INTEGRATED CARE for FRAIL ELDERLY PEOPLE of FORMAL
and INFORMAL CAREGIVERS

GREAT EXPECTATIONS OF INTEGRATED CARE

Benjamin JANSE

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An Investigation of Assumptions Regarding the Impacts of Integrated Care for Frail Elderly People on Formal and Informal Caregivers

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Great Expectations of Integrated Care:
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Dissertation Erasmus University
Rotterdam, the Netherlands

Cover & layout concept
Hamid Sallali

Layout & printing production
Off Page, Amsterdam

GREAT EXPECTATIONS OF INTEGRATED CARE
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HOGE VERWACHTINGEN VAN INTEGRALE ZORG
Een onderzoek van aannames over de effecten van integrale zorg voor kwetsbare oudere mensen op formele en informele zorgverleners

PROEFSCHRIFT

ter verkrijging van de graad van doctor aan de
Erasmus Universiteit Rotterdam
op gezag van de rector magnificus

Prof.dr. H.A.P. Pols

en volgens besluit van het College voor Promoties.
De openbare verdediging zal plaatsvinden op

26 april 2018, 15.30 uur

Benjamin Janse
geboren te Vlissingen

Erasmus University Rotterdam

PROMOTIECOMMISIE

Promotor
Prof.dr. R. Huijsman

Overige leden
Prof.dr. N. J. A. van Exel
Prof.dr. L. C. P. M. Meys
Prof.dr. M. M. N. Minkman

Co-promotor
Dr. I. N. Fabbricotti

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GENERAL INTRODUCTION

CHAPTER I

INTRODUCTION

Caring for the growing number of frail elderly people in the Netherlands is becoming increasingly challenging. The frail elderly suffer from a myriad of health, social and psychological problems that require a range of services from different organizations and caregivers over a prolonged period of time [1]. Professional or 'formal' caregivers however operate in a health system that is typically fragmented and focused on acute, short-term and reactive patient care [2]. Ongoing specialization and the segmentation into primary, secondary, health and social care foster professional territorialism and ethnocentricity and inhibit inter-professional collaboration [3-7]. Shortcomings in continuity, communication and coordination among different services lead to inefficiency, delays, errors, and inappropriate care. Caring for frail elderly patients is therefore typically time-consuming and frustrating for formal caregivers, adding to their already considerable workload and increasing the risk of job dissatisfaction and burnout [8, 9]. Meanwhile, the trend to replace institution-based care with community-based services means that care delivery for the frail elderly increasingly takes place in their own homes [10, 11].

At home, the frail elderly receive the greater part of care from their partner, family or close friends [12]. These 'informal' caregivers perform increasingly intensive and demanding care tasks over a prolonged period of time as the frail older person becomes progressively disabled [13,14]. Many informal caregivers of the frail elderly are therefore at risk of overburdening and experience deteriorations in health, functioning and quality of life [15-20]. However, the needs of informal caregivers are often overlooked by formal services, and many informal caregivers lack the information, equipment and support needed to cope with their caregiving responsibilities [11-13]. The shift towards the patient's home also means that care for the frail elderly is increasingly provided by both formal and informal caregivers [21,22]. This requires a degree of coordination and collaboration between formal and informal care that does not naturally occur in community care settings. Moreover, difficulties may arise due to conflicting views regarding the services needed and the division of tasks, mutual distrust and lack of confidence [23,24]. New care models for the frail elderly therefore aim to coordinate formal and informal care, often through the development of integrated care arrangements [25].

Integrated care is commonly defined as a 'coherent set of methods and models on the funding, and the administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment, and collaboration within and between the cure and care sectors' [26]. The underlying rationale is that a single service provider is unable to meet all care demands of a patient, and that all providers must combine their efforts in a coordinated manner [27,28]. The integration of health and social care services is considered a viable strategy to improve satisfaction, quality of life and health outcomes, particularly for the frail elderly [29-31]. However, not only patients are believed to benefit from integrated care but those who provide it as well. This view of integrated care as a mutually beneficial enterprise is based on three underlying assumptions relating to formal and informal caregivers and the relationship between them.

THREE UNDERLYING ASSUMPTIONS

Integrated care approaches for the frail elderly aim to incorporate the patient's entire social environment in the care process, promoting the active involvement of informal caregivers in care planning and decision-making [31]. This also offers more opportunities to improve informal caregivers' caregiving competence and coping abilities by providing the necessary support, advice and equipment to perform their care tasks, and adequate information regarding and access to available services [32]. Moreover, the proactive nature of integrated care enables the timely recognition of informal caregivers' unmet needs, based on which a new configuration of care tasks can be established that is more compatible with their wishes, abilities and personal lives [33-36]. It is this explicit focus on support and involvement to improve the caregiving situation through which integrated care arrangements are believed to protect against overburdening and other negative impacts of caregiving [11,12, 28-30]. In other words, the first assumption holds that:

> *Integrated care for the frail elderly safeguards informal caregivers against the negative impacts of caregiving.*

Integrated care delivery for the frail elderly is also believed to improve the work situation and experiences of formal caregivers. A more integrated process of care delivery ideally involves less inefficiency and duplication, relieves formal caregivers of certain administrative tasks in favor of patient-related activities, and reduces their overall workload [37-40.] Moreover, integrated working allows formal caregivers to overcome shortcomings in continuity, coordination and communication through inter-professional collaboration, making frail elderly care less time-consuming and frustrating [37,38]. Integrated care delivery is also thought to provide a wider scope of professional development and more opportunities to deliver patient-centered care, resulting in a more rewarding overall professional experience [41-43]. The second assumption is therefore that:

> *Integrated care for the frail elderly improves the work experiences and processes of formal caregivers.*

Integrated care arrangements aim to establish collaborative working relationships between formal and informal caregivers in order to achieve the degree of coordination and continuity that community-based frail elderly patients need [24-27]. Ideally, informal caregivers become an integral part of the care team, functioning as 'co-workers' of formal caregivers rather than 'co-patients' in need of care themselves [23]. As the interactions between formal and informal care increase in frequency and quality, formal caregivers shift their focus from reactively reducing deficiencies in informal care to proactively supporting and collaborating with informal caregivers. Informal caregivers, in turn, informal caregivers are better prepared and feel more competent to perform their care activities [44-46]. Over time, formal and informal caregivers renegotiate and redistribute the total care load based on each caregiver's particular competencies and characteristics [47]. The third assumption can be summarized as follows:

Integrated care for the frail elderly improves the interaction between formal and informal care.

However, doubts have also arisen about the assumed benefits of integrated care for formal and informal caregivers. Specifically, the question can be raised to what degree informal caregivers can be expected to become actual co-workers of formal caregivers in the delivery of integrated care for the frail elderly. For most informal caregivers, this likely involves an increase in care responsibilities and a more active role in decision-making and the planning, coordination and provision of care. Integrated care has therefore been argued to demand more inputs of time and energy from informal caregivers rather than less [32], thereby only increasing burden and further deteriorating the caregiving situation [11,48]. Similarly, it has been noted that integrated care delivery may actually have undesirable impacts on formal caregivers. These concerns stem from the idea that integrated care requires professional roles, practices and philosophies to be reshaped, and formal caregivers to acquire new routines and methods [4,37,39]. Formal caregivers may experience an erosion of their professional identity and autonomy and increased dissatisfaction [49]. Moreover, integrated care delivery might create more work rather than less work, as it implies additional coordination and communication activities that may increase inefficiency and duplication, making coordination more time-consuming [39,50-52]. Finally, the relationship between formal and informal caregivers may actually deteriorate as a result of integrated care delivery. Formal caregivers may continue to view informal caregivers primarily as co-patients rather than co-workers, using integrated care as a pretext to impose services on them [23]. Informal caregivers may distrust or have little confidence in formal caregivers, as a result of which they may increasingly isolate themselves and the elderly patient from formal services [23,24].

Although there is a wealth of literature indicating that integrated care can, in fact, improve the outcomes and quality of elderly care [36, 53-55], it remains unclear whether the assumptions regarding the benefits for formal and informal caregivers are justified. Relevant empirical evidence is limited due to a myopic focus on patient outcomes in research of integrated care. As a result, the concept of integrated care has become largely synonymous with its intended outcome, integrated *patient care* [3]. To fully understand the theoretical and empirical implications of integrated care for the frail elderly, its underlying assumptions regarding the impacts on formal and informal caregivers require further investigation. Besides the apparent scientific relevance of this investigation, it may also serve to inform a more realistic approach to integrated care practice and policy targeted at the frail elderly in communities.

AIM AND RESEARCH QUESTIONS

This main aim of this dissertation was to determine whether the expectations of integrated care for formal and informal caregivers are justified by investigating three corresponding assumptions. Based on extensive literature each assumption was operationalized into research questions involving a selection of outcomes for formal and informal care. These research questions were subsequently evaluated in the real-life setting of an integrated care intervention targeting frail elderly patients. The literature indicates that the impacts of integrated care on informal caregivers primarily involve objective and subjective burden, perceived health and quality of life [11,12,28-30]. Furthermore, improvements in care and support due to integrated care delivery are believed to impact informal caregivers' consumer satisfaction rates [36]. For formal caregivers, the main impacts are 'integration processes' (e.g. inter-professional coordination, communication, collaboration), satisfaction with care delivery, objective burden and job satisfaction [38-43]. Finally, changes in the interaction between formal and informal care have previously been operationalized as changes over time in the amount and type of care activities of caregivers [34]. The following research questions were thus formulated to investigate the three assumptions:

Assumption 1. *Integrated care for the frail elderly safeguards informal caregivers against the negative impacts of caregiving:*

- **Research Question 1:** What are the effects of an integrated care intervention for the frail elderly on the informal caregivers' perceived health, objective burden, subjective burden and quality of life?
- **Research Question 2:** What are the effects of an integrated care intervention for the frail elderly on the informal caregivers satisfaction with care and support?

Assumption 2. *Integrated care for the frail elderly improves the work experiences and processes of formal caregivers:*

- **Research Question 3:** What are the effects of an integrated care intervention for the frail elderly on the formal caregivers' perception of and satisfaction with integration processes?
- **Research Question 4:** What are the effects of an integrated care intervention for the frail elderly on the formal caregivers' objective burden and job satisfaction?

Assumption 3. *Integrated care for the frail elderly changes the interaction between formal and informal care:*

- **Research Question 5:** How does an integrated care intervention for the frail elderly affect the amount and type of formal and informal care over time?

THE INTERVENTION

The intervention that was used to answer the research questions was called the 'Walcheren Integrated Care Model' (WICM). The WICM was implemented in the Walcheren region of the Netherlands in 2010, and was specifically designed to target community-dwelling frail elderly people and their informal and formal caregivers. The aim of the WICM was to improve the quality and effectiveness of care for independently living frail elderly patients through the development, implementation and evaluation of an integrated care model in the region. Improvements in care quality and effectiveness were expected to benefit frail elderly patients and informal caregivers, and participating formal caregivers and organizations.

The WICM was deemed an appropriate real-life setting to investigate the impacts of integrated care on formal and informal caregivers because it is a comprehensive model that transcends different sectors and segments of the healthcare system and bridges financial, organizational, and professional boundaries. More specifically, the WICM incorporates all elements that have previously been proven effective; it includes the entire care continuum from prevention to care delivery; it explicitly involves and supports informal care; it changes funding, work processes, professional domains and roles; and it recognizes the importance of positive social relationships, a shared culture, goals and interests among formal caregivers to achieve integrated care. The following section describes usual care for the frail elderly and integrated care according to the WICM. Further details regarding the WICM can be found in the research protocol (Chapter 2) and the subsequent chapters of this dissertation.

USUAL CARE

Despite continuous efforts to improve primary care in the Netherlands, 'usual' care for frail elderly people in communities can still often be characterized as reactive, fragmented and mono-disciplinary. Elderly people and their informal caregivers typically consult with their general practitioner (GP) on their own initiative. These patients have access to a number of care and curative services through referral of their GP, whereas home-care services can be obtained from municipalities [56]. Primary care practices (PCPs) consist of one or several GPs supported by practice assistants. Many PCPs also include specialized nurses that manage their own population of patients with a particular chronic illness (e.g., COPD, heart failure, Diabetes Mellitus). Most GPs lack specialist geriatric knowledge, and it is usually not included in post-graduate education for GPs. Complex home-care services (e.g. injections, wound dressing) are available only after formal approval of an assessment agency. Home-care organizations deploy small community-based teams consisting of (specialized) nurses and domestic helpers that provide services ranging from around-the-clock supervision, specialized nursing care, home rehabilitation, to meal services, personal care, domestic assistance. However, primary care, home/community-based care services are generally provided separately, without structural coordination and communication between the organizations and formal caregivers involved. The funding of cure and care, social and health care, and welfare and housing is equally fragmented. Available support services for informal caregivers typically include respite care, psychosocial education, competence training and (group) counseling. Few informal caregivers are, however, aware of such support services. Moreover, informal caregivers of the frail elderly typically seek out formal support relatively late in the patient's care trajectory, when the caregiving situation has become unmanageable [21].

THE WICM

In contrast to usual care, the WICM had an outspoken proactive, integrative and multi-disciplinary character. A range of components was implemented to achieve integration at the financial, administrative, organizational, service-delivery and clinical level. To overcome fragmentation in funding, the regional health insurer ('CZ') provided an experimental financial module through which formal caregivers received remuneration for additional intervention-related costs. Administrative and organizational integration was achieved through the creation of a formal steering group and a geriatric care network. The steering group represented all professional groups involved in the WICM and oversaw the development and implementation of the WICM. The steering group formed the 'Joint Governing Board' of the geriatric care network, which was strengthened with consensus-based guidelines and formal agreements. The network consisted of participating PCPs, a hospital, a nursing home, the three largest regional home-care organizations, a mental health organization, allied health practices, and associations for elderly patients, informal caregivers and volunteers.

Integration at the service-delivery and clinical level involved the GP as single-entry point, frailty screening, comprehensive needs assessments, case management, individualized care plans, multi-disciplinary team meetings and care protocols, a shared ICT system, task specialization and task delegation. The PCP served as single-entry point and central 'hub' of the WICM, becoming the gateway through which elderly patients, informal caregivers and other formal caregivers could access information about and expertise of all health and social care providers. GPs identified frail elderly patients, led the multi-disciplinary team meetings held at PCPs, and made sure the proposed treatment plans were harmonized with elderly patients and informal caregivers. Moreover, GPs worked in close collaboration with case managers to ensure the adequate execution of treatment plans. These case managers were specialized geriatric nurse practitioners that worked for the PCPs. Tasks related to the coordination and planning of care, patient monitoring and managing medical records were delegated from GPs to case managers. Case managers were thus responsible for the timely and correct screening and assessment (using evidence-based instruments [56,57]) of frail elderly patients and their informal caregivers, and proposing individualized treatment plans to the multidisciplinary team. The core team consisted of the GP, case manager and the community nurse, and could be expanded with other formal caregivers relevant to the treatment plan (e.g. geriatrician, physiotherapist, nursing home doctor, psychologist). The community nurse represented home-care organizations and acted as liaison between home-care personnel and the WICM team. A shared information and communication system allowed formal caregivers to access and make adjustments to the patients' treatment plans, of which the entire team then received a notification – providing them with accurate and up-to-date patient information.

Upon the implementation of the treatment plan, the case manager was responsible for ensuring admittance to the required services, care planning and delivery, monitoring of the care situation and periodical evaluation of the treatment plan (at least every 6 months). The case manager arranged the team meetings and supported the necessary exchange of information among various formal caregivers. The responsibilities of GPs and case managers (and other formal caregivers involved) were formalized in protocols and predetermined referral agreements. To adequately fulfill their central role in the WICM, GPs completed an executive training in geriatric care, a course in GP consults, and received training in the use of the evidence-based (screening and assessment) instruments. GPs gained insight into the associations between diseases and the daily functioning of frail elderly patients, and how to provide an integrated response to their needs by reshuffling tasks between primary, secondary and tertiary care. All case managers were registered nurses who had specialized in geriatric care, and all received additional training in case management and the use of the evidence-based instruments. PCP-based nurses focused on 'single-disease' case management, whereas hospital-based geriatric nursing specialists focused on 'complex care' case management. GPs and case managers had access to specialist knowledge of a hospital geriatrician that was available for consultations, further strengthening the link between primary care and hospital care.

For informal caregivers, the WICM entailed an explicit attention to their needs and their importance in the care delivery process for the frail elderly. The first contact with the WICM is when the case manager visits the elderly patient at home to perform the assessment, in which the informal caregiver's needs and preferences are also identified. Informal caregivers are actively involved in the formulation of care goals and are encouraged to make suggestions for the treatment plan. After implementation of the treatment plan, informal caregivers remain involved in decision-making and care planning, coordination and delivery. Informal caregivers receive information and suggestions from case managers regarding available services based on their needs, and are linked to the relevant provider if needed. Informal caregivers may also receive practical advice and education from the case manager to improve coping and caregiving competencies. If needed, suggestions for additional interventions are discussed with the elderly patient and informal caregivers (e.g. temporary respite service if the informal caregiver is acutely overburdened). The case manager regularly reassesses the care situation with elderly patients and informal caregivers (by visit or phone), but is also available to them in between these evaluations.

DISSERTATION OUTLINE

The five research questions (RQ) are addressed in the ensuing chapters. This dissertation is thus organized as follows:

Chapter 2 describes the research protocol for the evaluation study of the 'Walcheren Integrated Care Model', providing details relating to the intervention components, outcome measures and expected results.

Chapter 3 reports the impacts of the 'Walcheren Integrated Care Model' on the objective burden, subjective burden, perceived health and quality of life of informal caregivers (RQ1). **Chapter 4** reports the impacts of the 'Walcheren Integrated Care Model' on the informal caregivers' satisfaction with care and support. A new measure was developed based on theoretical literature on informal caregiver satisfaction (RQ2).

Chapter 5 describes the evaluation of the impacts of the 'Walcheren Integrated Care Model' on the perception of and satisfaction with integration processes among formal caregivers (RQ3). Again, a new measure was developed based on the theoretical literature. **Chapter 6** presents the impacts of the 'Walcheren Integrated Care Model' on the job satisfaction and objective burden of formal caregivers (RQ4). This evaluation study involved questionnaires and an extensive analysis of comprehensive data from administrative systems.

Chapter 7 explores how 'Walcheren Integrated Care Model' affects formal and informal care over time (RQ5). This evaluation involved a comparison of the changes over time in the type and amount of formal and informal care in the 'integrated' and 'usual' care setting.

Chapter 8 provides a general discussion of the main study findings, methodological and theoretical considerations, and implications for research and practice.

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INTEGRATED CARE for FRAIL ELDERLY compared to USUAL CARE: a STUDY PROTOCOL of a QUASI-EXPERIMENT on THE EFFECTS on the FRAIL ELDERLY, THEIR CAREGIVERS, HEALTH PROFESSIONALS, and HEALTH CARE COSTS

CHAPTER

II

Fabbricotti, I.N., Janse, B., Looman, W.M.,
de Kuyper, R., Van Wijngaarden, J.D.H., Reiffers, A.
BMC Geriatrics 2013, 13:3

ABSTRACT

BACKGROUND

Frail elderly persons living at home are at risk for mental, psychological, and physical deterioration. These problems often remain undetected. If care is given, it lacks the quality and continuity required for their multiple and changing problems. The aim of this project is to improve the quality and efficacy of care given to frail elderly living independently by implementing and evaluating a preventive integrated care model for the frail elderly.

METHODS AND DESIGN

The design is quasi-experimental. Effects will be measured by conducting a before and after study with control group. The experimental group will consist of 220 elderly of 8 GPs (General Practitioners) who will provide care according to the integrated model (The Walcheren Integrated Care Model). The control group will consist of 220 elderly of 6 GPs who will give care as usual. The study will include an evaluation of process and outcome measures for the frail elderly, their caregivers and health professionals as well as a cost-effectiveness analysis. A concurrent mixed methods design will be used. The study population will consist of elderly 75 years or older who live independently and score a 4 or higher on the Groningen Frailty Indicator, their caregivers and health professionals. Data will be collected prospectively at three points in time: T0, T1 (3 months after inclusion), and T2 (12 months after inclusion). Similarities between the two groups and changes over time will be assessed with t-tests and chi-square tests. For each measure regression analyses will be performed with the T2-score as the dependent variable and the T0-score, the research group and demographic variables as independent variables.

