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General introduction

Mrs F was 93 years old and lived independently in the house she used to have a grocery store in. Even her children had been growing up in this house. For twenty years, she had been suffering from severe rheumatism. Due to difficulties in climbing the stairs, a stair lift had been installed in her house. Seven years ago, her husband had died of heart failure and she missed him every day ever since. Unfortunately, her physical complaints kept increasing and walking became more and more difficult. In the beginning, she refused to walk with a walking frame because she felt ashamed and was too proud. However, during her regular walks to the cemetery, she became increasingly afraid to fall so she started using her walking frame. But as her health kept deteriorating, walking outside became impossible. In the end, she spent her days reading the newspaper and watching television because she was still very interested in the world around her. However, she was bound to stay at home and went to bed very early. As time passed by, Mrs F started to feel lonelier and she became more and more emotional and slightly depressed. Mrs F always said: "I had a beautiful life". She did not want to complain but she was not feeling well and became forgetful. When she talked about her life and her husband, she often started crying.

Her children and grandchildren visited her regularly because Mrs F became increasingly dependent on their support. Her son became her main care giver and dropped by every day. Every morning he made coffee for her, which she could no longer do herself due to her rheumatism. Her daughter came by every other weekend and Mrs F was looking forward to her visits. They spent time at the kitchen table talking and reading the newspaper. Her daughter cooked and prepared meals that were supposed to last for several days. Her granddaughter bought groceries every Saturday. The house was cleaned by a cleaning lady every other week. Home care visits was arranged to undo the support stockings every night. Mrs F had an alarm system that she could use in case of emergencies. The GP visited her on several occasions, mostly because of her rheumatism. A few times she was admitted to the hospital because she fell, had low blood pressure levels or developed a kidney failure. During the recovery process in the hospital, she felt safe and she also liked the personal attention of both professionals and family. When she got discharged from the hospital, Mrs F's daughter arranged weekly visits to a community centre such that Mrs. F felt less lonely. Initially, Mrs F was not enthusiastic but as time passed by she actually enjoyed the activities and the company.

Unfortunately, the situation became more and more problematic and eventually untenable. Her son still came by every day getting her dressed, cooking her dinner but had difficulties with providing personal care. At some point in time Mrs F developed injuries to her feet which hindered her going out of bed to use the toilet. When, on

top of that, she developed problems breathing, she got admitted to the hospital again. Mrs F slept continuously, was confused and her health was deteriorating rapidly. The doctors were not able to determine a final diagnosis and they referred her to a revalidation hotel. During the referral process, the hospital accidentally forgot to inform the revalidation hotel that Mrs F. should take blood thinner medication. Not long thereafter, Mrs F. fell out of bed in the revalidation hotel, causing her blood circulation in her leg to stop. She got re-admitted to the hospital where she passed away.

Frailty

This is the story of my 93 years old grandmother and her ageing process. We know that ageing processes strongly differ between people due to genetic and environmental differences (Slaets, 2006). In other words: older people are not homogeneous (Lacas & Rockwood, 2012). Chronological age is not particularly informative since it does not reveal the severity of the ageing process or the health care needs of older people. Their health condition ranges from healthy agers to being completely care dependent (World Health Organization, 2015). The 'grey' area between these two extremes is referred to as frailty.

The term frail elderly was introduced by Charles F Fahey and the United States Federal Council of Ageing (Gobbens, 2010). Frailty is an important part of geriatric medicine and gerontology (Rockwood, Fox, Stolee, Robertson, & Beattie, 1994) and is clinically relevant to explain differences between older people. In fact, frailty has become a real buzz word (Manthorpe & Iliffe, 2015) and has been described as the most problematic expression of population ageing (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013). Research has shown that frailty is strongly related to a wide range of negative outcomes such as functional decline, loss of mobility, risk of falling, poor quality of life, hospitalization, institutionalization and mortality (Clegg et al., 2013; Fried et al., 2001; Gobbens, Luijckx, Wijnen-Sponselee, & Schols, 2010). However, still no clear consensus exists on the conceptualization of frailty (Dent, Kowal, & Hoogendijk, 2016). In general, we could say that frailty represents vulnerability to adverse outcomes of people of the same chronological age caused by accumulations of deteriorations in domains of human functioning (Clegg et al., 2013; Fried et al., 2001; Gobbens et al., 2010; Lacas & Rockwood, 2012; Slaets, 2006). Frailty is characterized by its complexity because the underlying problems in these domains influence and reinforce each other (Bergman et al., 2007; Gobbens et al., 2010).

