapter 9 provides an overview of the main findings in this thesis, followed by a discussion of methodological issues and recommendations for clinical practice, policy and further research. We concluded that:

- integrated care as implemented according to the Geriatric Care Model is not cost-effective compared to usual care for community-dwelling frail older adults in the Netherlands. Future research should look into long term effects, the (combination) of integrated care components that work best, and the target population for whom integrated care models work best;
- the adoption of the ASCOT and ICECAP-O as outcomes measures in economic evaluations of care interventions targeted at community-dwelling older adults is supported by the findings in this thesis. Future research should demonstrate whether the instruments are indeed responsive to changes in quality of life as a result of the impact of care services; and to changes in health, as this remains an important quality of life domain.