DISCUSSION

The biggest potential obstacle for this study will be the willingness of the elderly and their caregivers to participate. To increase willingness, the request to participate will be sent via the elders' own GP. Interviewers will be from their local region and gifts will be given. A successful implementation of the integrated model is also necessary. The involved parties are members of a steering group and have contractually committed themselves to the project. Trial registration Netherlands Organization for Health Research and Development: ZonMW313030201

BACKGROUND

With an aging population, caring for the increasing number of the frail elderly is a challenge for the Dutch healthcare system [1,2]. The frail elderly are those with a disease or infirmity associated with advanced age, which is manifested by demonstrable mental, psychological, emotional or physical dysfunction to the extent that the person is incapable of adequately providing for his or her own health and personal care presently or in the near future [3,4]. In 2010, 16% (2.6 million) of the Dutch population was 65 years or older, of which 10% was 75 years or older and 7% was 80 years or older [5]. Of the elderly population in 2010, 25% were considered frail. As a result of reduced mortality rates and the demographic shift, there will be a higher frail population in need of long-term care in the near future. The percentage of the frail elderly is estimated to increase to 68% in 2030 [6]. In the meantime, the demand for services already strains the professional workforce and caregiver burden [7-9].

The frail elderly are an important group within the elderly population because their diminished compensation capacities make them, their caregivers, and society most able to benefit from changes in social and healthcare arrangements [10,11]. Due to their complex and continuously changing health and social problems, the frail elderly need a wide range of services over a long period of time [12]. However, the reluctance of the frail elderly to report their growing impairments to their doctors impedes interventions at a stage when preventive care could diminish further mental, psychological or physical deterioration [13]. Approximately 30% of the Dutch frail elderly receive no domestic, personal, home or private care [14]. They solely rely on their own judgment or that of their caregivers for seeking help or for performing their daily activities. Timely recognition of unmet needs can avoid crisis situations or the overburdening of the caregiver. It can also improve social wellbeing [15-17].

Changes also occur in the attitudes of the elderly toward care. These changes also necessitate changes in the organization of care. The frail elderly no longer silently accept the care that they are given and now demand their care meets their needs. Patient-centeredness has become a legitimating base for healthcare provision and has been reinforced by laws that strengthen patient’s rights. These laws also force providers to provide the care that the elderly want and need at the right time and place [5,18-20]. A supply-oriented approach and the fragmentation in the organization of the elderly care today inhibit progress on this issue. Service is still often characterized by a lack of continuity and coordination on the behalf of involved providers. Responsibility for the whole continuum of care is absent and results in inefficient and ineffective care [21,22]. The specific needs of the frail elderly and their caregivers, budget restraints and patient-centered views call for new and more effective organizational structures.

The integration of health services and social services for the frail elderly has gained tremendous attention as a means to accomplish this. There is a widespread belief that the integration of these will enhance satisfaction, quality of life, efficiency, and health outcomes and will also decrease costs [23-26]. The rationale behind this stems from the fact that a single service provider is usually unable to respond to all the needs. This prohibits efficiency in the delivery process. To meet the multiple needs of the frail elderly in an efficient and effective manner, some claim that numerous service providers will need to combine their efforts in a coordinated manner [27-29]. There is also mounting evidence that confirms beliefs that the development of integrated care arrangements can be cost effective and enhance quality [30-38].

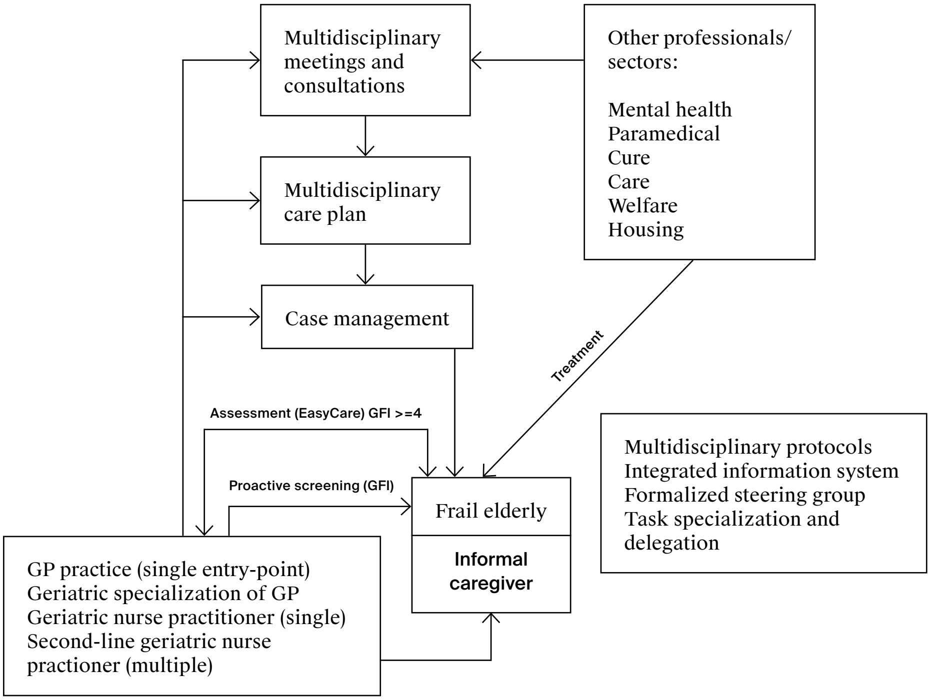
Though widely acknowledged and pursued, the implementation and evaluation of integrated services for the frail elderly has not yet reached its full potential. Much is still unknown regarding how services can be integrated and the effects of integration. In this study, a new integrated model for the frail elderly, the Walcheren Integrated Care Model, will be developed and evaluated. Walcheren refers to the region in the Netherlands where the study takes place. The Walcheren Integrated Care Model is in accordance with scientific evidence and addresses the design elements that affect the quality of care. It has an umbrella organizational structure involving case management, multidisciplinary teams, protocols, consultations, and patient files. It will be an organized provider network with evidence-based needs assessments [29,32,33]. All elements are embedded in the model. However, more types of health professionals participate in the model than other studies have previously investigated. General practitioners, geriatricians, home health care workers, paramedics, social workers, pharmacists, and mental health care professionals all take part in the designed model. In contrast with other models, this model also contains a preventive element: a screening tool to detect frailty in the elderly. Finally, the model is being evaluated on a broader range to obtain a comprehensive evaluation and determine possible trade-offs between effects.

This article describes the study design of the evaluation of the Walcheren Integrated Care Model compared with traditional care. The development and evaluation of the model are part of the National Care for the Elderly Program (NPO), which is funded by the Netherlands Organization for Health Research and Development (ZonMW; project number 313030201).

THE INTERVENTION

The Walcheren Integrated Care Model (WICM) is a comprehensive integrated model for the detection and assessment of needs and the assignment and evaluation of care for independently living frail elderly. The model comprises ten elements: a screening tool for the detection of frailty in the elderly, a single entry point, an evidence-based comprehensive need assessment tool, a multidisciplinary individualized service plan, case management, multidisciplinary team consultation and meetings, protocol-led care assignment, a steering group, task specialization and delegation, and a chain computerization system (see figure 1).

FIGURE 1. The Walcheren Integrated Care Model



The frail elderly aged 75+ years are identified by their general practitioner (GP) by the Groningen Frailty Indicator (GFI), a tool for the detection of frailty. The GFI is a 15-item questionnaire that measures decreases in physical, cognitive, social, and psychological functioning. Scores can range from 0 to 15 39,40. A geriatric nurse practitioner that works at the GP practice sends the GFI questionnaire to the homes of the elderly and then contacts them by telephone if they do not respond. When necessary, elderly are helped at home to complete the questionnaire. A geriatric nurse practitioner and GP calculate the GFI score. Elderly with a GFI ≥4 are identified as frail and assigned to a case manager. The geriatric nurse practitioner is the case manager for elderly with single needs. A secondary line geriatric nursing specialist is assigned as case manager if the needs are multiple or of a complex nature. The case manager then sets up a meeting with the elderly to assess their needs with the EASYcare instrument. EASYcare is an evidence-based comprehensive need assessment instrument that assesses (instrumental) activities of daily life, cognition, and mood. It also contains a module for converting care requirements relating to welfare, residence, and care into treatment goals[41]. The goals are drawn up in consultation with the elderly and their caregivers. Explicit attention is paid to the necessary support and guidance of the caregivers. The results of the assessment are described by the case manager in an individualized care plan. The case manager also creates a proposal for required care and care objectives.

The proposed plan is then discussed in a multidisciplinary meeting led by the GP. Depending on treatment goals, the meeting is also attended by other health professionals who may be needed. During the meeting, a multidisciplinary care plan will be approved, actions and care paths will be discussed, and agreements will be made about the care to be deployed and the activities of all persons involved.

The treatment plans of each professional are included in the care plan. The GP harmonizes the care plan with the elderly and their caregiver and obtains permission for its implementation. A chain computerization system accessible by the health professionals involved will be used for the multidisciplinary care plan. The professionals will automatically receive an email in the event of changes in use of care or a transfer.

The case manager is responsible for admittance to the required services, the planning and coordination of care delivery, and periodical evaluation of the care plan. Thus, the case manager arranges obligatory need assessment, monitors the elderly at least every six months for one year, and supports the multidisciplinary team by arranging meetings and streamlining the necessary exchange of information. The responsibilities and activities of the involved professionals and case manager are formalized in agreed protocols with predefined modes of referral and collaboration. During the process, the GP practice functions as a single entry point. It is the gate through which elderly and professionals can access the expertise and services of all health and social care professionals and organizations. The GP and case manager work in close collaboration to ensure timely and correct care assessment and provision. To be able to fulfill their tasks, the GPs must have completed an executive training in geriatric care, a course in GP consults and EASYcare training. The case managers must have successfully attended the EASYcare training and a course in case management.

METHODS AND DESIGN

AIM

The aim of the project is to improve the quality and efficacy of care given to frail elderly living independently by their caregivers and health professionals. It seeks to do this by implementing, evaluating, and disseminating an integral care model for the frail elderly. Living independently is defined as living at home or in a sheltered accommodation without receiving other forms of integrated care. The research questions for the evaluation study is as follows: What are the effects of the Walcheren Integrated Care Model on the caregivers, health professionals, the organization of care and the healthcare costs for the frail elderly, and what are the effects on the quality and efficacy of the care given to the frail elderly living independently?

STUDY DESIGN

The study has a quasi-experimental design in which the effects will be measured before and after the study. A control group will also be used. The study includes an evaluation of process and outcome measures for the frail elderly, their caregivers, and health professionals, as well as a cost-effectiveness analysis. To evaluate the effects, a combination of qualitative and quantitative research methods will be used. (See tables 1-4).

POWER CALCULATION

We will include 220 elderly in both the experimental and control group. We expect a 10% loss to follow-up (due to mortality, re-housing, impossibility or unwillingness to participate further) between inclusion and T1 and a 20% loss between T1 and T2. The sample is sufficient to detect changes in our primary measure of quality of life. Assuming an average effect size of 0.5 and significance of 5%, this gives a power of 0.997. If we assume a small effect size of 0.3 with a significance of 5%, this still supplies sufficient power at 0.837. Interfering variables will also play a role. At an average effect size (f2) of 0.15 and significance of 5%, assuming five independent variables, the power is 0.97. Even with 15 independent variables, the power remains sufficient at 0.856.

STUDY SAMPLE: SAMPLING AND ELIGIBILITY CRITERIA

Sampling will take place at GP practices in Walcheren. The experimental group will consist of the elderly patients of 8 GPs from 3 GP practices located in the east of Walcheren who will provide care according to the WICM. The control group will consist of 6 GPs from 5 GP practices in the north, south, and west of Walcheren who will provide traditional care. All elderly aged 75+ years in these practices who live independently will be asked to complete the GFI, along with several demographic questions and a consent form. Approximately 900 elderly in both the experimental and control practices will be contacted. The questionnaire is accompanied by a letter from the GP to raise the likelihood of response and assure that the elderly are well informed. After being sent a reminder, the elderly will be contacted by telephone or visited at home to be asked to participate and to help complete the questionnaire if necessary. These activities are expected to result in an 80% response rate. Elderly will be included if they score ≥4 on the GFI, if they have signed the consent form, or if they are able to make that decision themselves. Exclusion criteria are as follows: elderly on a waiting list for a nursing home, elderly who are not able to decide themselves if they want to participate (e.g., in case of dementia), and elderly with a life expectancy of <6 months due to a terminal illness. Included elderly will be asked to provide contact information for their informal caregiver. The caregivers will be contacted either by telephone or face-to-face during the first visit from the researchers at the home of the elderly subjects. They will be asked to fill in a written consent form if they agree to participate. Non-respondents will be contacted again by telephone. A response rate of 60% is expected. Health professionals will be selected based on their function and region of employment. An estimated 400 questionnaires will be sent to health professionals in the experimental and control groups. We expect a response rate of 50%.

DATA COLLECTION AND INSTRUMENTS: THE FRAIL ELDERLY

Outcome data and data on demographics (age, sex, living arrangement, education, and marital status) will be collected with questionnaires and file research at three points in time: T0, T1 (3 months after inclusion), and T2 (12 months after inclusion). Research has shown that effects can be expected 3 months after starting to use the EASYcare instrument [41]. The T2 measurement takes place to determine long-term effects. All elderly will be visited at home by trained interviewers recruited from the region of Walcheren to ensure a cultural fit with the elder. Interviewers will have a background in healthcare to ensure a high-quality interview. Every elder will be given a gift at T1 as a token of appreciation and to motivate further participation. File research will occur at the GP practices. The following instruments will be used (see table 1):

PERCEIVED HEALTH

SF-36 The SF-36 measures eight concepts: physical functioning, bodily pain, role limitations due to physical, personal, and emotional health problems, emotional well-being, social functioning, energy/fatigue, and general health perceptions [42,43]. The items regarding perceived current health and changes in health will be used.

SOCIAL FUNCTIONING

SF-36 The SF-36 question on social functioning 'During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?' will be used.

MENTAL WELLBEING

SF-36 The 5-items scale on emotional wellbeing from the SF-36 will be used.

QUALITY OF LIFE

ICECAP The ICECAP instrument was developed for elderly and measures their quality of life using the following 5 dimension on the capacity to perform certain actions and achieve certain states: attachment, security, role, enjoyment, and control. Each dimension consists of one question that can be scored on four levels [44].

EQ-6d The EuroQol (EQ6D) is used to measure quality of life in terms of valued health and is composed of the dimensions mobility, self-care, usual activities, pain/discomfort, anxiety/depression, and cognitive functioning [45,46]. Each dimension is scored on three levels: 'no problems,' 'some problems,' and 'severe problems.' The EQ-6d will also be used to calculate cost-utilities of health care.
SF-36 Questions based on the SF-36 on perceived current quality of life and the quality of life compared with one year ago will be used.

Cantril's self-anchoring ladder Perceived quality of life will be measured with the Cantril's ladder, a measurement technique that asks subjects to mark their satisfaction with life from 0 to 10 [47].

PHYSICAL FUNCTIONING

KATZ-15 The Katz-15 will be administered to measure physical functioning by means of 15 yes or no questions covering domains of activities of daily functioning, such as bathing, transferring, eating, and dressing [48,49].

HEALTH CARE USE

Questions on self-reported use. Use of healthcare will be measured with 16 questions regarding the use of seven domains of care (hospital admissions, unplanned care, respite care, medical, paramedic, psychosocial care, and daycare). Elderly will be asked if they make use of care, and if so, how often (in days or hours depending on the type of care).

File research The files of the elderly from the GPs will be analyzed regarding health care use. Data will be collected on the same domains as described above and compared with self-reported use.

TABLE 1. Outcome measures and data collection frail elderly

OUTCOME AND INSTRUMENT	METHOD	DATA COLLECTION TIME		
		T0	T1	T2
PRIMARY OUTCOMES				
QUALITY OF LIFE				
ICECAP	interview elderly	x	x	x
EQ-6d	interview elderly	x	x	x
SF-36	interview elderly	x	x	x
Cantril's self-anchoring ladder	interview elderly	x	x	x
SECONDARY OUTCOMES				
PERCEIVED HEALTH				
SF-36	interview elderly	x	x	x
SOCIAL FUNCTIONING				
SF-36	interview elderly	x	x	x
MENTAL WELL BEING				
SF-36	interview elderly	x	x	x
PHYSICAL FUNCTIONING				
KATZ-15	interview elderly	x	x	x
HEALTH CARE USE				
Self-reported	interview elderly	x	x	x
Reported by GP	file research	x	x	x

DATA COLLECTION AND INSTRUMENTS: CAREGIVERS

Outcome data and demographic data (e.g., age, sex, income, relationship, and living with loved one) from the caregivers will be collected with questionnaires at three time points: T0, T1 (3 months after inclusion), and T2 (12 months after inclusion). Caregivers will be sent a questionnaire or interviewed at the same time as the elder at their home. Caregivers will also be given a gift at T1. The questionnaire is composed of the following instruments (see table 2):

PERCEIVED HEALTH

SF-36 As for the elderly, the items on perceived current health and changes in health from the SF-36 health survey will be used.

OBJECTIVE BURDEN

Short version Erasmus iBMG instrument "objective burden informal care" This instrument measures and divides the time spent on the elderly into the following domains: household tasks, personal care, help with moving and contacts with family, friends and health care providers, and medical technical tasks [50]. Caregivers will be asked if they give help, and if so, how many hours per week.

SUBJECTIVE BURDEN

Carer-Qol: The CarerQol will be used to measure the impact of informal care [51,52]. The CarerQol-VAS assesses happiness with a horizontal Visual Analogue Scale (VAS) with 0 (‘completely unhappy’) and 10 (‘completely happy’) as endpoints. The CarerQol-7d describes seven dimensions of burden: fulfillment, support, relational and mental health problems, problems with combining daily activities, finances, and physical health. The answer categories are ‘no’, ‘some’ and ‘a lot of problems.’

Self-related burden VAS (SRB) The SRB will be used to measure the overall perceived burden. The SRB asks how straining the care for the loved one is with a horizontal VAS ranging from 0 (‘not straining at all’) to 10 (‘much too straining’) 53.

Caregiver Strain Index+ (CSI+) The CSI+ will be used to measure perceived strain. The CSI+ is an extended version of the 13-item instrument CSI, which only measures negative dimensions of the caregiver situation. The CSI+ adds 5 items on positive dimensions covering the areas of patient characteristics, subjective perceptions of the care-taking relationship by caregivers, and emotional health of caregivers [54,55].

Question on perseverance time The question of how long the caregiver anticipates being able to pursue his tasks as a caregiver will be asked, with answers ranging from less than two weeks to more than two years [56].

Assessment of the informal care situation (ASIS) To assess the desirability of the caregiving situation, the ASIS will be used, which is a horizontal VAS ranging from 0 (‘worst imaginable caregiving situation’) to 10 (‘best imaginable caregiving situation’) [51].

QUALITY OF LIFE

The same *SF-36* based questions and Cantril’s self-anchoring ladder for the elderly will be used.

USE OF COMMUNITY SERVICES

Community Service Attitude Inventory (CSAI): The CSAI is a 25-item Likert-type scale that will be used to measure the attitude and willingness of caregivers toward the use of community services [57]. *Survey question*: Caregivers will be asked if they use community services.

DATA COLLECTION AND INSTRUMENTS: HEALTH PROFESSIONALS

Data on the outcomes will be collected from GPs, nursing home doctors, geriatrists, geriatric nurse practitioners, secondary line geriatric nursing specialists, specialists in hospitals, home care employees, mental health professionals, and paramedical specialties with the following instruments (see table 3):

KNOWLEDGE

Questionnaire At the end of the project, a questionnaire will be distributed to the health professionals involved in the experimental and control groups by their organization of employment. This will help ensure the privacy of contact information. The questionnaire is composed of two questions regarding the assessment of the health professional. It assesses his or her knowledge on the frail elderly and his or her knowledge of the roles and tasks of other health professionals involved in the care for the frail elderly. Answers are given for the current situation and the situation 18 months previously and are measured with a VAS ranging from 0 to 10.

JOB SATISFACTION

Job Satisfaction Scale The job satisfaction scale will be part of the questionnaire. This instrument is a 10-item questionnaire with questions on extrinsic and intrinsic job satisfaction [58,59]. Health professionals will be asked to assess how satisfied they are now and 18 months previously on a scale ranging from 1 ('extremely unsatisfied') to 7 ('extremely satisfied').