Yet, researchers have not agreed upon the specific definition of frailty and what domains of human functioning should be included. Formerly, frailty was related to the physical domain of functioning. Fried and colleagues (2001) introduced the frailty phenotype with five characteristics: unintentional weight loss, exhaustion, weakness (low grip strength), slow walking speed and low physical activity. More recently frailty is also conceptualized from a broader, multidimensional perspective that not only incorporates the physical domain but also the psychological and social deficits (Gobbens et al., 2010; Markle-Reid & Browne, 2003; Rockwood & Mitnitski, 2007; Schuurmans, Steverink, Lindenberg, Frieswijk, & Slaets, 2004), including depression, feelings of anxiety and loneliness. Rockwood and colleagues developed the frailty index and consider frailty as an accumulation of a range of deficits (Rockwood et al., 2007). The prevalence of frailty strongly depends on the conceptualization of frailty and ranges from 4.0 to 59.1 % of the community-dwelling older people (Col-lard, Boter, Schoevers, & Oude Voshaar, 2012).

Context

Frailty should be considered in the context of population ageing. The age composition of the world population is changing and the absolute and relative number of older people that grow old is increasing rapidly. The number of people of 60 years and older worldwide will increase by 56 percent between 2015 and 2050. The group of oldest-old is also increasing rapidly (United Nations, 2015). The proportion of people of 60 years and older will increase to 30% in several countries (World Health Organization, 2015). Population ageing is caused by the increased life expectancy – rising to over 90 years old – and the decreased fertility rates (World Health Organization, 2015).

Due to this rapid increase of older people, national health policies are under pressure. Health and social care budgets are shrinking and have to be divided under this increasing number of older people. Health care systems throughout the world have encountered great challenges urging innovation in the organization of elderly care (Pavolini & Ranci, 2008). The need to provide high-quality, effective care for frail older people increases and it is essential to explore whether and how available resources can be optimally used.

An important aim of national health policies is the prevention of institutionalization because it is expensive. This implies ‘ageing in place’ (Wiles, Leibing, Guberman, Reeve, & Allen, 2012), which corresponds to the preference of older people to grow

old in their own homes (Friedman, Steinwachs, Rathouz, Burton, & Mukamel, 2005). This also implies that frail older people with their complex needs in multiple domains remain living in the community rather than being institutionalized in residential care or nursing homes (Wiles et al., 2012; de Groot, de Veer, Versteeg, & Francke, 2018). At the same time, national governments are shifting responsibilities to municipalities (Grootegoed & Van Dijk, 2012; Pavolini & Ranci, 2008). Citizens are stimulated to take their responsibility and use their own social network to address care needs (Grootegoed & Van Dijk, 2012). This asks for self-reliance and a more prominent role for informal caregiving in the care for frail older people.

Care for frail older people

Due to ageing in place, GPs and other primary care professionals become mainly responsible for the care for this growing number of frail older people. This means that the degree of complexity of the patient population in primary care is increasing (Boeckxstaens & De Graaf, 2011). Primary care professionals struggle with this complexity and the quality of care is under pressure (Schers, Koopmans, & Rikkert, 2009).

A major criticism on the current way of care delivery is the fragmentation. The increasing complexity of modern healthcare has led to specialization of health care professionals (Enthoven, 2009). Moreover, healthcare is characterized by silo thinking in all domains: policy, financing, organization, professionals and service delivery (Kodner, 2009). In order to address the needs of frail older people, cooperation between professionals with different backgrounds working in different organizations is required. Even though primary care professionals have a more generalist approach (Boeckxstaens & De Graaf, 2011), they are originally disease-orientated and tend to focus on single and acute health problems (Lette, Baan, van den Berg, & de Bruin, 2015). However, frail older people also have problems in the psychological and social domain that are strongly interrelated with health outcomes (Lloyd & Wait, 2005). Their needs extend the medical domain to the areas of prevention, care, housing and welfare (Ex, Gorter, & Janssen, 2003).