TABLE 2. Outcome measures and data collection caregivers

OUTCOME AND INSTRUMENT	METHOD	DATA COLLECTION TIME		
		T0	T1	T2
PERCEIVED HEALTH				
SF-36	interview caregiver or mailed questionnaire	x	x	x
OBJECTIVE BURDEN				
Short version iBMG instrument objective burden informal care	interview caregiver or mailed questionnaire	x	x	x
SUBJECTIVE BURDEN				
Carer-Qol	interview caregiver or mailed questionnaire	x	x	x
SRB	interview caregiver or mailed questionnaire	x	x	x
CSI+	interview caregiver or mailed questionnaire	x		x
Perseverance time	interview caregiver or mailed questionnaire	x		x
ASIS	interview caregiver or mailed questionnaire	x		x
QUALITY OF LIFE				
SF-36	interview caregiver or mailed questionnaire	x	x	x
Cantril's self-anchoring ladder	interview caregiver or mailed questionnaire	x	x	x
USE OF COMMUNITY SERVICES				
Self-reported	interview caregiver or mailed questionnaire	x	x	x
CSAI	interview caregiver or mailed questionnaire	x		x

SUBJECTIVE BURDEN

Self-related burden VAS Inspired by the SRB, a similar VAS will be used to measure the overall perceived burden. As the SRB was developed for caregivers, the question will be transformed into the question ‘How straining is it to give care to the frail elderly?’ Scoring measures the current situation and the situation 18 months previously with a horizontal VAS ranging from 0 (‘not straining at all’) to 10 (‘much too straining’).

OBJECTIVE BURDEN

File research and questionnaire File research and the questions on healthcare use by the elder as mentioned above will be used to determine the time spent on care. For the time calculation, the volume of care will be multiplied by a mean time determined by consensus with the health professionals (e.g., 40 minutes per house visit by a GP).

Time tracking form The GPs, geriatric nurse practitioner and secondary line geriatric nursing specialist will also keep track of the time spent on managing cases and coordinating tasks, time spent on conferring with health professionals, and time spent on multidisciplinary meetings per elder. A time tracking format will be developed to this end.

TABLE 3. Outcome measures and data collection health professionals

OUTCOME AND INSTRUMENT	METHOD	DATA COLLECTION TIME		
		T0	T1	T2
KNOWLEDGE				
Self-constructed VAS	mailed questionnaire	x		x
JOB SATISFACTION				
Job satisfaction scale	mailed questionnaire	x		x
SUBJECTIVE BURDEN				
SRB	mailed questionnaire	x		x
OBJECTIVE BURDEN				
Self-reported by elder	interview elderly	x	x	x
Self-reported by professional	time tracking form	x	x	x
Reported by GP	file research	x	x	x

DATA COLLECTION AND INSTRUMENTS: COST-EFFECTIVENESS

The question that is central to the economic analysis is whether the WICM is cost-effective compared with traditional care. The outcome parameter used is cost per QALY (quality-adjusted life-year). For this, the EuroQol (EQ-6D) will be used to measure the quality of life of the elderly persons and will subsequently be converted into disability-adjusted life-years (DALYs). For the cost calculation, the volume of care will be linked to the actual, integral cost per medical service [60]. This will be used to make the instructions for cost research in economic evaluations 61. Thus, the total care consumption of the elderly will be determined. The above-mentioned patient files, questionnaire, and time tracking form will provide insight into which care was received per elder, how much and from whom.

DATA COLLECTION AND INSTRUMENTS: PROCESS INDICATORS

To determine the level of coordination, coherence, and satisfaction with care processes, the following process indicators will be measured with questionnaires, file research, interviews, diaries, and focus groups (see table 4):

DEGREE OF INTEGRATION

Questionnaire To determine the degree of coherence, continuity, and co-operation, a questionnaire will be developed based on a systematic review of integration indicators and instruments for measuring integration. The questions will be part of the questionnaire sent to the health professionals as described above. Health professionals are again asked to assess the current levels of integration and those 18 months previously.

TABLE 4. Process measures and data collection

OUTCOME AND INSTRUMENT	METHOD	DATA COLLECTION TIME		
		T0	T1	T2
DEGREE OF INTEGRATION				
Self-constructed questionnaire	mailed questionnaire	x		x
SATISFACTION HEALTH PROFESSIONALS				
Self-constructed questionnaire	mailed questionnaire	x		x
Relational coordination Survey	mailed questionnaire	x		x
Self-reported satisfaction	diaries	x	x	
	interviews			x
	focusgroups	x	x	x
SATISFACTION FRAIL ELDERLY				
CQ-index	interview elderly	x	x	x
Self-constructed questionnaire	interview elderly	x	x	x
SATISFACTION CAREGIVER				
CQ-index	interview caregiver or mailed questionnaire	x	x	x
Self-constructed questionnaire	interview caregiver or mailed questionnaire	x	x	x

HEALTH PROFESSIONALS' EXPERIENCES WITH THE QUALITY AND PROCESS OF CARE

Questionnaire Questions on satisfaction with the process of care and level of integration will be derived from the above-mentioned results of the systematic review. *Relational coordination survey for patient care* The quality of the relationships and communications between health professionals will be measured with the relational coordination survey for patient care, an instrument covering the following dimensions: shared goals, knowledge and respect, frequency and timing of communication, and problem-solving orientation of the communication [62,63].

Diaries The geriatric nurse practitioner and secondary line geriatric nursing specialist will be asked to keep a diary of their experience with the WICM. Every 3 months, a researcher will briefly interview the geriatric nurses over the telephone to discuss their experiences based on the diary.

Interviews After the completion of the experiment, interviews will be held with involved professionals. Discussions will cover their experience with the WICM, conducive and non-conducive factors that played a role and any adjustments that the model may require.

Focus groups For both the experimental and control regions, 3 focus groups will be organized for the health professionals and patient organizations involved. These focus groups will be used to gain insight into satisfaction with the model and its integration. The groups will also strengthen the analysis by reflecting on the results of the study.

THE FRAIL ELDERLY AND CAREGIVER EXPERIENCES WITH THE QUALITY AND PROCESS OF CARE

Consumer Quality Index (CQ-index) The CQ-index, a Dutch standardized method for measuring experiences of patients/clients with health care, will be used. Covered domains are quality of the health professionals, information, participation, treatment, communication, and received care [64,65]. CQ-questionnaires are developed for different types of care. The CQ-questionnaire for home care will be used as a reference point and be completed with questions on the coherence and coordination of care. Elderly will be asked at T0, T1, and T2 regarding their experience of the care and care processes. Caregivers will be asked at T0, T1, and T2 regarding their experiences of the care given to their elder and the care and attention that they receive from health professionals.

DATA ANALYSIS

The experimental and control groups will be described at every point in time with descriptive statistics. Similarity of characteristics between the two groups will be assessed with t-tests, chi-square tests, and Fisher's exact tests. Bivariate analyses and regressions with the demographic characteristics will determine multicollinearity and correlations with the process and outcome measures. All analyses will be controlled for differences in baseline characteristics and demographic characteristics. For the self-constructed questionnaires, factor analyses and reliability analyses will be performed to determine construct validity. To determine changes over time, t-tests will be performed for each process and outcome measure. For each measure, regression analyses will be performed with the T2-score as the dependent variable and the T0-score, the research group (experimental or control), and demographic variables as independent variables. With subgroup analyses, potential variation between study results between subgroups will be analyzed.

DISCUSSION

IMPLEMENTATION OF THE MODEL

The development, evaluation, and dissemination of the Walcheren Integrated Care Model depend on its successful implementation. Research has shown that the implementation of integrated care is a very difficult and laborious task [66,67], especially regarding the proposed model because it focuses on integration across the entire continuum of care for all frail elderly. Other developmental strategies mainly focus on small programs for a targeted group or on a small part of the care process [26].

Additionally, when integrated arrangements are being implemented successfully in one setting, one is often unable to achieve dissemination on a wider scale [32]. Furthermore, developing integrated care arrangements is as much a process of social and cultural integration as it is structural integration. The success of implementation is shaped by the interests and cultures of the health professionals and the social relationships between them. Integration involves aligning the work of health professionals and convincing them to work together from a patient-centered viewpoint [29,68]. Several activities are and will be deployed to ensure that these challenges are overcome.

The involved professionals are all represented in a steering group that forms the umbrella under which the model is developed and disseminated. The steering group forms a Joint Governing Board that provides the necessary provider network, which is further strengthened with guidelines and protocol-led agreements. All patient representatives support the project, and the health insurer CZ is supporting the project financially. The basis for collaboration is also laid down in the formalization of agreements on the regional policy and involves integrated care for all elderly: the so-called 'structured care of the elderly module.' The project follows from these structures and will be able to make use of them.

Though administratively secure, the project will eventually be affected by the willingness of the partners to review tasks and delegate and accept new responsibilities thrust upon them. Acceptance of the role of a GP as coordinator is an essential aspect of this. GPs cannot claim this coordinating role for themselves. It will have to be given to them based on the confidence of all 'players' and by an agreement that a coordinating role for the GP is a suitable mechanism for improving the care for the frail elderly. A basis for this has already been established. The Walcheren GP Co-operation Care Group, the GP Co-operation in Veere, a working group of elderly patients and various partners in the region have agreed, within the recommendations and preconditions of the National Association for GPs (NHG), that creating a single entry point from the GP practices is the point of departure for setting up structured care of the elderly in Walcheren.

The feasibility of the experiment will also be enhanced by knowledge obtained in the region regarding instruments and collaboration that includes the elderly. Knowledge about using the GFI instrument was obtained during a pilot with the GFI instrument among elderly persons aged 85+ years. Consultations with elderly patients aged 65+ years have already started in three practices. Due to the broad involvement and experiences of health professionals, no major obstacles are expected regarding the model implementation. The pressures on providing care may increase for GPs because the use of the GFI instrument will provide them with information about the frail elderly who were previously unknown. This additional work pressure will be calculated in advance to prepare the GPs for the workload. The extra burden on GPs in the control region is particularly related to time registration and participation in interviews. These extra efforts will also be discussed with them in advance.

Embedding the experiment in other projects is essential over the long term. The experiment does not stand-alone. A dementia care-chain and CVA care-chain are also being developed in Walcheren. The protocols developed will guarantee the link with the EASYcare instrument as used in this experiment. The steering group will ensure coherence between the various projects. The GPs in this project are also involved with developing the dementia care-chain. Their personal involvement in both projects will guarantee harmonization.

EVALUATION STUDY

The choice for a quasi-experimental design instead of a randomized control trial may seem suboptimal to some. However, in many studies on organizational change, randomization is impractical, impossible or even undesirable [69]. This is the case in our study as health professionals cannot give traditional care and care according to the model at the same time. Blinding is impossible. For the elderly, it is undesirable to receive care from a different GP or organization from one previously used.

However, choosing for a quasi-experimental design presents our study with some challenges. The absence of randomization makes results subject to contamination by confounding variables [70]. Potentially confounding variables have been accurately defined based on literature, experiences of health professionals and comparable studies. Inclusion and exclusion criteria are set. However, there is no guarantee that some confounding variables will be missed. It is also conceivable that differences found in the experimental group are not the result of the intervention but of the additional attention given by both health professionals and interviewers [71]. It is debatable if this “Hawthorne-effect” is really problematic because increased and patient-centered attention for the frail elderly is one of the goals of the model. Irrespective of the design chosen, the biggest potential obstacle is the willingness of the elderly and their caregivers to participate in this study over the longer term. To increase willingness, a request to participate will be sent, as described above, via the elders’ own GPs, interviewers will be from the region and gifts will be given.

LIST OF ABBREVIATION

WICM	Walcheren Integrated Care Model
GP	General practitioner
GFI	Groningen Frailty Indicator
SF-36	Short form (36) health survey
ICECAP	Index of capability for older people
EQ-6d	EuroQol (6 dimensions)
SRB	Self-related burden
VAS	Visual analogue scale
CSI	Caregiver strain index
ASIS	Assessment of the informal care situation
CSAI	Community service attitude inventory
iBMG	institute of Health Policy and Management
Qaly	Quality adjusted life years
Dalys	Disability adjusted life years
CQ-index	Consumer quality index

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THE EFFECTS of an INTEGRATED CARE INTERVENTION for the FRAIL ELDERLY on INFORMAL CAREGIVERS: a QUASI-EXPERIMENTAL STUDY

CHAPTER

III

Janse, B., Huijsman, R., de Kuyper, R.D.M., Fabbricotti, I.N.
BMC Geriatrics 2014, 14:58

ABSTRACT

BACKGROUND

This study explored the effects of an integrated care model aimed at the frail elderly on the perceived health, objective burden, subjective burden and quality of life of informal caregivers.

METHODS

A quasi-experimental design with before/after measurement (with questionnaires) and a control group was used. The analysis encompassed within and between groups analyses and regression analyses with baseline measurements, control variables (gender, age, co-residence with care receiver, income, education, having a life partner, employment and the duration of caregiving) and the intervention as independent variables.

RESULTS

The intervention significantly contributed to the reduction of subjective burden and significantly contributed to the increased likelihood that informal caregivers assumed household tasks. No effects were observed on perceived, health, time investment and quality of life.

CONCLUSIONS

This study implies that integrated care models aimed at the frail elderly can benefit informal caregivers and that such interventions can be implemented without demanding additional time investments from informal caregivers. Recommendations for future interventions and research are provided. Trial registration: Current Controlled Trials ISRCTN05748494. Registration date: 14/03/2013.

BACKGROUND

Informal caregivers of the frail elderly often experience the demands placed on them as a heavy burden and a threat to their quality of life. Informal care refers to the unprofessional and unpaid assistance provided by partners, family or close friends [1]. Frail elderly people suffer from age-related problems in different domains of daily functioning, such as physical, psychological and social domains, and are at risk of severe problems in the future, such as falls, hospitalization, disability and death [2]. As a result of the myriad of continuously changing problems and the chronic nature of frailty, providing informal care to these patients often entails increasingly intensive care tasks over a prolonged period of time [3]. Referred to as the objective burden of care, such tasks typically require a substantial expenditure of time and energy [4]. Consequently, many informal caregivers experience restrictions on their personal lives as time to spend with friends, to fulfill family obligations or to pursue leisure activities becomes increasingly scarce [5, 6]. Informal caregivers may also feel compelled to reduce their working hours, to rearrange their work schedules or to take unpaid leave, affecting their financial situation [5]. Such a multitude of difficulties can lead to an increase in the subjective burden, i.e., the perception of the impact of the objective burden [4]. Moreover, as a result of persistent subjective burden, many informal caregivers perceive deteriorations in their physical health, their social and psychological functioning, their well-being and ultimately their quality of life [7, 8].

Despite the potential vulnerability of informal caregivers, their needs are still largely overlooked [9]. Moreover, due to population aging and the trend of replacing institutionally based elderly care with home-based care, informal caregivers are increasingly relied upon [10, 11]. Because formal support services for informal caregivers are often inadequate [9], concerns have arisen about the growing burden shouldered by informal caregivers [12]. The involvement of informal caregivers in integrated care arrangements is increasingly considered to benefit both the frail elderly and their informal caregivers [13]. Thus, there has been a trend toward integrated care arrangements that incorporate elderly persons' entire social systems, including informal caregivers [12]. Integrated care is defined here as a 'coherent set of methods and models on the funding, and the administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment, and collaboration within and between the cure and care sectors' [14].

Integrated care arrangements targeting the patient- caregiver dyad are believed to reduce the burden and improve the overall quality of life and health of informal caregivers [12, 13, 15]. The proactive nature of integrated care is thought to enable the timely recognition of any unmet needs of informal caregivers [16]. Additionally, providing informal caregivers with adequate information (e.g., regarding available services), improving access to care and support services and increasing their competence in coping with their care responsibilities is thought to act as a safeguard against overburdening and deteriorating health [12, 17]. Furthermore, it has been argued that certain characteristics of integrated care, such as the emphasis on informal caregiver participation in care planning and provision and increased collaboration with professionals, may result in changes in the division of tasks [18, 19]. Perhaps informal caregivers are relieved of some of their more demanding and time-consuming tasks, while enabling them to attend to tasks that are more compatible with their own wishes, their physical abilities and personal lives. Conversely, it has also been suggested that the emphasis on the participation of informal caregivers might actually demand more inputs of time and energy, thereby increasing their burden and ultimately affecting their health and quality of life [1, 11, 17, 20].

However, evidence to substantiate these assumptions is scarce. Whereas the beneficial effects of integrated care on the frail elderly are well established [15], very few studies have reported outcomes for informal caregivers [13]. In a systematic review, Eklund & Wilhelmson [15] found only two studies, both reporting no effect on subjective burden [21, 22]. Similarly, Melis et al. [20] reported no effects in terms of both subjective as objective burden. Other authors have described effects of integrated care on informal caregivers, such as reduced caregivers' stress [23, 24], enhanced life satisfaction [25], improved general mental health [26], reduced time investments [17] and, conversely, greater time investments [27, 28].

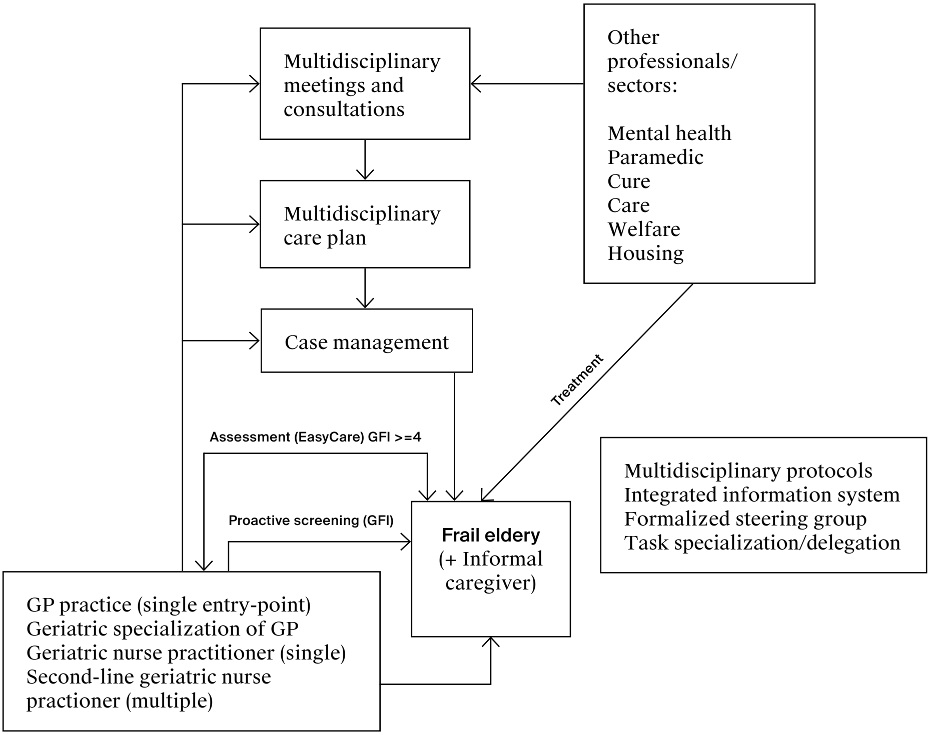
The scarcity and inconsistency of the evidence call for a more coherent and in-depth investigation of the effects of integrated care arrangements on the informal caregiver. To this end, the current study aims to evaluate the effects on informal caregivers of a specific integrated care intervention for the frail elderly, the Walcheren Integrated Care Model (WICM). This model was recently implemented in Walcheren, a region in the southwest of the Netherlands. The current paper describes the investigation of the effects of this intervention on a selection of outcome measures: perceived health, objective burden, subjective burden and quality of life. While it is expected that the WICM will contribute to improvements in these outcome measures, the occurrence of adverse effects as described in existing literature must also be taken into account. Therefore, the research question guiding the current study is formulated accordingly: What are the effects of the WICM on the perceived health, objective burden, subjective burden and quality of life of informal caregivers?

INTERVENTION

The WICM focuses on frail elderly individuals living independently (living in their own homes or in a specific type of assisted living facility) and their informal caregivers. The study protocol containing an extensive description of the intervention has been published previously [16]. The WICM has an umbrella organizational structure and includes evidence-based preventive frailty screening and needs assessments of the elderly patient, and needs assessment of the informal caregiver. It contains a single entry point, a multidisciplinary care plan, case management, multidisciplinary consultations and meetings, protocols, a steering group, task specialization/ delegation and an integrated information system supporting the entire chain of care (Figure 1).

The WICM entails explicit attention to the potential needs of informal caregivers and recognizes the roles of these individuals in the care process. The involvement of the informal caregiver starts after the patient has been screened for frailty using the Groningen Frailty Indicator (GFI) [29]. After being identified as frail, patients are visited by a case manager who performs a comprehensive assessment of needs using an evidence-based instrument. In this phase, the informal caregiver's needs for support and guidance are also identified. The case manager determines the care goals in consultation with the care recipient and the informal caregiver,

FIGURE 1. The Walcheren Integrated Care Model



after which a care plan is formulated. Consequently, the plan is discussed, refined and approved in a multidisciplinary meeting. The general practitioner (GP) contacts the care recipient and informal caregiver to provide the opportunity for any last adjustments. A case manager implements the care plan and coordinates care delivery. Periodic evaluations of the care plan ensure adequate monitoring of the needs of care recipient and informal caregiver. Available services for informal caregivers normally include respite care services aimed at temporary relief, as well as psychosocial interventions, such as education and training or (group) counseling. In the WICM, the case manager provides the informal caregiver with relevant information, advice and suggestions regarding available services based on the caregiver's specific needs. The case manager functions as a link to all relevant organizations and professionals and if needed, the informal caregiver is brought into contact with them. Case managers may also provide practical advice (e.g., how to make certain care tasks less burdensome) or emotional support.

METHODS

STUDY DESIGN AND PARTICIPANTS

The study had a quasi-experimental design included before/after measurements and a control group. A baseline measurement (T0) was performed prior to the intervention; the follow-up measurement (T1) was performed twelve months after T0. The study protocol (protocol number MEC-2013-058) was reviewed by the medical ethics committee of the Erasmus Medical Centre Rotterdam, the Netherlands. They waived further examination, as the Medical Research Involving Subjects Act did not apply.

Eight GP practices in the Walcheren region participated in this study as intervention practice or control practice. Frail older patients and their informal caregivers were recruited as participants through these practices. Both control and experimental practices provided the researchers with the names and contact information of patients that were 75+ years of age. These patients were mailed an information leaflet, the screening questionnaire (GFI) and an informed consent. Upon return, frailty scores were computed (GFI score of 4+) [29]. Inclusion followed if patients did not meet the exclusion criteria of being terminally ill and living in a nursing home. Subsequently, their informal caregivers were recruited by asking the included frail older patients whether they received informal care and, if so, from whom. It was explained to patients that informal care involves all non-professional and unpaid assistance provided by partners, family or close friends and neighbors. The informal caregivers were then mailed an information leaflet and informed consent, which they were asked to fill out and return.

Of the 8 participating GP practices, 3 practices (6 GPs) provided care according to the WICM and constituted the experimental group. The remaining 5 practices (5 GPs) continued to provide care as usual and thus constituted the control group. Care as usual for the frail elderly can be described as reactive, as GPs are usually consulted at the patient's initiative. As gatekeepers, GPs refer frail elderly patients to both care and curative services in the secondary and tertiary echelons [30]. Care as usual does not include case management or formal multidisciplinary collaboration.

DATA COLLECTION

The questionnaire was developed as part of a large-scale national program initiated by the Ministry of Health, Welfare and Sports [31]. With a budget of 80 million euros, This National Care for the Elderly Program (NPO) aims to improve care for the elderly by initiating interventions and providing platforms for the dissemination of study results. All interventions operating within the NPO-program use the questionnaire, thereby ensuring optimal data-sharing [32]. Data were collected by trained interviewers who visited participating patients at home. If the informal caregiver was present, the data were collected in a face-to-face interview. If not, questionnaires were sent by mail to the informal caregiver's home address. All interviewers had previously worked in elderly care and lived in the region.

OUTCOME MEASURES

No hierarchical division of outcome measures into primary and secondary outcomes was made in the current study. Perceived health was measured using 2 items from the RAND-36 [33]. On the first item, the respondent indicates his or her current perceived health on a 5-point Likert scale ranging from 1 (poor) to 5 (excellent). On the second item, the respondent indicates the changes in perceived health in comparison to 12 months ago on a 5-point Likert scale ranging from 1 (a lot worse) to 5 (a lot better).

Objective burden was measured with the short form of the 'Objective Burden of Informal Care Instrument' [34]. This instrument operationalizes objective burden as the amount of time spent and the nature of care tasks. Thus, respondents indicate the nature of performed tasks (household, personal care and instrumental care tasks) and the amount of time spent on each category of tasks during the week of measurement. In addition, respondents indicate whether other informal caregivers provide assistance and if so, what their time investments are.

Subjective burden was measured with the CarerQoL [35], the Process Utility (PU) Scale [36] and the Self-Rated Burden (SRB) Scale [37]. While all 3 instruments aim to measure subjective burden, their approaches differ and thus these instruments are considered to be complementary to each other. The CarerQoL describes the caregiver's situation in terms of both positive and negative aspects of informal care, thereby providing a balanced measure of subjective burden. Negative aspects are the experience of problems in physical health, mental health, financial situation, relationships and in combining care tasks with personal activities. Positive aspects are the experience of support from others and feelings of fulfillment. Respondents indicate the degree to which each aspect is applicable to their current situation (response categories: none/ some/ a lot). A weighted sum score (0–100) describes the specific caregiver's situation, in which a higher sum score indicates a more favorable situation. In addition, the CarerQoL includes a visual analog scale (VAS) that provides an indication of the current general happiness ranging from 0 (completely unhappy) to 10 (completely happy). The VAS for process utility (PU) provides a measure for the respondent's happiness derived from caregiving. Respondents indicate their degree of happiness ranging from 0 (completely unhappy) to 10 (completely happy) with a hypothetical scenario in which all care tasks are assumed by a professional caregiver. The final measure for subjective burden is the SRB, a VAS ranging from 0 (not at all burdensome) to 100 (way too burdensome) indicating the degree to which informal care is experienced as burdening.

Quality of life was measured using Cantril's Self-Anchoring Ladder [38]. The respondents rate their current quality of life on a scale from 0 to 10. Two additional items were used to assess quality of life and changes in quality of life in comparison with 12 months ago. These items were based on the items on perceived health from the RAND-36 [33]. Just as the items for perceived health, respondents indicate their current quality of life on a 5-point Likert scale ranging from 1 (poor) to 5 (excellent) and the changes in quality of life in comparison to 12 months ago on a 5-point Likert scale ranging from 1 (a lot worse) to 5 (a lot better).

CONTROL VARIABLES

Literature indicates that being female, being older, having a lower level of education, having a low income, the relationship to the care-recipient (child versus spouse), co-residence with the care recipient, being employed and providing informal care for a longer duration of time increases the informal caregiver's burden [1, 39–41]. Thus these factors served as control variables in the current study. The level of education was assessed using Verhage's categorization [42]. Income was assessed relative to the average income in the Netherlands in 2010 (33,500 €) on a five-point scale from 1 (much less than 33,500 €) to 3 (approximately 33,500 €) to 5 (much more than 33,500 €).

ANALYSIS

TRANSFORMATIONS

A number of outcome measures required transformations prior to analysis. The items for perceived health (RAND-36) and the items for quality of life (based on the RAND-36 items) were reversely recoded so that a higher score signified better health and quality of life. As specified in the RAND-36 manual [33], the 5-point Likert scale was converted into a 100-point scale. As for the CarerQoL [35], the negative dimensions were assigned the values 0 (a lot), 1 (some) and 2 (none); the positive dimensions were assigned the values 0 (none), 1 (some) and 2 (a lot), so that high scores signified higher well-being. Process utility was derived through the computation of a difference score between the CarerQoL-VAS (happiness now) and the PU-VAS (happiness if care tasks are taken over a by professional) resulting in a score ranging from –10 to 10. In addition, to enable the inclusion of the control variables income and education in further analyses, these variables were transformed into dichotomous variables (with values 'low' and 'high') by creating groups of approximately equal size.

WITHIN- AND BETWEEN GROUP ANALYSES

Mean scores were computed for all outcome measures and were subsequently analyzed using t-tests, thus providing a description of the scores of the groups at T0 and T1. Specifically, within-group changes between T0 and T1 were determined using a paired t-test, McNemar's test or Wilcoxon's signed rank test. To compare scores between groups, difference scores were computed for all outcome measures, which were then analyzed using independent t-tests and chi-square tests (or Fisher's exact test). Significant effects indicate that changes in scores between T0 and T1 differ substantially between groups.

REGRESSION ANALYSES

To further investigate the contribution of the intervention to the observed differences in scores between groups, regression analyses were performed. Linear regression analyses were used for the outcome variables perceived health, subjective burden, quality of life and amount of time spent, while logistic regression analyses were performed on the binary variables related to objective burden i.e., informal caregivers performing household tasks, personal care tasks and instrumental care tasks. Regression analyses consisted of 3 consecutive models containing the baseline scores of the specific outcome variable (Model 1), control variables age, gender, income level, education level, co-residence, employment, having a life partner and the duration of caregiving in months (Model 2) and the intervention (Model 3). As the regression analyses aimed to assess the contribution of the intervention, controlling for baseline scores and control variables, only the output of Model 3 (coefficients and significance) is reported in this paper.

Models and effects of the WICM were considered significant if $p < 0.05$. However, as the definitive study sample was relatively small, p-values of < 0.1 were also reported [43]. Additionally, to determine the degree of multicollinearity between control variables, the values of tolerance (<0.2) and the variance inflation factor (>10) were checked [44]. This revealed that multicollinearity indeed existed between the variables 'relationship to care recipient' (child versus spouse) and 'co-residence with the care recipient'. Consequently, it was decided to drop the variable that explained the least amount of variance i.e., the variable 'relationship to care recipient'.

RESULTS

At T0, a total of 377 patients were included as a participant in the WICM (Table 1). The majority of patients was female, had an average age of 82 years and an average frailty score (GFI) of around 6. Most patients did not have a partner (anymore) and most lived independently. Comparison of the care recipient characteristic between groups revealed that the percentage of female care recipients was significantly higher in the experimental group than in the control group. In addition, the experimental group consisted of significantly more care recipients with assisted living arrangements or that lived in a nursing home.

Of the total of 377 care recipients, 262 indicated to receive care from an informal caregiver. However, due to a loss to follow-up (N = 103), this number had reduced to a total of 159 at T1. The majority of these losses to follow-up were due to informal caregivers not responding after the initial contact (N = 53/103). Others were unwilling to continue to participate in the study (N = 16/103) or felt the definition of informal caregivers did not apply to them (N = 15/103). Some of these informal caregivers indicated that their care tasks had been taken over by formal caregivers since the baseline measurement, while others considered their caregiver role as their duty rather than deserving of a distinctive label. Finally, a number of losses to follow-up were the result of the progressive inability or death of the care recipient (N = 19/103). The definitive study population of informal caregivers consisted of all respondents of which data were available for both T0 and T1. This amounted to 83 informal caregivers in the experimental group and 76 informal caregivers in the control group.

Subsequent comparison between groups on control variables and baseline scores on all variables showed that informal caregivers in both groups were equal except on the variable age. Specifically, the mean age of informal caregivers in the control group was significantly higher than the mean age of informal caregivers in the experimental group. In general, the age of informal caregivers in the study population was 63 years. A large majority was female, and most had a life partner. In addition, most had a low educational level and a low income. Sons and daughters (in law) constituted the largest group of informal caregivers, followed by partners. Half of the informal caregivers in the experimental group and nearly 40 % in the control group were employed during the study period. The average duration of caregiving in both groups was approximately 8 years. Around one-third of informal caregivers in both groups co-resided with the care recipients.

PERCEIVED HEALTH

While both the experimental and the control group showed a decline in perceived health between T0 and T1, only the decline in the control group was significant ($p = 0.007$). Subsequent analysis of difference scores showed a moderately significant difference between groups ($p = 0.087$) (Table 2).

TABLE 1. Response and Study Population

CHARACTERISTICS OF CARE RECIPIENTS

BACKGROUND VARIABLES	EXPERIMENTAL GROUP (N=184)	CONTROL GROUP (N=193)	TOTAL (N=377)
Frailty (GFI score)	6.0 (2.0)	5.8 (1.8)	5.9
Female*	70%	60%	65%
Age	81.8 (SD: 4.7)	82.3 (SD: 5.3)	82
Partner (married or cohabiting)	37%	42%	39%
Single (or widowed)	63%	58%	61%
Independent living	72%	82%	77%
Assisted living / nursing home*	28%	18%	23%
Receiving informal care	144 (78.3%)	118 (61.1%)	262 (69.5%)
Caregiver loss to follow-up	61	42	103 (39.3%)
Caregivers participating	83	76	159

CHARACTERISTICS OF INFORMAL CAREGIVERS

BACKGROUND VARIABLES	EXPERIMENTAL GROUP (N=83)	CONTROL GROUP (N=76)	TOTAL (N=159)
Female	71.0%	75.0%	73%
Age*	60.7 (SD: 12.2)	65.6 (SD: 11.2)	63.2
Co-residing with care recipient	28.9%	40.8%	34.9%
Relationship to care recipient:			
Partner	26.5%	36.8%	31.6%
Son/daughter	68.7%	51.3%	60.0%
Other (e.g. neighbor, friend)	4.8%	11.9%	8.4%
Low education	65.4%	66.2%	65.8%
High education	34.6%	33.8%	34.2%
Low income	58.0%	65.8%	61.9%
High income	42.0%	34.2%	76.2%
Having life partner	89.0%	88.2%	88.6%
Employed (yes)	50.0%	38.4%	44.2%
Duration (in months)	92.8 (SD: 93.8)	97.3 (SD: 115.7)	95.1

$p<0.05$

SUBJECTIVE BURDEN

Measures used to assess the effects of the intervention on subjective burden were the CarerQoL sum score and VAS, Process Utility (PU) and the Self-Rated Burden Scale (SRB). Although these measures yielded somewhat mixed scores, overall, results were more favorable for the experimental group. The experimental group showed a significant improvement of CarerQoL sum scores between T0 and T1 ($p = 0.008$), while the control group showed a slight (non-significant) reduction of CarerQoL sum scores. Both groups showed reductions in CarerQoL-VAS scores between T0 and T1, although the reduction was only significant for the control group ($p = 0.008$). PU scores did not change between T0 and T1 for the experimental group, while the control group showed a moderately significant reduction of

TABLE 2. Within-group and Between-group Differences in Mean Scores at T0 and T1

OUTCOME VARIABLES	EXPERIMENTAL GROUP		CONTROL GROUP		BETWEEN-GROUPS COMPARISON
	T1	△ T0	T1	△ T0	△
PERCEIVED HEALTH					
Perceived health (0–100)	46.91	−1.23	44.00	−6.33*	#
Perceived change in health (0–100)	46.30	−2.16	46.00	−2.00	-
SUBJECTIVE BURDEN					
CarerQoL sum score (0–100)	84.93#	3.88*	80.73	−0.55	*
CarerQoL-VAS (0–10)	7.16	−0.07	6.97	−0.49*	#
Process Utility (−10-10)	2.59	−0.09	2.38	−0.71#	-
Self -Rated Burden (SRB) Scale (0–10)	3.97	0.54#	3.95	0.63#	-
OBJECTIVE BURDEN					
% of caregivers performing household tasks	87.2%	7.7%	76.7%	−1.4%	-
% of caregivers performing personal care tasks	30.5%	4.9%	41.3%	14.6%*	-
% of caregivers performing instrumental care tasks	79.3%	−4.8%	69.7%	−6.6%	-
% reporting other informal caregivers	45.0%	6.2%	34.2%	4.1%	-
Hours spent per week on household tasks	7.25	1.46	8.93	2.44#	-
Hours spent per week on personal care tasks	1.86	0.76#	2.17	0.50	-
Hours spent per week on instrumental care tasks	2.51	0.46	1.79	−0.43	-
Total hours spent per week	11.15	2.44#	12.53	2.25	-
Total hours spent per week (incl. other caregivers)	13.25	3.14*	13.03	1.57	-
QUALITY OF LIFE					
Quality of life (0–100)	55.63	−1.87	54.67	−5.67*	-
Change in quality of life (0–100)	48.15	−4.63#	46.33	−4.67#	-
Rating of quality of life (0–10)	7.35	−0.04	7.37	−0.29*	-

*#p<0.10; *p<0.05; **p<0.01; ***p=0.000; "-"= no significance; △ T0 = difference between T1 and T0; △ = difference between control and experimental groups*

PU scores ($p = 0.071$). Both the experimental group ($p = 0.057$) as the control group ($p = 0.072$) showed moderately significant increases in SRB score between T0 and T1. Comparison of the within-group differences over time revealed a significant difference between groups for the CarerQoL sum score ($p = 0.033$) and a moderately significant difference between groups for the CarerQoL-VAS ($p = 0.060$).

OBJECTIVE BURDEN

Objective burden constituted the number of hours that informal caregivers spent on care and the categories of care tasks. The number of hours spent on household tasks increased in both groups between T0 and T1. However, only the increase in the control group was moderately significant ($p = 0.084$). Similarly, both groups showed an increase in the number of hours spent on personal care tasks, although the increase was only moderately significant for the experimental group ($p = 0.094$). Both groups showed no significant changes in the hours spent on instrumental care tasks. The total time investment also increased significantly for the experimental group, both including additional informal caregivers ($p = 0.045$) and excluding additional informal caregivers (*p* = 0.067). The control group showed a significant and substantial increase between T0 and T1 in the percentage of caregivers performing personal care tasks (*p* = 0.013). However, none of these changes over time within the groups resulted in significant differences between groups.

QUALITY OF LIFE

While the control group showed decreased scores on all 3 items for quality of life between T0 and T1, the experimental group only showed a decrease of 1 item. Specifically, the control group showed reductions in perceived quality of life (*p* = 0.023), adverse changes in quality of life (*p* = 0.080) and in overall ratings of quality of life (*p* = 0.032). The experimental group only showed a moderately significant adverse change in quality of life (*p* = 0.071).

REGRESSION ANALYSIS

The WICM resulted in a significant reduction of subjective burden (*p* = 0.053) as measured with the CarerQoL sum score. In addition, logistic regression analyses showed that the WICM significantly increased the likelihood of informal caregiver's performing household tasks (*p* = 0.048). The intervention showed no effects on the outcomes perceived health and general quality of life (Table 3). Baseline scores were the dominant predictors for most outcomes, followed by co-residence and gender. Co-residence negatively affected perceived health, general quality of life and subjective burden (CarerQoL sum score and VAS) while it increased the amount of hours spent on household tasks. Additionally, co-residence resulted in increased likelihood of informal caregivers performing personal care tasks. Female caregivers experienced higher subjective burden (as measured by CarerQoL sum scores and SRB scores) and were more likely to perform instrumental care tasks than male caregivers.

QUALITY OF LIFE

While the control group showed decreased scores on all 3 items for quality of life between T0 and T1, the experimental group only showed a decrease of 1 item. Specifically, the control group showed reductions in perceived quality of life (*p* = 0.023), adverse changes in quality of life (*p* = 0.080) and in overall ratings of quality of life (*p* = 0.032). The experimental group only showed a moderately significant adverse change in quality of life (*p* = 0.071).

Additionally, female caregivers perceived their health and general quality of life to be poorer than male caregivers. The longer informal caregivers provided care, the poorer they perceived their health to be. Conversely, longer periods of caregiving reduced the amount of hours spent on household tasks and increased the process utility of caregiving. A higher income enhanced the general quality of life ratings and increased the likelihood of caregivers performing household tasks. A higher education increased the amount of hours spent by other informal caregivers and increased the subjective burden (CarerQoL sum score). Having a life partner reduced the number of hours spent on household tasks and the number of hours spent by other informal caregivers. Being employed resulted in more hours spent by other informal caregivers and poorer perceived health. The regression models for instrumental care tasks and changes in quality of life were not significant. Additional file 2 summarizes the significance and the contribution to the explained

TABLE 3. Regression/Logistic Regression Analyses with Baseline Scores, Control Variables and the Intervention as Predictors

	INDEPENDENT VARIABLES									
OUTCOME VARIABLES	T0	Gender	Age	Co-residing	Employment	Partner	Education	Income	Duration	WICM
PERCEIVED HEALTH										
Perceived health (0–100)	**0.673*****	**−0.134#**	−0.73	**−0.190#**	−0.102	0.059	−0.112	0.061	−0.036	0.079
Perceived change in health (0–100)	**0.148#**	**−0.226***	−0.092	**−0.396****	**−0.181#**	0.008	−0.005	0.084	**−0.216****	−0.043
SUBJECTIVE BURDEN										
CarerQoL sum score (0–100)	**0.571*****	**−0.219***	0.144	**−0.261***	−0.053	−0.090	**−0.135#**	−0.003	−0.042	**0.132#**
CarerQoL-VAS (0–10)	**0.562*****	0.013	0.108	**−0.216#**	0.034	0.052	0.012	−0.066	0.045	0.096
Process Utility (PU) (−10-10)	**0.605*****	−0.067	−0.034	−0.135	−0.069	0.018	−0.031	−0.076	**0.222***	0.041
Self-Rated Burden (SRB) Scale (0–10)	**0.373*****	**0.288****	0.151	0.069	0.118	0.119	0.021	0.059	0.017	0.052
OBJECTIVE BURDEN										
Caregivers performing household tasks (log)	**8.795*****	3.345	1.088	0.157	1.311	0.129	1.313	**0.200***	1.000	**3.590***
Caregivers performing personal care tasks (log)	**10.357*****	2.458	1.023	**5.829***	1.493	1.045	2.164	0.654	1.000	0.666
Caregivers performing instrumental care tasks (log)	**12.825*****	**4.785***	0.964	1.433	0.444	2.560	0.782	2.133	1.003	1.281
Additional informal caregivers (log)	**9.929*****	1.040	1.171	**0.157***	1.608	0.379	**2.314#**	0.980	0.998	1.171
Hours spent on household tasks	**0.457*****	0.009	0.064	**0.278***	−0.026	**−0.166***	0.058	−0.060	**−0.192****	0.020
Hours spent on personal care tasks	**0.569*****	0.007	0.049	0.188	−0.006	0.050	0.007	0.004	−0.022	0.009
HOURS SPENT ON INSTRUMENTAL CARE TASKS	-	-	-	-	-	-	-	-	-	-
Total hours spent	**0.577*****	0.032	0.132	0.146	−0.003	−0.101	0.033	−0.024	**−0.137***	0.071
Total hours spent + other caregivers	**0.585*****	0.041	0.108	0.166	0.042	−0.084	0.087	−0.042	−0.118	0.107
QUALITY OF LIFE										
Quality of life (0–100)	**0.361*****	**−0.161#**	−0.041	**−0.421****	−0.096	0.106	−0.034	0.056	−0.013	−0.046
Change in quality of life (0–100)	-	-	-	-	-	-	-	-	-	-
Rating of quality of life (0–100)	**0.318*****	0.097	0.136	**−0.320***	−0.010	0.037	−0.007	**0.155#**	−0.001	0.059

*#p<0.10; *p<0.05; **p<0.01; ***p=0.000 (significant coefficients/Exp(B) shown in bold); (log) = logistic regression analyses; WICM = Walcheren Integrated Care Model.*
Note: Positive Beta values signify better scores for all outcomes with a 0–10 or 0–100 range, except for the outcome Self-Rated Burden (SRB); for SRB, positive Beta values signify increased experienced burden.

variance of each regression model. This overview confirms that Model 1 (baseline scores) explained the greatest proportion of the variance, followed by Model 2 (control variables). Model 3 (the intervention) contributed relatively little to the explained variance.