The fragmentation of care is further characterized by a lack of continuity and coordination (Kodner, 2009), leading to inefficient and ineffective care (Gröne & Garcia-Barbero, 2001; Lloyd & Wait, 2005). Services are not delivered coherently, nor in accordance with the dynamic needs of frail older people (Lloyd & Wait, 2005; Nies, 2004). Transfers between primary and secondary care (and reverse) need improve-

ment, because information exchange is generally limited and professionals in secondary care have knowledge deficiencies on services in the community (Boeckxstaens & De Graaf, 2011). Moreover, no one is truly responsible for the coordination of the care for community-dwelling frail older people. Professionals mostly communicate bilateral by referral letters and sporadic phone calls. GPs have insufficient time to coordinate care and often have little knowledge of the available services outside the GP practice (Boeckxstaens & De Graaf, 2011).

In addition, the current methods of delivering primary care are reactive rather than proactive with a minor role for prevention. Frail older people consult care professionals such as their GP on their own initiative. The needs of frail older people are often not addressed in a timely manner, leading to crisis situations such as visits to the Emergency Departments (Boeckxstaens & De Graaf, 2011; Vedel et al., 2009). The early recognition of frailty could prevent further deterioration and even delay negative health and social outcomes and institutionalization (Challis, Chessum, Chesterman, Luckett, & Woods, 1987). Prevention is an important task of primary care but the current approach is quite narrow and related to specific disease-related problems such as stimulating physical activity for diabetes patients or fall prevention programmes for older people (Boeckxstaens & De Graaf, 2011). Prevention may well focus on maintaining quality of life and independence of frail older people.

Preventive, integrated care

In view of the problems concerning the care for frail community-dwelling older people, integrated care is advocated to solve these problems. Integrated care is described as “a well-planned and well-organised set of services and care processes, targeted at multi-dimensional needs/problems of an individual client, or a category of persons with similar needs/problems” (Nies, 2004). Integrated care is an umbrella term that is related to terms such as managed care, transmural care, disease management and care management (Kodner & Spreeuwenberg, 2002; Kodner, 2009). Two crucial features of integrated care are person-centeredness and continuity. First, integrated care is demand oriented rather than supply oriented, implying that care is delivered according to client needs (Mur-Veeman, Hardy, Steenberg, & Wistow, 2003) by professionals from different disciplines and sectors cooperating to address these needs (Grone, Garcia-Barbero 2001; Kodner Kyriacou 2000). The second important feature of integrated care is continuity: the set of services should be delivered coherently, seamlessly and in accordance with clients’ changing needs (Lloyd & Wait, 2005; Nies, 2004). Preventive, integrated care for frail older people starts with the

identification of the target group who would benefit most from integrated care (Collard et al., 2012). Frailty should be identified quickly and correctly (Challis 1987; Strandberg & Pitkala 2007) to prevent or postpone the negative outcomes of frailty.

Integrated care is a complex phenomenon and involves overcoming several barriers in the fragmented health care system (Kodner, 2009; Valentijn, Schepman, Opheij, & Bruijnzeels, 2013). Numerous interventions for frail older people have been developed (Oliver, Foot, & Humphries, 2014) and consist of many different (interacting) elements to integrate care such as screening, comprehensive geriatric assessments, preventive home visits, case management, multidisciplinary teams, protocols and discussions, information systems (Beswick et al., 2008; Fabbriotti, 2007; Hebert, Durand, Dubuc, Tourigny, & Group, 2003; Huss, Stuck, Rubenstein, Egger, & Clough-Gorr, 2008; Johri, Beland, & Bergman, 2003; Kodner & Kyriacou, 2000). In particular, case management is a well-known strategy to integrate care around complex patients such as frail older people and pays close attention to informal caregivers (Ross et al 2011). Since all aspects of the health care system tend to be fragmented (Kodner, 2009), integration should also occur at different levels of the health care system, such as the service delivery, professional, organization, financial and policy level (Kodner & Spreeuwenberg, 2002; Lloyd & Wait, 2005; Valentijn et al., 2013). The assumption is that adopting more strategies at different levels is essential to achieve effectiveness (Kodner & Kyriacou, 2000; Kodner & Spreeuwenberg, 2002).