DISCUSSION

This study explored the effect of the WICM on the perceived health, objective burden, subjective burden and the general quality of life of informal caregivers of frail elderly patients. Our results show that the WICM reduced the subjective burden of informal caregivers. In addition, the likelihood of informal caregivers assisting with household tasks increased as a result of the WICM.

The reduction of subjective burden that was observed in this study was measured with the CarerQoL, an instrument that describes the caregiver's situation in 7 common dimensions of informal care provision. Thus, this positive outcome indicates that informal caregivers experienced fewer problems and more support and satisfaction as a result of the intervention. Certain components of the WICM may have contributed to this positive outcome, such as the proactive character, the needs assessment, explicit attention to the support of informal caregivers and periodic monitoring. Etters et al. [45] concluded that prevention, early detection and periodic screening are effective in identifying informal caregivers at risk of being overburdened. Similarly, Sörensen et al. [46] emphasized the importance of targeting unmet needs and providing opportunities for respite care. In addition, others have emphasized that the dynamic needs of the informal caregivers of the frail elderly require regular monitoring [47, 48]. Although the current study suggests that these components have contributed to the improvements in the informal caregiver's situation, they may have asserted their effect independently or interdependently and thus causality cannot be determined [49]. Alternative explanations may be provided by the possibility of improved patient outcomes and improved relationships between the patient and the informal caregiver. An abundance of evidence exists of the beneficial effects of integrated care on the elderly patient's physical abilities, functional abilities and well-being [50]. There is also evidence that such improvements can result in less intensive and exhausting informal care tasks, thereby reducing the informal caregiver's distress [51, 52]. In the context of improved relationships, Schultz and Martire [40] noted that informal caregiving occurs by definition in a social context and that informal caregiver outcomes cannot be viewed separately from the relationship with the care recipient. A reciprocal negative affect between spousal care recipients and informal caregivers has been previously described [53, 54], suggesting an association between the quality of the relationship and outcomes for caregivers.

A second finding of this study was that although the WICM did not affect the time investments of informal caregivers, it did increase the likelihood of informal caregivers assuming household tasks. Although changes in tasks were considered as possible outcome of the WICM, the direction of such changes was unclear. As described in the background section of this paper, this may have been the outcome of changes in the division of tasks between professionals and informal caregivers [18, 19]. The emphasis on the informal caregiver's participation in care planning and provision might have resulted in a 'negotiation process' between the case manager and the caregiver, through which the latter may have become more aware of his or her role in the care process. Perhaps this has prompted informal caregivers to take up those tasks that can easily be performed by non-professionals, such as household tasks. Alternatively, it has been suggested that the care recipient's health status affects the nature of informal care tasks [55]. It can thus be argued that the shift towards household tasks observed in the current study may have been the result of changes in the degree of impairment of the care recipient.

The finding that the time investments were not affected by the WICM is consistent with the findings of previous research [11, 20], although other studies suggest that integrated care increases time investments of informal caregivers [17, 27]. Weuve et al. [11] provided an explanation, suggesting that certain intervention components (e.g. case management, training or consultation) may increase the competence of informal caregivers, thereby buffering the potential increase in time investment.

No effect was found on the perceived health of the informal caregivers. This observation might be explained by the relative stability of self-rated health over time [56]. A study period of 12 months may be too short to observe meaningful changes in perceived health. Similarly, no effects were found on the general quality of life. This result is somewhat unexpected, as previous studies have demonstrated the existence of an association between subjective burden and quality of life of informal caregivers [7, 8, 39]. The failure of the current study to observe such an association may have been the result of the use of non-validated measures for quality of life.

Overall, it can be argued that the effects of the WICM on informal caregivers are promising but modest. Several factors may have somehow inhibited the effectiveness of the intervention. First, the majority of informal caregivers did not co-reside with the care recipients. Perhaps these informal caregivers were less affected by the intervention, which would mitigate its effectiveness. It has been argued that integrated care interventions aimed at the frail elderly may be less appropriate for certain subgroups of informal caregivers, such as those that do not live with the care recipient [48]. If so, integrated care interventions that allow a more flexible approach to informal caregivers could be more effective, for instance by applying different strategies for different subgroups. Second, it is possible that the modest results of the current study are related to a suboptimal implementation of the intervention, which could have resulted in a limited exposure of the target populations to the intervention [57]. It can be argued that the evaluation period of 12 months used in this study may have been too short for the intervention to reach its full potential. If so, stronger effects can be expected if longer evaluation periods are used as the likelihood of interventions affecting informal caregivers increases [58]. Some rationale for such long-term effects are provided by the results of the within- and between-group analyses, with indicated that deteriorations in perceived health and happiness (CarerQoL-VAS) were larger in the control group than in the experimental group, which resulted in significant between-group differences. While the regression analyses showed that the intervention did not contribute to these group differences over a 12-month period, perhaps the contribution of the intervention might increase over a longer period of time. Specifically, it provides some basis for the hypothesis that integrated care interventions such as the WICM may protect informal caregivers against the natural decline in health and well-being that is associated with providing care in the context of the progressive trajectory of frailty. However, identifying such long-term effects requires a control group that remains intact over an extended period. This might prove to be difficult as over time the control group might become 'contaminated' when certain elements of integrated care are adopted into the control condition.

LIMITATIONS

The use of non-validated items for general quality of life is a limitation of this study. However, the questionnaire was developed by an expert group, which considerably enhanced its face validity. The relatively low proportion of variance that was explained by the intervention constitutes another limitation. This is especially relevant in light of the moderate significance of the effect that was observed in this study and thus, this result must be interpreted with caution. Another limitation is the relatively low contribution of the control variables to the explained variance, suggesting that additional variables need to be taken into account. For instance, the degree of frailty and the nature of disability of the care recipients might be of influence [40]. All patients in the current study were identified as frail based on their frailty scores and were thus considered to be fairly similar in terms of their disabilities. However, as frailty scores showed some variation in the patient group, they have asserted influence on the outcomes. While the current study only used caregiver characteristics as control variables, including frailty scores as a control variable might have yielded more robust regression models. Additionally, dysfunctional family relations, personality traits of the informal caregiver or preexisting medical conditions have been proposed as mediating factors [46]. Another limitation is the relatively large loss to follow-up, which increases the risk of selection bias and threatens the generalizability of the study results. These substantial losses justify a post-hoc analysis of the non-response group to determine their characteristics. However, as around 50 % of losses occurred prior to baseline measurement, the data needed to assess the effect of the loss to follow-up were not available. Nonetheless, it is conceivable that the individuals that dropped out of the study were actually the most burdened and in greatest need of a supportive intervention [48]. A final limitation of this study is the large number of statistical tests that were performed without applying corrections for multiple comparisons.

RECOMMENDATIONS

Future research is recommended to focus on matching intervention components to informal caregiver outcomes. Research should also focus on the associations between improvements in the abilities of the elderly, the quality of the relationship and the outcomes for informal caregivers in integrated care interventions. Future research is recommended to investigate which aspects of integrated care interventions lead to specific shifts in tasks, especially the shift toward household tasks as observed in this study. Furthermore, the effect of integrated care on the time investment of informal caregivers requires further investigation. Future studies should consider using evaluation periods longer than 12 months to increase the likelihood of observing more robust effects. A longer time-frame would provide more opportunity to allow a start-up period for an optimal implementation of the intervention, in which all actors can become accustomed to new working arrangements. Finally, integrated care interventions aiming at both the frail elderly and their informal caregivers may be more effective when a certain differentiation between subgroups can be made, particularly in regard to co-residing and non-co-residing informal caregivers.

STUDY STRENGTHS

Very few studies have specifically aimed to evaluate the effects of an integrated care intervention on informal caregivers. This study aimed to fill this gap by using a sound study design, a broad range of control variables, outcome variables and several validated instruments.

CONCLUSIONS

Our main conclusion is that the WICM reduced the subjective burden by improving the situation of the informal caregivers and increased the likelihood of informal caregivers assisting with household tasks. Our results indicate that integrated care interventions can benefit informal caregivers. In addition, this study shows that time investments of informal caregivers do not necessarily increase as a result of integrated care. We believe that this finding should be interpreted as a positive outcome. Integrated care has been shown to benefit the frail elderly, to improve the quality of care and to reduce costs. This study indicates that these outcomes can be achieved while reducing the subjective burden and retaining the level of commitment of informal caregivers. Given the increasing pressure on informal caregivers of the frail elderly, it is vital to find effective means to support these individuals. Our findings indicate that integrated care provides a viable solution.

LIST OF ABBREVIATION

WICM	Walcheren Integrated Care Model
GP	General Practitioner
SRB	Self-Rated Burden
VAS	Visual Analogue Scale
PU	Process Utility
CarerQoL	Care-Related Quality of Life
NPO	Nationaal Programma Ouderenzorg (National Care for the Elderly Programme)
GFI	Groningen Frailty Indicator

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THE EFFECTS of an INTEGRATED CARE INTERVENTION for the FRAIL ELDERLY on INFORMAL CAREGIVERS' SATISFACTION with CARE and SUPPORT

CHAPTER IV

Janse, B., Huijsman, R., de Kuyper, R.D.M., Fabbricotti, I.N.
BMC Health Services Research 2014, 14:140

ABSTRACT

BACKGROUND

This study explored the effects of an integrated care model for the frail elderly on informal caregivers' satisfaction with care and support services.

METHODS

A 62-item instrument was developed and deployed in an evaluative before/after study using a quasi-experimental design and enrolling a control group. The definitive study population (n = 63) consisted mainly of female informal caregivers who did not live with the care recipient. Analysis of separate items involved group comparisons, using paired and unpaired tests, and regression analyses, with baseline measurements, control variables (sex, age and living together with care recipient) and the intervention as independent variables. Subsequently, the underlying factor structure of the theoretical dimensions was investigated using primary component analysis. Group comparisons and regression analyses were performed on the resulting scales.

RESULTS

Satisfaction with the degree to which care was provided according to the need for care of the recipients increased, while satisfaction with the degree to which professionals provided help with administrative tasks, the understandability of the information provided and the degree to which informal caregivers knew which professionals to call, decreased. Primary component analysis yielded 6 scales for satisfaction with care and 5 scales for satisfaction with caregiver support, with sufficient reliability.

CONCLUSIONS

The results suggest that expectations regarding the effects of integrated care on informal caregiver satisfaction may not be realistic. However, the results must be seen in light of the small sample size and should therefore be considered as preliminary. Nonetheless, this study provides guidance for further research and integrated care interventions involving informal caregivers.

BACKGROUND

Informal caregivers of frail elderly people often perform a substantial number of care tasks over a prolonged period of time [1]. By definition, informal care is non-professional and unpaid and is provided by family members, partners or close friends [2]. Frail elderly people suffer from age-related problems in different domains of daily functioning, such as physical, psychological, and social problems [3]. Their informal caregivers must frequently interact with the healthcare system to obtain the information, services, and equipment needed to counter such problems [4]. However, many informal caregivers experience the healthcare system as fragmented, rigid and difficult to access [5]. In addition, while it is evident that providing informal care can lead to substantial deteriorations in health and quality of life [6-8], support services for informal caregivers are still often inadequate [9,10]. This lack of explicit attention to informal caregivers denotes a serious gap in healthcare [5]. Consequently, many authors have called for more consideration of informal caregivers' needs for attention and support [7,11-13], as well as greater insight into their perceptions and satisfaction with such services [14].

As a result, increased attention has been paid to the involvement and support of informal caregivers of frail elderly patients [15-17]. In this context, particular interest has been given to including informal caregivers in integrated care arrangements [10,18]. Integrated care is defined here as a 'coherent set of methods and models on the funding and on the administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment, and collaboration within and between the cure and care sectors' [19]. Integrated care has been proposed to increase the coherence, continuity and quality of elderly care [19,20] and to provide more adequate and effective support for informal caregivers [9]. The proactive nature of integrated care is assumed to increase the likelihood of a timely recognition of unmet needs of both the care recipient and informal caregiver [21]. In addition, as it includes coordination mechanisms, such as case management, integrated care is believed to benefit informal caregivers by linking them to adequate formal services [22]. Such characteristics are assumed to increase the satisfaction of informal caregivers with the care provided to the care recipients, as well as with the way these services support themselves as caregivers [18,23].

Although the call for greater attention to the informal caregiver dates back as far as 1990 (e.g., [12]), little is known regarding caregivers' satisfaction with services [5]. Moreover, despite the substantial number of studies produced in recent years regarding integrated care arrangements, the role of informal caregivers therein has largely been neglected [9]. Consequently, a gap exists in the literature regarding the effects of integrated care on informal caregivers' satisfaction [23]. Some studies have reported outcomes regarding this subject and have confirmed that integrated care indeed increases informal caregivers' satisfaction with services [15,18,24]. However, the interventions and their subsequent evaluations were aimed primarily at improving care for elderly patients. Although these interventions acknowledged informal caregivers by involving them to some degree in the care process, they were regarded more as partners in care than as potential individuals in need of care and support. Satisfaction assessment in these studies was therefore related only to the care provided to the care recipients and was not related to the care and support provided to the informal caregivers themselves. To our knowledge, there have been no studies that have investigated the effects of integrated care on informal caregiver satisfaction with the care received by the care recipient in combination with their satisfaction with the care and support they personally received. This study therefore describes the construction of a caregiver satisfaction instrument and its use in the evaluation of informal caregiver satisfaction with a specific integrated care intervention.

STUDY AIM

The aim of the current study was to investigate the effects of integrated care on informal caregivers' satisfaction with the care received by care recipients and on the satisfaction with the care and support the caregivers' themselves received. To this end, a specific integrated care intervention aimed at frail elderly patients was evaluated. This intervention, the Walcheren Integrated Care Model (WICM), has been implemented in the Walcheren region in the southwest of the Netherlands. The research question guiding this study was: What are the effects of the Walcheren Integrated Care Model on the satisfaction of informal caregivers with care and support services?

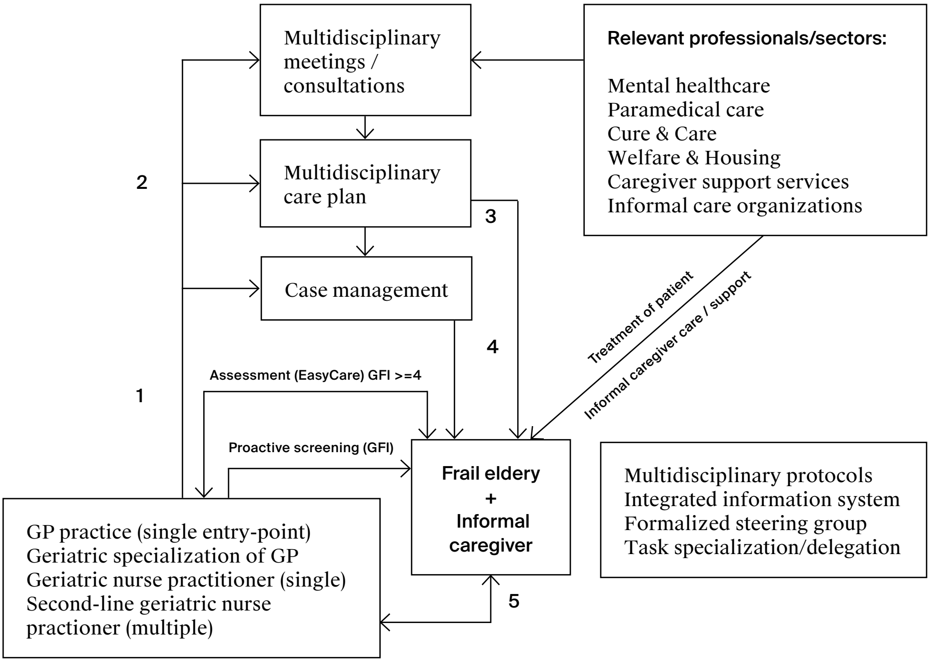
INTERVENTION

The study protocol and an extensive description of the intervention have been described elsewhere [21]. The Walcheren Integrated Care Model targets independently living frail elderly individuals (living in their own homes or in some form of assisted living) and their informal caregivers. It contains several evidence-based components: a screening tool for the detection of frailty in the elderly, a single entry point, an evidence-based comprehensive need assessment tool, a multidisciplinary individualized service plan, case management, multidisciplinary team consultation and meetings, protocol-led care assignment, a steering group, task specialization and delegation, and an Integrated Information System (Figure 1). The model was implemented in the Walcheren region in the southwest of the Netherlands in 2010 by the regional cooperative of general care practices and was funded by the regional healthcare insurer. Planning, design and funding of the WICM aimed to provide sustainable integrated care to frail elderly patients beyond period of evaluation of the current study (12 months).

Usual care for frail elderly patients in the Netherlands can be described as reactive and mono-disciplinary. General practitioners (GPs) are generally only consulted on the initiative of their patients. Patients have access to a number of care and curative services through referral of their GP, while other services, such as home-care and personal care services are arranged by municipalities [25]. Complex care services (e.g., injections, decubitus care) are available after formal approval by an assessment agency. Care as usual does not include multidisciplinary coordination or cooperation between these professionals, organizations and professionals. In contrast, the WICM has an outspoken proactive and multidisciplinary character, with the GP and primary care practice (PCP) functioning as a single-entry point for all care requests. This proactive character of the model adds a strong preventive element to the process.

The involvement of informal caregivers begins after screening and needs assessment of the care recipient during a visit by the case manager (step 1 in Figure 1). During this phase, the informal caregiver's needs for support and guidance are identified. Available services for informal caregivers normally include respite care or other forms of relief, as well as psychosocial interventions such as education and training or (group) counseling. In the WICM, the case manager provides the informal caregiver with relevant information, advice and suggestions regarding these services. If needed, the informal caregiver is brought into contact with relevant organizations or professionals. In addition, case managers may also provide practical advice (e.g., how to make care tasks less burdensome) or emotional support, depending on the informal caregiver's needs.

FIGURE 1. The Walcheren Integrated Care Model.



The case manager draws up care goals containing proposals for needed assistance and support in consultation with the care recipient and informal caregiver, ensuring the explicitly involved of the informal caregiver in the planning and subsequent provision of care (step 2 in Figure 1). The care plan is then discussed in a multidisciplinary meeting, which is attended by the general practitioner (GP), the case manager and any other care professionals relevant to the care process of the patient. During this meeting, tasks are assigned to the relevant professional based on multidisciplinary protocols. After final approval by professionals, the patient and the informal caregiver (step 3 in Figure 1), the care plan is incorporated into an Integrated Information System accessible to all relevant professionals. The case manager coordinates all care provision and periodically evaluates the care plan with the care recipient and informal caregiver (visits/telephone) to ensure adequate monitoring of their needs (step 4 in Figure 1). The frequency of periodic evaluations ranges from once a month to once a year, depending on the specific situation and needs of the care recipient and informal caregiver. In addition, patients and informal caregivers can contact their case manager at any time in between evaluations (step 5 in Figure 1).

Rather than being a global construct, satisfaction with care is generally regarded as a multi-dimensional construct [26]. Therefore, the literature on informal caregiver satisfaction with various types of care and support services was reviewed to determine the potential dimensions.

The first dimension of satisfaction with care is information provision. Informal caregivers greatly value clearly formulated care arrangements, adherence to these arrangements by professionals and adequate coordination [27-29]. In a study on satisfaction with case management, informal caregivers indicated that such clarity should extend to all information that is provided [27], including information regarding when, how and by whom care is provided, as well as information regarding the care recipient's disease trajectory and available care and support services [15,27-29]. Informal caregivers also need information to address patients' care and treatment demands themselves. Such information must be relevant, clear and understandable [4]. Furthermore, information provision should be directed toward relieving informal caregivers' uncertainties and managing their expectations [30,31]. Informal caregivers appreciate timely and ongoing communication, especially when changes have been made in care provision arrangements [27,32,33]. Care professionals should take sufficient time to convey such information adequately [4]. In addition, it is appreciated when communication occurs through one central source (e.g., the case manager or GP) [34].

A second dimension is associated with the feelings of control and involvement of informal caregivers. Satisfaction of informal caregivers depends on the degree of control over when, how and by who care is delivered [27]. Several studies have emphasized that it is necessary to involve informal caregivers actively in all aspects of care provision and care planning [28,29,34]. To foster informal caregiver satisfaction, care professionals should therefore collaborate with both the care recipient and his or her caregiver in the development and implementation of care plans [27,35]. Feeling part of a team and being treated as an equal by care professionals can contribute to informal caregiver satisfaction [34]. This sense of control also applies to informal caregivers knowing what is expected from them in terms of their roles and care responsibilities [27]. In this context, satisfaction can increase by discussing and determining the appropriate tasks of care professionals and informal caregivers [36].

A third dimension is best described as client-centeredness and professionalism. Client-centeredness is expressed by attentiveness to the needs, abilities and specific circumstances of care recipients and their informal caregivers [34]. It also involves care professionals being informed about the likes, dislikes and routines of the care recipients [5,27]. Professionalism is the manner in which care professionals approach and treat informal caregivers and care recipients. Empathy, supportiveness, compassion [5,34] and sensitivity [37] have been reported to be vital characteristics of care professionals that contribute to informal caregiver satisfaction. Informal caregivers want to be treated with respect and their care recipients to be treated with dignity [35].

The fourth and final dimension involves the quality and amount of care. Care and support services that are flexible and compatible with the needs of both the care recipient and informal caregiver have been reported to contribute to informal caregiver satisfaction [5,15,27-29,38]. Informal caregivers see the monitoring of the quality of care as an important part of their role [39]. Therefore, dissatisfaction can occur when there is a lack of adequate services, if the quality of services is perceived as insufficient or if there are considerable limitations to accessibility (e.g., long waiting lists) [27,34,40]. Dissatisfaction can also occur if many different care professionals are involved, especially when their composition is constantly changing [34]. In terms of support services for informal caregivers, it has been noted that the provision of assurance, advice and emotional support is important [15,35]. In addition, the provision of one-on-one professional guidance and ongoing case co-ordination is highly valued [5,15].

METHODS

STUDY DESIGN AND PARTICIPANTS

The design of this study was quasi-experimental and included before and after measurements and a control group. Baseline measurements (T0) were obtained prior to the intervention. Follow-up measurements (T1) were obtained 12 months after T0. The study protocol (protocol number MEC-2013-058) was reviewed by the medical ethics committee of the Erasmus Medical Centre Rotterdam in the Netherlands. The committee waived further examination, as the Medical Research Involving Subjects Act did not apply. The study subjects were informal caregivers of frail elderly patients in 8 primary care practices (PCPs) in the Walcheren region. Prior to the intervention, these patients were asked whether they received informal care, and if so from whom. Inclusion of informal caregivers as subjects in the current study was only possible if the patients received a type of formal care. This criterion was required, as informal caregivers would have to be able to assess formal care services. Written informed consent was obtained from all of the participating elderly patients and their informal caregivers.

Three PCPs (6 GPs) provided care according to the WICM and constituted the experimental group. The control group consisted of 5 PCPs (6 GPs) delivering care as usual. As patients (and their informal caregivers) that participated in the WICM were approached by the researchers, control practices were blind regarding the participation of patients and informal caregivers as control subjects. Thus, the possibility of patients being treated differently was ruled out.

DATA COLLECTION

Trained interviewers visited the participating frail patients at home. All of the interviewers lived in the region and had a background in elderly care. If the informal caregiver was present, data were collected using the questionnaire by face-to-face interview. If not, contact information was obtained from the elderly patient and the informal caregiver was approached by mail or telephone.

QUESTIONNAIRE

A literature search yielded no validated instrument to measure informal caregiver satisfaction applicable to the specific context of the current study. Other studies have used the Client Satisfaction Questionnaire (CSQ-8), a validated instrument to measure global patient satisfaction with services [41], and have adapted it for informal caregivers

[15,18,42]. However, the SCQ-8 was not deemed appropriate for the current study because of its global character. The authors decided that this global character would lack the sensitivity to the different components of (integrated) care services. Other instruments for assessing informal caregiver satisfaction exist, but they have only been validated for other types of care, such as hospital stroke care (e.g., [43,44]).

A questionnaire was thus constructed by the researchers based on the main dimensions derived from the literature. From these dimensions and from existing questionnaires [44,45], operationalizations were made (see Additional files 1 and 2 for the original questionnaire in Dutch and an English translation). One particular instrument that has been widely used in the Netherlands for the assessment of patient satisfaction, the Dutch Consumer Quality Index [45,46], served as the questionnaire's framework (e.g., form of questions, response categories). The final questionnaire consisted of 62 items: 29 regarding satisfaction with the care services provided to care recipients; and 33 regarding informal caregiver support services. The majority of items were designed using a Likert scale ranging from 1 (never) to 5 (always). Some of the items could only be answered with yes/no. Other questions demanded additional response categories: 'I do not know/No experience with that', 'not applicable', and 'not applicable/not necessary'. Items regarding age, sex and whether the informal caregiver lived with the care recipient were included as control variables [15]. In addition, the questionnaire contained several blank lines to allow subjects to note any additional comments. Filling out the questionnaire took an average of 20 minutes.

ANALYSIS

Analysis of the data occurred at the item level as well as at the dimension level. Before the analysis, all items containing more than 10% missing values were excluded. The Consumer Quality Index dictated that some items had to be recoded [47]. For items containing 2 response categories (no/yes), 'no' was recoded as 1 = never and 'yes' as 4 = always. Items 27, 33, 38, 45, 57 and 58 were coded in this manner. For items containing 3 response categories (never, once a year, several times a year), 'never' remained the same, and the 2 remaining categories were recoded as 4 = always. Items 14 and 43 were coded in this manner. Items 28 and 61 were contra-indicatively formulated. These items were re-coded in reverse order, allowing a low score to indicate low satisfaction.

ANALYSIS AT ITEM LEVEL

Within-group changes in item scores between T0 and T1 were determined using paired t-tests, McNemar's test or Wilcoxon's signed ranked test. For between-groups comparison, independent t-tests and the Chi-square tests (or Fisher's exact test) were used. The effect of the WICM was evaluated with linear regression or logistic analyses for each item. To assess the individual influences of variables, regression analysis was performed using 3 consecutive models. Model 1 contained the baseline measurement of the relevant item, Model 2 contained the control variables (age, sex, living together with the care recipient), and Model 3 contained the intervention as a variable. The significance of each model was assessed (<0.05). Individual effects were then assessed using a significance level of $p < 0.05$. However, in light of the relatively small sample, effects within the range of $p < 0.10$ have been reported as well.

FACTOR ANALYSIS

Using factor analysis, it was investigated whether the items of each theoretical dimension indeed constituted an underlying dimension. Primary component analysis (PCA) with oblimin rotation was used to evaluate and extract the factors of each dimension. These analyses were based on T0 scores, as there were no differences in the care delivery models at baseline. The dimensions served as a starting point for the PCA, and the items that were considered to operationalize the same dimension were therefore initially assessed for an underlying factor. Some dimensions lacked a 1-factor structure and therefore could not be made into a scale using their intended items. The subsequent process entailed the iterative inclusion and exclusion of remaining items in other scales to determine their potential fit. An important aspect of this iterative process was the alternation between quantitative and qualitative interpretation of the resulting scales. The contribution of adding and deleting items to the strength and reliability of the scales was assessed. After this quantitative assessment, the content of the items of the resulting scale was interpreted, thereby ensuring the qualitative consistency of the items. This iterative process of interpretation continued until the resulting items optimally represented their dimensions, both quantitatively and qualitatively. Items that could not be included in any scale were grouped together and assessed for underlying factors, to determine the existence of a potential new scale. Factor structures were checked by obtaining eigenvalues (>1) and scree plots. To assess the fit and significance, the KMO-Bartlett test (>0.6) and Bartlett's test of sphericity ($p < 0.05$) were performed [48]. Factor loadings of >0.4 were considered sufficiently high. After the factor analysis, scales were constructed. Scales with a Cronbach's alpha of >0.60 were considered to be reliable.

ANALYSIS OF SCALES

Scores for the resulting scales were calculated by computing the mean score for each respondent. The maximum for the missing values was one third of the items of a particular scale (half of the items for scales containing 4 items) [47]. The absence of a response constituted a missing value (not in case of 'not applicable'). As with the analyses of the items, the outcomes per scale were analyzed with t-tests, McNemar's test or Wilcoxon's signed ranked test, independent t-tests and Chi-square tests (or Fisher's exact test) and linear and logistic analyses. The regression models contained Model 1(baseline score of scale), Model 2 (control variables) and Model 3 (the intervention).

RESULTS

RESPONSE AND STUDY POPULATION

A total of 377 patients participated in the intervention with an average age of 82 years and an average GFI frailty score of 6/15. The majority of patients was female (65%), lived alone (61%) and lived independently (77%). Of these patients, 220 indicated to receive informal care. After identification, these informal caregivers were approached by mail or telephone (Table 1). The response rate of informal caregivers at T0 was relatively low at 47% (n = 104). A subsequent analysis of non-response indicated that this was primarily due to the fact that a substantial proportion of the care recipients received care from only one care professional or organization and therefore informal caregivers judged themselves unable to adequately assess (coordinated) services. An additional loss to follow-up of 39% (n = 41) between T0 and T1 resulted in a definitive study population of 63 respondents: 36 in the experimental group and 27 in the control group. This was substantially lower than expected in advance, as it was assumed that each group would contain approximately 150 patients and an equal amount of informal caregivers. Given a medium effect size of 0.15, significance of 5% and 5 independent variables, this would yield a power of 0.97. Due to the smaller sample, power was reduced to 0.60. Loss to follow-up was primarily the result of terminal illness or the death of the care recipient, the respondents not categorizing themselves as informal caregivers or changes in contact information. The majority of the definitive study population was female and did not live together with the care recipients. The respondents in the control group were significantly older than the respondents in the experimental group.

ANALYSIS AT ITEM LEVEL

The item regarding the rating of support for informal caregivers in general (0-10) was excluded from further analysis due to a large number of missing values. The groups showed differences on several separate items at both T0 and T1. In addition, a number of within and between-group differences were observed for both the experimental and control group. See Additional file 3 for an overview of scores on all items at T0 and T1 and the analysis of within and between-group differences.

TABLE 1. Response, loss to follow-up and description of study population

	EXPERIMENTAL GROUP	CONTROL GROUP
Informal caregivers approached	117	103
Response at T0	55	49
Loss to follow-up	19	22
Definitive study population	36	27
Age#	58 (sd = 9.5)	62 (sd = 9.5)
Male	19%	30%
Female	81%	70%
Living together (yes)	11%	15%

#$p < 0.10$; sd = standard deviation.

Regression analyses for each item showed that the WICM resulted in an increase in satisfaction with the degree to which care was provided according to the wishes of the care recipient ($p = 0.003$) (Table 2). Conversely, the model resulted in a decrease in satisfaction with the amount of help provided with administrative tasks ($p = 0.019$). In addition, the model showed a decrease in satisfaction with the understandability of the information provided ($p = 0.070$) and the degree to which informal caregivers knew which professional to call in cases of complaints, problems or emergencies ($p = 0.091$). For all of the items, T0 scores were the main predictor of scores at T1. In addition, the results showed that female informal caregivers were less satisfied with the degree to which care was provided according to the wishes of care recipients (*p* = 0.049), and older informal caregivers knew better which professionals to call (*p* = 0.087).

TABLE 2. Adjusted R2, β and p-values of dependent variables in regression analysis of item scores

SATISFACTION WITH CARE	ADJ. R2	T0	AGE	SEX	LT	WICM
Care provided according to wishes	30%	**.37****	.14	**-.29***	-.12	**.38****
Sufficient help with administrative tasks	37%	**.58****	-.25	.07	.27	**-.45***
SATISFACTION WITH SUPPORT	**ADJ. R2**	**T0**	**AGE**	**SEX**	**LT**	**WICM**
Understand information	23%	**.44****	-.10	-.03	.20	**-.24#**
Know who to call	29%	**.36****	**.27#**	-.20	.02	**-.20#**

*#p < 0.10; *p < 0.05; **p < 0.01; ***p < 0.001 (shown in bold). LT = living together; WICM = Walcheren Integrated Care Model.*

PRINCIPAL COMPONENT ANALYSIS

The principal component analysis indicated that the resulting scales only partly overlapped with the dimensions derived from literature. The Kaiser-Meyer-Olkin measurement verified the sampling adequacy, which ranged from 0.66 to 0.86. Bartlett's test of sphericity indicated that the correlations between the items of each scale were sufficiently strong (*p* < 0.05).

Satisfaction with care resulted in 6 scales (Table 3). Three items could not be included in any scale: satisfaction with the frequency with which professionals visited the care recipient; satisfaction with the promptness of services; and a general rating of the care provided. Items regarding satisfaction with the support provided to informal caregivers were categorized into 5 scales (Table 4). Five items could not be included in any scale: understanding the information provided; having control over one's role and care tasks; the evaluation of care by professionals with the informal caregiver; information provision regarding in-home adaptations; and assistance in finding activities.

ANALYSIS AT SCALE LEVEL

WITHIN-GROUP AND BETWEEN-GROUPS ANALYSIS.

No significant changes were found for scores on the scales for informal caregiver satisfaction with the care provided to the care recipient (Table 5), which was also the case for the scores for T1, for the difference between T0 and T1 within the groups and for changes between the groups. However, differences were found for the scales rating satisfaction with support. Within-groups analysis revealed that scores on the scale of 'being involved' significantly increased between T0 and T1 for both the experimental (*p* = 0.048) and control (*p* = 0.086) groups. Scores on the scale of 'attention to health and support' were higher at T1 for the experimental group (*p* = 0.058). However, these changes over time did not result in any significant differences between the experimental and the control group.

TABLE 3. Factor loadings of items on the scales for satisfaction of informal caregivers with the care provided to care recipients

SCALES						
ITEMS	CARE ARRANGEMENTS	INFORMATION/ INVOLVEMENT	PERSONAL INTERACTION	PROFESSIONALISM	CLIENT-CENTEREDNESS	SUFFICIENT ASSISTANCE
Professionals use care plan	.843					
Professionals coordinate visits	.739					
Professionals adhere to arrangements	.693					
Time of visits is suitable	.653					
Professionals involve care recipient in decisions		.829				
Professionals provide sufficient information		.804				
Care recipient understands information		.683				
Professionals evaluate care process frequently		.590				
Professionals coordinate care tasks			.767			
Professionals respond adequately to questions			.707			
Professionals are attentive to needs			.691			
Professionals are polite			.684			
Professionals have sufficient time			.612			
Professionals know needs of care recipient				.809		
Professionals are careful with belongings				.791		
Professionals collaborate well with others				.766		
Professionals provide good quality of care				.758		
Professionals are attentive to changes in health					.861	
Professionals are attentive to overall well-being					.833	
Professionals take functional ability into account					.794	
Professionals provide care according to wishes					.597	
Professionals help sufficiently with administrative affairs						.909
Professionals pay sufficient attention to safety						.849
Professionals help sufficiently with finding activities						.798
Professionals provide sufficient (emotional) support						.772
The care recipient receives sufficient care						.691

TABLE 3. (continued)

SCALES						
ITEMS	CARE ARRANGEMENTS	INFORMATION/ INVOLVEMENT	PERSONAL INTERACTION	PROFESSIONALISM	CLIENT-CENTEREDNESS	SUFFICIENT ASSISTANCE
KMO	.666	.711	.768	.721	.716	.812
Bartlett's Chi-square test	27.664***	23.591**	34.417***	51.327***	61.764***	42.232***
Eigenvalue	2.164	2.147	2.410	2.441	2.423	3.259
% variance	54%	54%	48%	61%	61%	65%
α T0	.71	.68	.71	.78	.78	.85
α T1	.73	.77	.80	.86	.78	.75

**$p<0.005$; ***$p<0.001$

TABLE 4. Factor loadings of items on the scales for satisfaction of informal caregivers with their support

SCALES					
ITEMS	INFORMATION	BEING INVOLVED	PROFESSIONALISM	COMMUNICATION/ ACCESSIBILITY	ATTENTION TO HEALTH/SUPPORT
Professionals provide sufficient information: care	.938				
Professionals provide sufficient information: services	.931				
Professionals provide sufficient information: expectations	.901				
Professionals provide sufficient information: how to care	.866				
Arrangements for emergency situations	.722				
Professionals discusses tasks with caregiver		.933			
Sufficiently involved in care decisions		.883			
Availability of professionals in case of problems		.853			
Professionals make arrangements if care changes		.845			
Professionals react adequately to questions/suggestions			.870		
Feel safe in proximity of professionals			.867		
Professionals take me seriously			.865		
Professionals have sufficient time			.863		
Professionals listen carefully			.863		
Professionals are attentive to needs			.851		
Professionals are polite			.613		
Professionals are easily accessible by phone				.964	
One professional/contact point				.875	
Know where to go/whom to go to with complaints				.861	
Information is provided about waiting time				.837	
Professionals keep each other informed				.631	
Professionals take needs into account					.974
Sufficient assistance and support are provided					.937
Professionals pay attention to changes in health					.930
Professionals pay sufficient attention to well-being					.922

TABLE 4. (continued)

SCALES					
ITEMS	INFORMATION	BEING INVOLVED	PROFESSIONALISM	COMMUNICATION/ ACCESSIBILITY	ATTENTION TO HEALTH/SUPPORT
Professionals provide sufficient emotional support					.852
Professionals take functional abilities into account					.850
KMO	.856	.827	.831	.762	.813
Bartlett's Chi-square test	98.932***	91.356***	193.426***	37.108***	91.119***
Eigenvalue	3.830	3.091	4.846	3.535	4.988
% variance	77%	77%	69%	71%	83%
α T0	.92	.89	.92	.86	.96
α T1	.86	.83	.82	.62	.92

***$p < 0.001$

REGRESSION ANALYSIS FOR SCALES

The WICM did not affect any scale measuring satisfaction with care (Table 6). Satisfaction with care at T1 was primarily a function of satisfaction with care at T0, with baseline score of the scales showing significance values ranging from 0.05 to 0.000. The greater the satisfaction with care was at baseline, the greater it was at follow-up. In addition, older informal caregivers were more satisfied with client-centeredness ($p = 0.060$). Regarding satisfaction with support, regression analyses revealed that the WICM had a marginal effect on the scale of 'attention to health and support', with a p-value just greater than the significant range ($p = 0.10$). Again, baseline scores were the main predictor of the scales and items measuring satisfaction with support, with significance values ranging from 0.01 to 0.000. An additional positive effect was found for living together on satisfaction with the degree of involvement ($p = 0.051$). For the scale of 'professionalism (IC)', the regression model was not significant.

DISCUSSION

This study explored the effects of the Walcheren Integrated Care Model on the satisfaction of informal caregivers with the care provided to elderly care recipients and with the support the caregivers received themselves. The WICM had no substantial effect on informal caregiver satisfaction with care and support services. At the item level, an increase was observed in the satisfaction with the degree to which care was provided according to the needs of care recipients. In addition, the WICM resulted in decreased satisfaction with the degree to which professionals provided sufficient help with administrative tasks, the understandability of the information provided and the degree to which informal caregivers knew which professional to call in cases of problems, complaints or emergencies.