Despite the complexity of integrated care, professionals, policy makers and researchers perceive integrated care as a promising solution. They have high expectations of integrated care (Minkman, 2012; World Health Organization, 2016) and the wide range of aims it might achieve. Integrated care should lead to greater coherence in the care process, improvements in the quality of care, clinical results, quality of life, consumer satisfaction, higher system efficiency, and cost-effectiveness (Kodner & Spreeuwenberg, 2002; Kodner, 2009; Leichsenring, 2004). Therefore, researchers have increasingly been involved in the evaluation of integrated care in order to test its effectiveness (Eklund & Wilhelmson, 2009; Kodner, 2009) and more recently also its cost-effectiveness (Evers & Paulus, 2015; Tsiachristas, Stein, Evers, & Rutten-van Mölken, 2016).

Relevance

It remains unclear whether integrated care can meet these high and diverse expectations. This thesis will, therefore, provide more in-depth insights in the effectiveness

and cost-effectiveness of preventive, integrated care for frail older people. Integrated care is a relatively new research field and several questions remain unsolved (Minkman, 2016). One of the assumptions that needs to be verified is whether vulnerable and complex patients will benefit the most from integrated care (Kodner, 2009; Leutz, 1999). Moreover, there remains a need for examining what specific combination of integrated care elements and level of integration is optimal to achieve outcomes (Kodner & Spreeuwenberg, 2002). In this thesis, the effectiveness and cost-effectiveness of a specific intervention, the Walcheren Integrated Care Model (WICM), will be explored and will be related with comparable (inter)national preventive, integrated care interventions for frail older people. Similar to integrated care, the research field of frailty is currently expanding rapidly (Clegg et al., 2013; Manthorpe & Iliffe, 2015). However, a clear conceptualization of frailty is still lacking (Dent et al., 2016) which implies that frail older people receiving integrated care interventions are a diverse group that strongly differs between interventions. However, in integrated care research, frailty is narrowed to a binary identity (not frail-frail). In this thesis, frailty will be specified by developing frailty subpopulations that will be set against the effectiveness of integrated care.

Furthermore, research is necessary to explore whether integrated care is able to solve current problems in elderly care. Currently care is fragmented, lacks coordination and is reactive. On local, national and international level, we are still searching for innovative ways to improve elderly care and providing value for money. This thesis will investigate whether integrated care is the innovative solution. But after all, it is about the older people facing frailty every day. Older people do not identify themselves with the term frailty (van Campen, 2011) and they do not care about interventions. Integrated care for them is about seamless, smooth care processes (Lloyd & Wait, 2005) addressing their needs and being able to prevent or postpone negative outcomes of frailty and, most of all, maintain their quality of life.

Research aims & outline of this thesis

The research aim of this thesis is to explore to what extent preventive, integrated care for community-dwelling frail older people is effective and cost-effective.

The four subquestions of this thesis are:

- Is the WICM effective and cost-effective?
- What is the evidence on the effectiveness and cost-effectiveness of preventive, integrated care for community-dwelling frail older people?

- To what extent can frailty subpopulations in integrated care arrangements be distinguished?
- Is preventive, integrated care more effective for certain subpopulations of frail older people?

Part A of this thesis contains the empirical evaluation of the effectiveness and cost-effectiveness of a promising preventive, integrated care intervention, the WICM. In 2008 in the Netherlands, the Dutch National Care for the Elderly Program was enrolled in which several proactive, integrated care interventions for older person with complex care needs were developed, implemented and evaluated in close collaboration with older people. More than 50 interventions were evaluated with The Older Persons and Informal Caregivers Survey Minimum Dataset to collect uniform information (Lutomski et al., 2013). One of these projects is the WICM. Walcheren is a specific region of the Netherlands in which the proportion of older people is increasing more rapidly than in other regions of the Netherlands. Younger people move to other parts of the Netherlands which also leads to a decrease in the capacity of health care professionals. In close collaboration with these professionals, the WICM was developed including many different elements that were effective in singularity were combined into one comprehensive intervention with specific attention for prevention and the informal caregiver.