The positive effects that were found suggest that from the informal caregiver's perspective, integrated care has the potential to provide care according to the needs of the care recipient. This finding provides some confirmation of one of the major objectives of integrated care [19]. The negative results were rather surprising, as the WICM explicitly aimed to address issues of transparency and information provision. In addition, the observed adverse effects were not in agreement with other studies, which reported increased caregiver satisfaction as a result of integrated care interventions similar to the WICM [15,18]. Both studies reported on the same intervention (SIPA), which included patient screening, care plan development, case management, a multidisciplinary team, protocols and a single entry point [49]. However, the SIPA intervention did not include the explicit involvement of informal caregivers in the planning and provision of care, while the WICM did. Moreover, the WICM paid substantial attention to the optimization of information provision to informal caregivers regarding available services and how to obtain these services. This difference between the WICM and SIPA intervention might also provide some explanation for the negative effects observed in the current study. Perhaps the additional efforts with the WICM to maximize information provision to informal caregivers regarding available services and how to obtain these services, as well as advice regarding how to perform certain care tasks adequately, were experienced by informal caregivers as interference. Potentially, the sum of such well-in-

TABLE 5. Within and between-group analysis of scale mean scores at T0 and T1

	EXPERIMENTAL GROUP			CONTROL GROUP			Δ GROUP
SATISFACTION WITH CARE	T0 (sd)	T1 (sd)	Δ	T0 (sd)	T1 (sd)	Δ	p
Care arrangements	3.3 (0.48)	3.3 (0.52)	0.03	3.4 (0.47)	3.3 (0.39)	-0.09	-
Information/involvement	3.3 (0.60)	3.2 (0.73)	-0.12	3.2 (0.69)	3.3 (0.41)	0.07	-
Personal interaction	3.3 (0.46)	3.4 (0.46)	0.07	3.4 (0.31)	3.4 (0.38)	0.02	-
Professionalism	3.5 (0.50)	3.4 (0.57)	-0.06	3.6 (0.45)	3.5 (0.43)	-0.05	-
Client-centeredness	3.4 (0.55)	3.4 (0.54)	0.05	3.5 (0.46)	3.4 (0.36)	-0.10	-
Additional assistance	2.9 (0.76)	2.9 (0.72)	-0.04	2.8 (0.85)	3.0 (0.55)	0.23	-
SATISFACTION WITH SUPPORT							
Information	2.1 (1.08)	1.9 (0.98)	-0.18	2.6 (1.30)	2.2 (0.88)	-0.41	-
Being involved	2.5 (0.92)	2.8 (0.87)	0.31*	2.8 (0.93)	3.1 (0.72)	0.25#	-
Professionalism	3.3 (0.54)	3.4 (0.39)	0.15	3.4 (0.44)	3.4 (0.45)	0.00	-
Communication/accessibility	3.2 (0.81)	3.2 (0.88)	-0.01	3.3 (0.78)	3.5 (0.58)	0.12	-
Attention to health/support	2.2 (1.08)	2.7 (1.26)	0.50#	3.1 (0.77)	2.8 (0.82)	-0.32	-

*#p < 0.10; *p < 0.05; **p < 0.01; ***p < 0.001. sd = standard deviation; Δ = difference between T0 and T1; Δ Group = difference between groups.*

TABLE 6. Adjusted R2, β and p-values for all scales

SCALES CR	ADJ. R2	T0	AGE	SEX	LT	WICM
Care arrangements	26%	.43**	-.26	-.08	-.03	-.06
Information/involvement	30%	.59**	-.04	-.01	-.19	-.12
Communication	18%	.39*	.12	-.17	-.00	.09
Professionalism (CR)	32%	.51***	.21	-.11	-.07	.02
Client-centeredness	43%	.57***	.27#	-.17	-.07	.17
Additional assistance	43%	.48***	.27	-.11	-.02	-.12
SCALES IC	**ADJ. R2**	**T0**	**AGE**	**SEX**	**LT**	**WICM**
Information	55%	.57***	-.06	-.22	.27	-.09
Involvement	47%	.53***	.14	.09	.27#	-.03
Professionalism (IC)	n.s.	-	-	-	-	-
Communication/accessibility	30%	.48***	.14	-.09	.09	-.11
Attention to health/support	61%	.73**	.29	-.04	.14	.35

*#p < 0.10; *p < 0.05: **p < 0.01; ***p = 0.000. LT = live together; WICM = Walcheren Integrated Care Model. CR = care recipient; IC = informal caregiver; n.s = model not significant*

tentioned efforts might have actually been counterproductive, resulting in information overload, thus reducing the understandability of the information provided and increasing the uncertainty and confusion of informal caregivers. Such counterproductive effects were described by Winslow [50], who noted that information overload by formal services is often experienced by informal caregivers as a major 'hassle'. Similarly, it is conceivable that the introduction of a case manager reduced clarity for informal caregivers regarding which professional would be the most appropriate to call in cases of problems, complaints and emergencies. While case management in the WICM aimed to provide a central source of information, one-on-one professional guidance and ongoing case coordination, such counterproductive mechanisms could not be ruled out. Indeed, Fabbricotti [51] noted that the introduction of coordinating roles, such as a case manager, could actually decrease clarity for care recipients and their informal caregivers, as they would need to interact with yet another professional.

Our instrument might provide another explanation for our results. While the SIPA studies [15,18] used a measurement of general satisfaction [41], the current study constructed an instrument that was thought to be more sensitive to various service elements, specifically those associated with integrated care. In addition, our approach incurred the risk of assessing satisfaction on a range that might have been too broad. Perhaps our instrument contained items regarding services that respondents simply had no experience with, in which case it would have been difficult to find effects. Another study regarding the effects of integrated care on informal caregiver satisfaction also used a self-constructed instrument [24]. However, those authors did not provide a description of the process of questionnaire construction or of the content of the questionnaire, making interpretation of their results difficult. Another issue related to the measurement of satisfaction is the fact that studies of satisfaction tend to produce high scores, making it difficult to detect changes (e.g., [15]). In addition, satisfaction scores are often robust over time, evidenced in the current study by T0 scores being the best predictor of T1 scores. However, as the range of scores in this study provided sufficient room for variance, any occurrence of improvements would have been detected.

A final explanation might be provided by the unequal distribution of co-residing and non-co-residing informal caregivers in the study population. The majority of our population did not live with care recipients, perhaps reducing the likelihood of interaction occurring between caregivers and formal services and professionals. In such cases, informal caregivers would have lacked experience with important characteristics of services, such as client-centeredness, professionalism and the manner and content of communication. Without such experiences, informal caregivers would not have been able to adequately assess these services, making it difficult to validly assess their satisfaction. In addition, it has been noted that spousal informal caregivers, i.e., those who co-reside with the care recipient, assess services differently than those who do not co-reside [4]. However, whether this difference affected our results remains unclear, as the relatively small sample of this study did not allow for subgroup analyses [52].

Some secondary results were observed, such as a reduction in satisfaction with the degree to which the care recipient's needs were taken into account for female informal caregivers and better knowledge of which professional to call in cases of emergency, problems or complaints for older informal caregivers. Co-residing informal caregivers showed greater satisfaction on the scale of being involved by professionals, and older informal caregivers showed greater satisfaction on the scale of client-centeredness.

LIMITATIONS

Constructing an instrument for a specific study context inherently entails a trade-off with the validity of the instrument, which constituted a limitation of the current study. However, while the benefits of validated instruments, such as the SCQ-8 [41], are evident, its use would require adaptations for informal caregivers [15,18,42], thereby substantially undermining the instrument's validity. The relatively small variance that was explained by the regression models indicated the existence of other control variables. Indeed, other variables have been shown to be associated with informal caregiver satisfaction with care services, such as increased level of impairment or more frequent disruptive behavior of the care recipient, the informal caregiver being part of a cultural minority in a country [53], education, marital status, social status [15] and employment status [54]. The relatively small sample size was another limitation as it substantially reduced the statistical power. The observed trend in increased satisfaction with attention to needs and health suggests that an effect might have been found with a larger sample [55]. Differences between groups may constitute a final limitation. Besides the observed age difference, it seemed that there was some overall difference in satisfaction at baseline. This makes it more challenging to show effects of the intervention.

ARE THE EXPECTATIONS JUSTIFIED?

This study raises the question of whether the existing expectations of the effects of integrated care on informal caregiver satisfaction are justified. Specifically, the lack of substantial positive effects, in addition to some negative effects, found in this study suggests that the assumption that integrated care increases informal caregiver satisfaction might not necessarily be true. While there is some evidence for positive effects, studies have simply been too scarce to draw any decisive conclusions. Moreover, this scarcity of evidence is in stark contrast with the substantial body of literature regarding integrated care. In the absence of evidence, the possibly inflated expectation of the beneficial effects of integrated care on informal caregiver satisfaction will continue to exist without being contested. In this sense, the debate on integrated care and informal caregiver satisfaction could benefit if the academic community would be more attentive to adverse effects. To this end, studies yielding no or negative results should be equally eligible for publication as those yielding positive results. As both integrated care and informal care have become major priorities in research and policy agendas, this need is even more urgent. Researchers and policymakers might need to consider the possibility that under some conditions, including informal caregivers in integrated care arrangements may have a downside. In other words, we should not readily assume that more informal caregiver involvement is always better, as the opposite might be true: perhaps less is more.

RECOMMENDATIONS

We recommend the development and validation of a comprehensive instrument to assess informal caregiver satisfaction with services. The resulting scales in the current study might provide guidance in this process. Future studies should also consider including a broader range of control variables. We also propose that in the design and implementation of integrated care arrangements, the possibility of adverse effects on informal caregiver satisfaction is considered. In addition, future studies of integrated care should investigate the assumption that co-residing informal caregivers react differently to interventions than caregivers who do not co-reside. This goal might be achieved by including a study population that is sufficiently large to allow for adequate subgroup analyses. Furthermore, it is recommended that the issue of co-residence also be taken into account in future integrated care interventions. This goal could be met by mapping the specific needs of co-residing informal caregivers qualitatively prior to designing the intervention.

CONCLUSION

The WICM did not substantially affect informal caregivers' satisfaction with the care for the care recipient or their satisfaction with the support the caregivers received themselves. The question can be raised whether the expectations regarding the beneficial effect of integrated care on informal caregiver satisfaction are justified.

LIST OF ABBREVIATION

WICM	Walcheren Integrated Care Model
GP	General practitioner
PCP	Primary care practice
CSQ	Client Satisfaction Questionnaire
PCA	Primary component analysis
SIPA	Système de services intégrés pour personnes âgées en perte d'antonomie.

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Do INTEGRATED CARE STRUCTURES foster PROCESSES of INTEGRATION? A QUASI-EXPERIMENTAL STUDY in FRAIL ELDERLY CARE from the PROFESSIONAL PERSPECTIVE

CHAPTER V

Janse, B., Huijsman, R., de Kuyper, R.D.M., Fabbricotti, I.N.
International Journal of Quality in Health Care 2016; 28(3), 376-383

ABSTRACT

OBJECTIVE

This study explores the processes of integration that are assumed to underlie integrated care delivery.

METHODS

A quasi-experimental design with a control group was used; a new instrument was developed to measure integration from the professional perspective. Setting and participants: Professionals from primary care practices and home-care organizations delivering care to the frail elderly in the Walcheren region of the Netherlands. Intervention: An integrated care intervention specifically targeting frail elderly patients was implemented. Main outcome measures: structural, cultural, social and strategic integration and satisfaction with integration.

RESULTS

The intervention significantly improved structural, cultural and social integration, agreement on goals, interests, power and resources and satisfaction with integration.

CONCLUSIONS

This study confirms that integrated care structures foster processes of integration among professionals. Trial registration: Current Controlled Trials ISRCTN05748494.

INTRODUCTION

Health systems worldwide are increasingly implementing integrated care as a strategy to deliver high-quality care to the growing number of elderly people. Integrated care is defined as 'a coherent set of methods and models on the funding, and the administrative, organizational, service delivery and clinical levels designed to create connectivity, [1]. Policy imperatives and reforms have been directed towards achieving more synergy within health systems, whereas local programmes and interventions have been implemented to coordinate clinical care for targeted populations in the community [2-4]. Frail elderly populations in particular are believed to benefit from integrated care, as their complex and continuously changing health and social problems render them in need of a wide range of services over a long period of time [5]. Integrated care interventions targeting frail elderly patients generally involve a multi-disciplinary team (led by a general practitioner), case management, patient care plans, shared ICT, multidisciplinary protocols and the delegation and specialization of tasks, often in conjunction with financial (e.g. integrated funding) and organizational arrangements (e.g. partnerships/network organization) [6, 7]. Whilst empirical evidence suggests that such combinations of (multi-level) components improve accessibility, quality and outcomes of care, there is considerable uncertainty as to how these improvements are achieved [6-9]. It is assumed that integrative structures foster processes of integration in the entire organization of care delivery, and that these processes are the prerequisite of effective integrated patient care [10, 11]. However, whether and to what extent integration occurs in the actual delivery of care remains unclear [3, 12].

Early integration efforts involved the redesign of organizational structures, centralized governance and top-down implementation strategies, but mostly failed to demonstrate better outcomes [13-15]. Research suggested that structural changes alone are insufficient for integrating services and patient care, prompting scholars to recognize the complex and nonlinear nature of the integration process [3]. For instance, professionals may fail to adopt integrative structures (e.g. shared protocols, meetings and ICT) into existing practice routines or may fail to establish the social and cultural bonds needed to collaborate effectively across professional boundaries. If so, the clinical care itself is likely to remain unchanged, even when organizational and administrative integration is achieved [16, 17]. The emphasis in the scientific discourse on integration subsequently shifted to operational activities (e.g. teamwork, knowledge exchange and communication) and cognitive, cultural and power differences between professional groups [16-18].

Despite the apparent importance of professionals in the success of integration efforts, there is a paucity of research on integrated care from their perspective [19, 20]. As a result, the processes of integration that are assumed to occur among professionals have thus far remained a 'black box' [7, 12]. Integration efforts are often costly, laborious and prone to failure. To identify the most effective integration strategies, insight into this black box is needed. As professionals have operational knowledge and insight into work processes, their perspective is one of the most reliable indicators of integration [11, 17, 21].

STUDY AIM

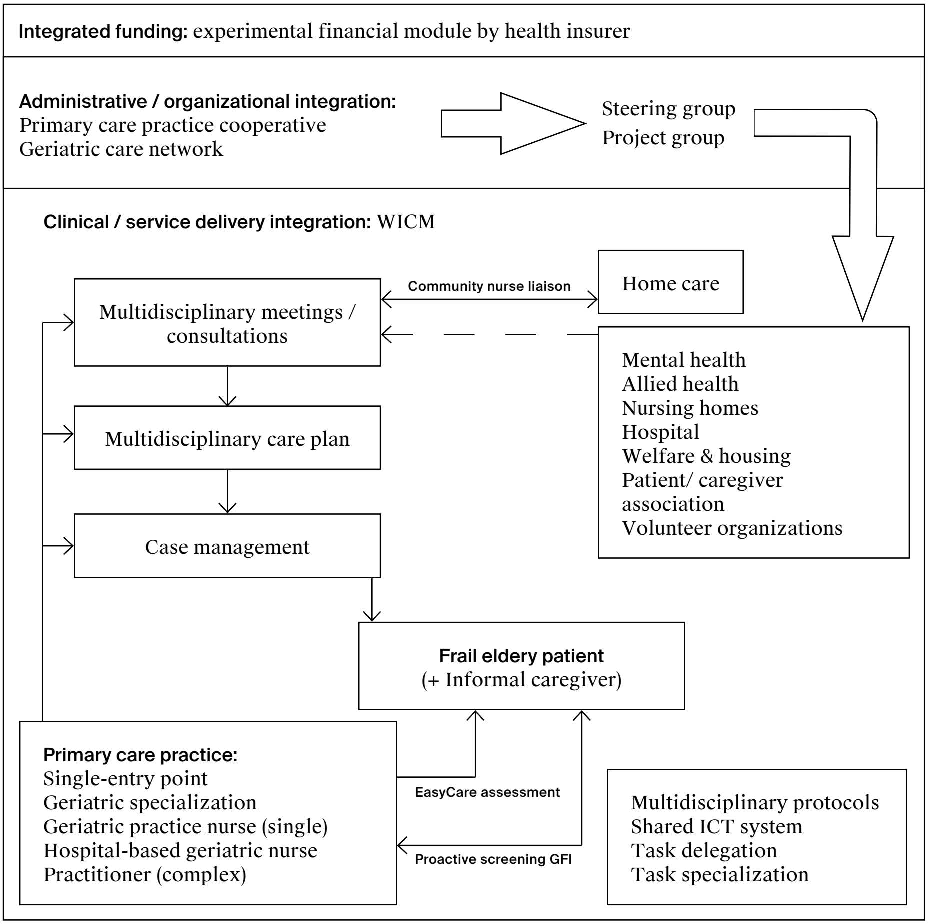
This study aimed to measure integration processes in the delivery of integrated care as perceived by professionals. In addition, satisfaction with integration was measured as this is rarely taken into account in evaluations of integrated care [10]. An intervention specifically targeting frail elderly patients was implemented in the Walcheren region of the Netherlands in 2010. The following research question was used: what is the impact of an integrated care intervention for frail elderly patients on the professionals' perception of and satisfaction with processes of integration?

INTERVENTION

A local cooperative of primary care practices (PCPs) initiated, developed and implemented the Walcheren Integrated Care Model (WICM). The WICM took a multi-level approach to achieve integration at the funding, administrative, organizational, service delivery and clinical level (Fig. 1). Integrated funding involved an experimental 'financial module' provided by the regional healthcare insurer to reimburse intervention-related costs to participating PCPs. Organizational and administrative integration was achieved through the creation of a geriatric care network, consisting of the PCP cooperative a hospital, a nursing home, the three largest home-care organizations, a mental health organization, allied health practices and elderly patient-, informal care and volunteer associations. Home-care organizations were important network partners, as they provide various services in the elderly patients' homes through small community-based teams consisting of a community nurse, general and specialized nurses and domestic helpers. Services range from around-the-clock supervision and/or specialized nursing care, home recovery/rehabilitation, home meal services, personal care and domestic assistance. Network partners, governmental social care/welfare organizations and the municipalities formed a 'steering group' that was responsible for the further development and planning of the WICM. A 'project group' of professionals was responsible for the development of multidisciplinary protocols.

To achieve integration at the service delivery and clinical level, PCPs served as a 'single-entry point' for patients, informal caregivers and professionals. Practices introduced 'preventive screening, case management, task delegation' and 'task specialization'. Specifically, the GP proactively screened all elderly patients (75+) for frailty using an 'evidence-based screening tool' (Groningen Frailty indicator) [22]. Tasks related to the coordination and planning of care, patient monitoring and managing medical records were delegated from the GP to case managers. Specialization involved the differentiation between a 'single-disease' case manager (a practice nurse) and a 'complex care' case manager (a hospital geriatric nurse-specialist). In addition to receiving specialty geriatric training, GPs and case managers had access to specialist knowledge of a hospital geriatrician that was available for consultations. After screening, frail elderly patients were assigned to a case manager who then performed a 'comprehensive assessment of needs' using a second evidence-based instrument (EASYcare) [23]. The case manager transformed the assessment results into an 'individualized care plan' that was then discussed in a 'multi-disciplinary group meeting'. These meetings were led by the GP and attended by the case manager, a community nurse and other relevant professionals, such as a hospital geriatrician, nursing home doctor, geriatric physiotherapist, social worker or psychologist. The community nurse represented the home-care organizations and acted as liaison by relaying the wishes, observations and suggestions of home-care nurses and domestic helpers to the WICM team. This arrangement aimed to better utilize the unique information and signaling function of home-care personnel, owing to their close proximity to patients and informal caregivers. After approval of the care plan by the team, tasks were assigned to the appropriate team member based on 'multi-disciplinary care protocols'. Subsequently, each professional could access the care plan through a 'shared information and communication system'. The care plan was periodically evaluated in a meeting, the frequency of which ranged from once a month to once a year, depending on the patient's condition.

FIGURE 1. The Walcheren Integrated Care Model



THEORY

CONCEPTUAL FRAMEWORK

In Donabedian's model of quality assessment, structures refer to the presence of the elements and resources needed to deliver care in a particular setting, processes denote the use of these structures in the actual delivery of care and outcomes are the consequences of processes [10]. Integrated care structures, processes and outcomes have often been conceptualized in a similar manner, starting with the placement of integrative structures that promote processes of integration, which eventually produce the desired outcomes [11, 19]. This generic framework has proved useful in previous evaluations of integration [10-15] and was therefore adopted in this study.