The intervention is presented in figure 1.1. All GP patients aged 75 and older were screened with the Groningen Frailty Indicator; a 15-item questionnaire screening for frailty that measures decreases in physical, cognitive, social and psychological functioning. GFI scores range from 0 to 15; patients with a score of 4 or higher were considered frail (Peters, Boter, Slaets, & Buskens, 2013; Schuurmans et al., 2004). Frail older patients are visited by a nurse practitioner who assessed their functional, cognitive, mental and psychological functioning using EASYcare, an evidence-based instrument to assess care needs (Melis et al., 2008). A multidisciplinary treatment plan is then formulated in consultation with the elderly and their informal caregiver(s). Case management is provided by the nurse practitioner who coordinated care within the multidisciplinary team which implies monitoring the frail older person's condition, arranging the admittance to the required services, being the contact person for the involved professionals to coordinate their care and periodically evaluating the multidisciplinary treatment plan. The evaluation occurs in multidisciplinary meetings. Multidisciplinary meetings are attended by the GP, the nurse practitioner and other professionals, depending on the care required by the frail older people, such as geriatric physiotherapists, geriatricians, pharmacists, district nurse, nursing home doctors and mental health workers. The entire process is supported by web-based

patient files and multidisciplinary protocols. In the WICM, the GP functions as care coordinator and as a partner in prevention. The GP practice is a single entry point for the elderly, their informal caregivers and health professionals. The intervention requires task reassignment and delegation between nurses and doctors, and among GPs, nursing home doctors and geriatricians. Consultations occur among primary, secondary, and tertiary care providers. At the organizational level, a steering group serves as an umbrella organization under which the WICM is developed and disseminated. This steering group, which consists of representatives from all involved organizations, forms a Joint Governing Board that provides the necessary provider network.

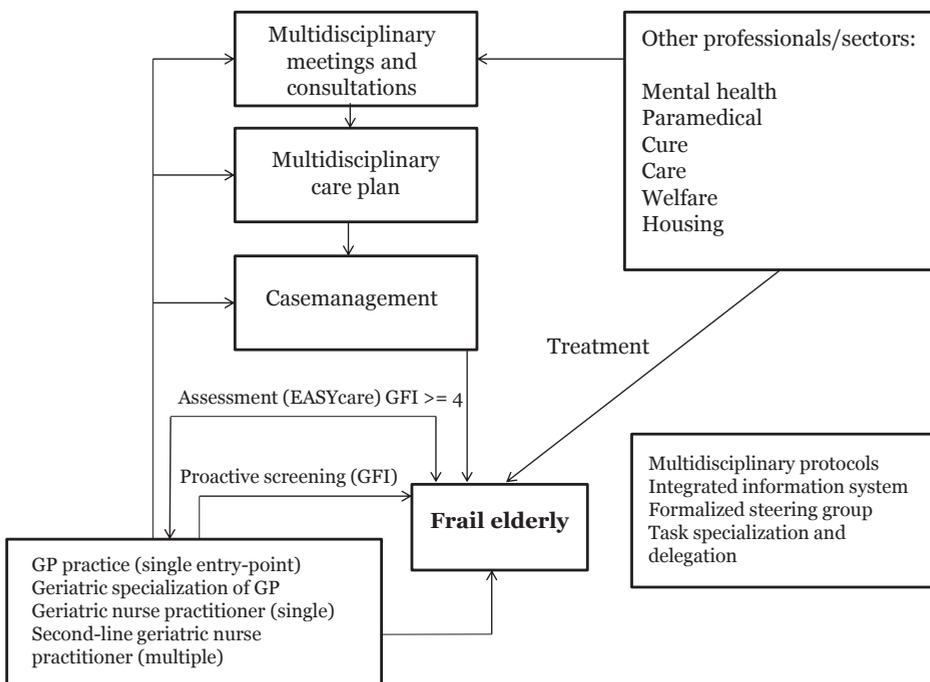


Figure 1.1: Walcheren Integrated Care Model

The WICM combines effective elements such as geriatric assessments, case management, multidisciplinary teams, a single entry point (Johri et al., 2003), multidisciplinary protocols and discussions, web-based patient files, and a network structure (Fabbricotti, 2007; Hebert et al., 2003; Kodner & Kyriacou, 2000) into one intervention. The intervention focuses on the entire chain, from detection to the provision of care, in the fields of prevention, cure, care, welfare and residence, in primary, secondary and tertiary care.

The evaluation study of the WICM has a quasi-experimental design with before and after measurements, at three and twelve months. The intervention is implemented in three GP practices in Walcheren and compared with care as usual and the control group is recruited in the same region and consists of six GP practices. Effectiveness is determined for a wide range of outcomes including health outcomes, functional abilities and quality of life. The cost-effectiveness of the WICM is determined, being an important aim of integrated care. With the current budget cuts in health and social care, it is crucial to provide good value for money. The cost-effectiveness analysis is studied from a societal perspective which means all costs are considered irrespective who pays for them, including the costs of informal care. The intervention costs of the WICM are studied extensively with data from different sources such as questionnaires, GP files and time registrations. This means that the intervention costs such as time spent on multidisciplinary meetings and case management could be determined for each individual frail older person participating in the WICM.

Part B of the thesis questions the concepts and methodologies used to explore the (cost-) effectiveness of integrated care for frail older people and places the results of part A in a broader perspective. A systematic review presents the current body of evidence on preventive, integrated care for community-dwelling frail older people, including the WICM. All types of outcomes of integrated care interventions are considered; being able to present the bigger picture. Furthermore, different elements and levels of integration adapted from the Rainbow Model of Integrated Care (Valentijn et al., 2013) are explicitly related to the outcomes of integrated care. In part B of thesis, the target group of the integrated care interventions is also examined more closely. Frailty is widely acknowledged in both research and practice but has also converted into a container term without a clear conceptualization (Dent et al., 2016). Therefore, frail older people are a heterogeneous group of older people who have different health issues and needs. In this thesis, frailty is further specified by developing frailty profiles are developed with the TOPICS-MDS dataset containing data from 40,000 older people. Latent class analysis is used to develop subpopulations of similar individuals within this larger population. The individuals within these subpopulations have more in common with each other than with the individuals in the other subpopulations. By identifying frailty profiles, care may be tailored to the needs of specific frailty subgroups. Therefore, the frailty profiles are related to integrated care by exploring whether the effectiveness of integrated care differs for certain profiles of frail older people. This is tested by means of an individual-patient-data analysis of eight integrated care interventions. The data of the WICM and seven comparable integrated primary care interventions of Dutch National Care for the

Elderly Program are combined in order to explore the effectiveness of integrated care for each profile in terms of health outcomes, functional abilities and quality of life.

Reading guide

Chapter 2 is the study protocol of the WICM describing the intervention and its different integrated care elements and level of integration in detail. Moreover, the methodology of the evaluation study is extensively described such as the study design, data collection and instruments. Chapter 3 is the short-term evaluation of the WICM with a follow-up period of three months in order to investigate whether quick wins of preventive, integrated care can be expected. Chapter 4 contains the evaluation of the WICM after twelve months in terms of health outcomes, functional abilities and quality of life to explore the full potential of the intervention. Chapter 5 reports on the cost-effectiveness of the WICM.

Part B starts with a systematic review on the effectiveness and cost-effectiveness of preventive, integrated for frail older people in chapter 6. In chapter 7 frailty profiles are developed that are used in chapter 8 to explore whether integrated care is (more) effective for certain profiles of frail older people. Chapter 9 is the general discussion of this thesis which contains the main findings of this thesis, the theoretical and methodological reflections and a future research agenda on integrated care for frail older people.

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