PROCESSES OF INTEGRATION

Integration is typically considered to be a multi-dimensional concept that consists of structural, social, cultural and strategic processes [24]. ‘Structural integration’ refers to the availability and functioning of mechanisms that promote inter-professional collaboration, coordination of tasks, functions and activities, and frequent, adequate and timely communication [25, 26]. Positive social relationships are developed as professionals gain mutual understanding, trust, respect and appreciation, and become aware of each other’s tasks [27]. These processes of ‘social integration’ further promote collaboration as professionals increasingly accept and use each other’s working methods and approaches [25]. ‘Cultural integration’ occurs when professionals develop shared norms and values, resulting in a shared culture [24, 25]. Developing a shared strategy is central to integration at the administrative and organizational levels and can therefore be referred to as ‘strategic integration’. A shared strategy describes the organizational structures and processes that further shape, govern and manage joint activities [28]. Developing a shared strategy in pursuit of integration requires ‘domain consensus’, which refers to the alignment of the goals and interests of stakeholders and reaching agreement on the distribution of power and resources. Insufficient domain consensus among professionals hinders the development of a shared strategy and, thus, of the entire integration process [25, 28].

METHODS

STUDY DESIGN AND PARTICIPANTS

The medical ethics committee of the Erasmus Medical Centre Rotterdam reviewed and approved the study protocol (No. MEC-2013-058). This study involved a quasi-experimental design with a control group. The experimental group consisted of professionals providing care to the frail elderly in the areas surrounding the three PCPs (six GPs) working with the WICM located in eastern Walcheren. The control group consisted of professionals providing usual care to the frail elderly in the areas surrounding the five control PCPs (five GPs) located in northern, southern and western Walcheren. Usual care for frail elderly patients in the Netherlands can be described as reactive and monodisciplinary. Patients generally consult their GP on their own initiative and can only access care and curative services through the referral of their GP. Participants were professionals from the eight participating PCPs (GPs, practice nurses, practice assistants and case managers) and the three largest home-care organizations (registered nurses and domestic helpers).

QUESTIONNAIRE DEVELOPMENT

Operationalizations and design

The few measures of integration that are currently available are limited to structural and cultural aspects of integration [19, 20]. The exceptions focus either on general aspects of integration at the system level [13] or one aspect of integration in a specific professional group [16]. A new questionnaire was therefore developed. On the basis of work of Fabbricotti [25], Gittell [26] and existing measures of integration [11, 14, 15], key indicators of structural, cultural, social and strategic processes of integration were selected and operationalized. Items were phrased to capture the professionals' perceptions of integration processes on a five-point Likert scale from 1 (not at all) to 5 (completely). Items relating to satisfaction were based on the key indicators, of which a selection was made to maintain the questionnaire's feasibility. Satisfaction items involved a seven-point Likert scale from 1 (extremely dissatisfied) to 7 (extremely satisfied), following a widely used measure in healthcare [29]. Items were included to account for age, gender, number of hours work per week, current position and number of years working in the current position. An additional item was included to determine the location(s) at which respondents were (most) active as professionals, through which they could be allocated to the control or experimental group. The questionnaire was designed according to the 'post-then-pre' principle, i.e. post- and baseline-measurements were performed simultaneously [30].

A panel of five professionals (one GP, three registered nurses and one domestic helper) assessed the face validity and clarity of the questionnaire. On the basis of their feedback, a number of items were simplified and a case description of a frail elderly patient was included. The aim of this case was to determine whether respondents were actually involved in the care to frail elderly patients; respondents were asked to indicate whether they regularly encountered similar patients in their work; if not, they did not have to fill out the questionnaire. The panel approved the revised questionnaire for distribution.

DATA COLLECTION

The questionnaires were distributed after all eligible elderly patients were included in the WICM, i.e. 18 months after implementation. In accordance with the post-then-pre principle, 'the current situation' equaled the post-measurement and 'the situation 18 months ago' equaled the baseline-measurement. Home-care organizations distributed the questionnaires internally to protect the privacy of their employees, and PCPs were sent questionnaires by mail. Supra-regionally operating care providers such as hospitals, nursing homes and allied health practices could not be allocated to the control or experimental group and were therefore excluded from the study.

ANALYSIS

Scale construction

All items satisfied our criterion of a maximum of 10% missing values, and therefore, none were excluded from further analysis. Negatively phrased items were reversed. Primary component analysis (PCA) with oblimin rotation was used to evaluate and extract the factors of each dimension based on baseline scores. For dimensions consisting of more than one factor, new scales were created. Items that could not be included in a scale were analyzed separately. Factor structure, fit and significance was assessed using Eigenvalues (>1), scree plots, the Kaiser–Meyer–Olkin measure (>0.7) and Bartlett's test of Sphericity ($p < 0.05$). Factor loadings of >0.4 and Cronbach's α of >0.70 (internal consistency) were considered sufficient.

Analysis of scales

The study population was described using means, standard deviations and percentages. The mean scale scores were calculated, after which linear regression analyses were performed to assess the effect of the intervention on these scores. Each analysis involved three regression models: Model 1 contained the scale's T0 scores (i.e. baseline 18 months prior), Model 2 added the control variables and Model 3 added the intervention. Control variables were age, gender, hours per week, years in the current position and 'employed by a PCP'. The latter was a transformation of the 'current position' variable into a dichotomous variable (yes/no) to better capture the central role of primary care in the intervention. It was expected that this central role would translate into primary care respondents perceiving higher degrees of integration than home-care respondents. All models and effects were considered significant at $p< 0.1$.

RESULTS

RESPONSE AND STUDY POPULATION

A total of 626 questionnaires were sent, of which 196 were returned. A total of 16 respondents were excluded because they were not involved in care delivery to frail elderly patients (n = 10) or because they could not be allocated to a group (n = 6). Hence, the definitive study population consisted of 180 respondents, which constitutes a response rate of 29% (Table 1). The majority of the study population was female; most respondents were domestic helpers (performing household and/or personal care tasks) employed by a home-care organization. The age of respondents was around 44 years; they had worked ~9 years in their current position and worked 21 h per week on average. The experimental and control group were equal in age, years in current position and hours per week, but differed significantly in terms of gender ($p = 0.071$) and the distribution of primary care practice professionals, i.e. GPs and nurses ($p = 0.001$).

PRINCIPAL COMPONENT ANALYSIS

The Kaiser–Meyer–Olkin of all scales ranged from 0.75 to 0.93, verifying the sampling adequacy of the analysis (Table 2). Bartlett's test showed that the correlations between the items in each scale were sufficiently large for principal component analysis ($p < 0.001$). All Eigenvalues were >1, ranging from 2.446 to 6.929. The total variance explained by the items in each scale ranged from 61 to 74%. Scales could be constructed for social and cultural integration and for satisfaction with integration. The items 'appropriateness of care' and 'timeliness of care' could not be included in the structural integration scale. Furthermore, the strategic integration dimension yielded two distinct scales that were labeled 'agreement' and 'hindering' of (differences in) goals, power and interests. All scales met the internal consistency criterion of >0.70, with most scales reaching values above 0.8.

MEAN SCORES AND REGRESSION ANALYSES

The mean scores ranged from 3.0 to 4.1 (1–5) on the integration scales and items and from 4.9 to 5.5 (1–7) on the satisfaction scale (Table 3). All scores increased between T0 and T1 in the experimental group, whereas several scores remained

TABLE 1. Response and Study Population

QUESTIONNAIRES SENT N=626	RESPONSE[A] N=180 (29%)	TYPE OF PROFESSIONAL	CONTROL N=120	EXPERIMENTAL N=60
Primary Care Practices** N=48	N=28 (58%)	GP	3	7
		CM/Practice nurse	3	5
		Practice assistant	5	5
Home-Care organizations N=578	N=152 (26%)	Domestic helper	85	36
		Registered nurse	24	7
Control variables		Male[#]	3%	10%
		Age	44.6 (SD 12.7)	43.7 (SD 11.6)
		Years	9.1 (SD 8.3)	8.4 (SD 7.6)
		Hours per week	20.8 (SD 9.6)	22.3 (SD 11.5)

GP= general practitioner, CM= case manager, SD= standard deviation.
*[a]response after exclusion #$p<0.1$, **$p<0.001$*

unchanged in the control group. Subsequent regression analyses indicated that the intervention significantly improved integration on all scales except 'hindering' (Table 4). Specifically, the intervention significantly improved structural integration (p = 0.005), social integration (p = 0.074), cultural integration (p = 0.031), the agreement on goals, interests, power and resources (p = 0.059), the satisfaction with integration (p = 0.000) and the appropriateness (p = 0.040) and timeliness of care (p = 0.019). Baseline scores were significant predictors for all scales and items (p = 0.000), 'working hours' was a significant predictor of structural and social integration, agreement, and satisfaction with integration (p = 0.042; 0.089; 0.086; 0.011, respectively) 'being employed by a PCP' was a significant predictor of structural integration (p = 0.033) and timeliness of care (p = 0.017). Finally, gender was the only significant predictor for 'hindering' (p = 0.041).

DISCUSSION

This study explored the processes of integration that are assumed to underlie integrated care delivery. The results showed significant improvements in structural, cultural and social integration, agreement on goals, interests, power and resources and satisfaction with integration after implementation of an integrated care intervention targeting frail elderly patients. This study thus confirms the widely held assumption that integrated care structures foster processes of integration among professionals [10-20].

It has been argued that integration merely indicates an organizational improvement that does not necessarily result in integrated patient care [17]. As well, the integration process has often been described as a complex and time-consuming undertaking that takes years to translate into actual changes in care delivery [11, 18, 21]. However, this study demonstrates that such changes can be achieved within a relatively short time span of 18 months. It also shows that local integrated care interventions such as the WICM provide a fertile ground for a fundamental

TABLE 2. Factor Loadings, PCA Statistics and Cronbach's Alpha of Scales

	SCALES OF INTEGRATION					
ITEMS	STRUCTURAL INTEGRATION	SOCIAL INTEGRATION	CULTURAL INTEGRATION	STRATEGIC INTEGRATION: AGREEMENT	STRATEGIC INTEGRATION: HINDERING	SATISFACTION WITH INTEGRATION
Professionals coordinate their activities (who does what)	.877					
Professionals keep each other informed regarding changes	.875					
Appropriateness of patient-related communication	.820					
Professionals coordinate their visits (who visits when)	.818					
Professionals collaborate adequately in case problems arise	.815					
Timeliness of patient-related communication	.800					
Accuracy of patient-related communication	.798					
Professionals evaluate their care provision jointly	.784					
Frequency of patient-related communication	.779					
Professionals involved in the patient's care understand each other		.902				
Professionals involved in the patient's care trust each other		.890				
Professionals involved in the patient's care appreciate each other		.874				
Professionals involved in the patient's care respect each other		.873				
Professionals are aware of each other's tasks and expertise		.753				
Professionals accept each other's methods of care provision			.862			
Professionals approach the patient in similar ways			.849			
Agreement amongst professionals regarding how care is provided			.825			
Professionals have similar values and standards in care provision			.817			
Professionals have similar goals in care provision				.822		
Professionals agree with the distribution of resources				.787		
Professionals have similar interests in care provision				.785		
Professionals agree with the distribution of power				.732		
Differences in distribution of power hinder integration					.895	
Differences in interests hinder integration					.868	
Differences in goals hinder integration					.822	

TABLE 2. (continued)

	SCALES OF INTEGRATION					
ITEMS	**STRUCTURAL INTEGRATION**	**SOCIAL INTEGRATION**	**CULTURAL INTEGRATION**	**STRATEGIC INTEGRATION: AGREEMENT**	**STRATEGIC INTEGRATION: HINDERING**	**SATISFACTION WITH INTEGRATION**
Differences in distribution of resources hinder integration					.810	
Satisfaction with the distribution of resources						.872
Satisfaction with methods of care provision						.837
Satisfaction with interaction between professionals						.825
Satisfaction with the distribution of power						.799
Satisfaction with shared goals						.793
Satisfaction with coordination of the content of care						.791
Satisfaction with the type of care that is provided						.779
Satisfaction with care to the frail elderly in general						.778
Satisfaction with how the patient is approached						.756
Satisfaction with timeliness of information						.746
Satisfaction with accuracy of information						.744
KMO	0.927	0.875	0.819	0.752	0.816	0.929
Bartlett's test Chi-Square	1043.75***	582.535***	297.677***	187.204***	326.354***	1314.063***
Eigenvalue	6.038	3.698	2.810	2.446	2.888	6.929
% Variance	67.1%	74.0%	70.3%	61.1%	72.2%	63.0%
α T0	0.94	0.91	0.86	0.79	0.87	0.94
α T1	0.93	0.89	0.81	0.71	0.86	0.92

***$p<0.001$

TABLE 3. Mean Scores (M) and Standard Deviations (sd) for T0 and T1

	EXPERIMENTAL GROUP		CONTROL GROUP	
	T0	T1	T0	T1
SCALES (RANGE)	M (sd)	M (sd)	M (sd)	M (sd)
Structural integration (1-5)	3.5 (0.81)	3.7 (0.71)	3.5 (0.70)	3.5 (0.70)
Social integration (1-5)	3.9 (0.66)	4.1 (0.49)	3.8 (0.64)	3.9 (0.62)
Cultural integration (1-5)	3.7 (0.59)	3.9 (0.47)	3.5 (0.66)	3.6 (0.57)
Strategic integration: agreement (1-5)	3.7 (0.54)	3.8 (0.42)	3.5 (0.56)	3.6 (0.50)
Strategic integration: hindering (1-5)	3.0 (0.89)	3.1 (0.89)	3.1 (0.81)	3.1 (0.80)
Satisfaction with integration (1-7)	5.1 (0.91)	5.5 (0.62)	4.9 (0.94)	5.0 (0.86)
Item: appropriateness of care (1-5)	4.0 (0.80)	4.1 (0.59)	3.9 (0.72)	3.9 (0.68)
Item: timeliness of care (1-5)	3.8 (0.73)	3.9 (0.58)	3.6 (0.76)	3.7 (0.65)

TABLE 4. Regression Analyses: Models, Adjusted R2, Coefficients (β) and Significance (p)

SCALE	MODEL	ADJ. R2	BASELINE	GENDER	AGE	HOURS	YEARS	PCP	WICM
Structural integration	1	68.9%	.831***	-	-	-	-	-	-
	2	72.4%	.861***	-.031	.008	.087#	-.076	.135**	-
	3	73.6%	.853***	-.016	.015	.102*	-.070	.100*	.119**
Social integration	1	54.9%	.743***	-	-	-	-	-	-
	2	57.0%	.745***	-.018	-.087	.096	.012	.087	-
	3	57.6%	.735***	-.006	-.083	.107#	.017	.058	.095#
Cultural integration	1	54.0%	.737***	-	-	-	-	-	-
	2	56.1%	.767***	-.048	-.014	.087	-.083	.086	-
	3	57.1%	.744***	-.030	-.007	.102	-.077	.049	.116*
Strategic integration: agreement	1	57.8%	.762***	-	-	-	-	-	-
	2	59.0%	.790***	-.049	-.001	.097	-.064	.046	-
	3	59.6%	.773***	-.036	.006	.106#	-.060	.015	.099#
Strategic integration: hindering	1	73.5%	.858***	-	-	-	-	-	-
	2	74.0%	.856***	-.102*	-.021	-.028	-.058	.028	-
	3	74.0%	.857***	-.098*	-.018	-.024	-.057	.018	.036
Satisfaction integration	1	48.5%	.699***	-	-	-	-	-	-
	2	53.6%	.708***	-.069	-.012	.136*	-.095	.106#	-
	3	57.3%	.679***	-.040	-.009	.160*	-.080	.049	.206***
Appropriateness of care	1	64.4%	.804***	-	-	-	-	-	-
	2	65.6%	.822***	-.051	-.032	.019	-.071	.092#	-
	3	66.2%	.809***	-.038	-.029	.029	-.066	.065	.097*
Timeliness of care	1	67.1%	.821***	-	-	-	-	-	-
	2	70.3%	.879***	-.037	.023	.070	-.068	.151**	-
	3	71.1%	.862***	-.027	.025	.079	-.063	.119*	.104*

#$p<0.10$; *$p<0.05$; **$p<0.01$; ***$p<0.001$; Adj. R2= Adjusted explained variance
PCP=employed by primary care practice; WICM=intervention

change in the process of care delivery. It is increasingly recognized that system and organization redesign in itself is insufficient or even unnecessary for achieving integrated care delivery, and that more focused interventions and micro-level approaches may be more appropriate [17]. Moreover, local integration efforts targeting specific patient groups may contribute to system-wide integration for all patients in the long run [2-4]. In this study, the 'integrators' (i.e. PCP professionals) constituted a small minority in a study population that was dominated by home-care professionals. The entire population nonetheless experienced improvements in integration, suggesting that, integrated working at intervention-practices affected other areas of care delivery as well, including community- and homecare. Alternatively, the intervention may have allowed home-care personnel to interact more frequently with case managers, providing them with better access to advice, support and equipment, and the opportunity to contribute to more effective care plans. If so, this study contradicts the popular belief that successful integration requires the active involvement of all professionals [17, 18, 21].

Our instrument proved a reliable measure of integration from the professional perspective, consisting of empirically and theoretically consistent scales. This instrument may be particularly useful in conjunction with other measures of integration. There is a growing consensus in the literature that multi-perspective evaluation frameworks that include system, organization, professional and patient inputs are needed to demonstrate the added value of integrated care [3, 19, 20]. The current instrument may contribute to the development and refinement of such frameworks.

The main limitation of this study is the relatively low response. A possible explanation is that only a certain subset of professionals was involved in the care for the frail elderly, resulting in the nonresponse of the majority. Another limitation is the lack of a process evaluation, as a result of which each intervention components' contribution to integration remains uncertain [2]. Finally, a pre-then-post design may evoke socially desirable responses. Although this does not outweigh its advantages, such as the minimal time investment for respondents, guaranteed anonymity and the reduced risk of response shift bias [30]. Future research is recommended to further test and validate the instrument developed for this study, preferably in conjunction with a process evaluation. More research is also needed to determine the impact of local interventions on system-wide integration, the role of (indirect) professional involvement and the explicit inclusion of home-care in the implementation of integrated care.

In conclusion, this study demonstrates that integrated care structures foster integration within the relatively short time span of 18 months, and without the active involvement of all professionals. These results, and the instrument that was developed, may contribute to the ongoing efforts to demonstrate the added value of integrated care.

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Delivering INTEGRATED CARE to the FRAIL ELDERLY: The IMPACT on PROFESSIONALS' OBJECTIVE BURDEN and JOB SATISFACTION

CHAPTER

VI

Janse, B., Huijsman, R., de Kuyper, R.D.M., Fabbricotti, I.N.
International Journal of Integrated Care 2016, 16 (3): 7

ABSTRACT

BACKGROUND

The impact of integrated working on professionals' objective burden and job satisfaction was examined. An evidence-based intervention targeting frail elderly patients was implemented in the Walcheren region of the Netherlands in 2010. The intervention involved the primary care practice as a single entry point, and included proactive frailty screening, a comprehensive assessment of patient needs, case management, multidisciplinary teams, care plans and protocols, task delegation and task specialization, a shared information system, a geriatric care network and integrated funding.

METHODS

A quasi-experimental design with a control group was used. Data regarding objective burden involved the professionals' time investments over a 12-month period that were collected from patient medical records (n = 377) time registrations, transcripts of meetings and patient questionnaires. Data regarding job satisfaction were collected using questionnaires that were distributed to primary care and home-care professionals (n = 180) after the intervention's implementation. Within- and between-groups comparisons and regression analyses were performed.

RESULTS

Non-patient related time was significantly higher in the experimental group than in the control group, whereas patient-related time did not differ. Job satisfaction remained unaffected by the intervention.

CONCLUSION AND DISCUSSION

Integrated working is likely to increase objective burden as it requires professionals to perform additional activities that are largely unrelated to actual patient care. Implications for research and practice are discussed. Current Controlled Trials ISRCTN05748494.

BACKGROUND

Integration is emerging as a central tenet of health systems [1]. As a result, professionals are increasingly required to deliver integrated care, particularly with respect to the growing population of community-dwelling frail elderly patients that are in need of complex and long-term care services from multiple organizations and providers [1-3]. Integrated care is generally defined as a 'coherent set of methods and models on the funding, and the administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment, and collaboration within and between the cure and care sectors' [3]. For professionals, it involves a shift from the traditional and hierarchical organization of care based on clinical disciplines towards patient-centered care delivery based on horizontal work processes [4-6]. To meet these new requirements professionals must reshape their roles, practices and philosophies and must acquire new routines and methods [6-10]. It thus seems inevitable that integrated care places new demands on professionals and changes their daily work. The question arises whether these changes are to the benefit of professionals.

Integrated care delivery is widely believed to eliminate inefficiency and duplication in work processes and to relieve professionals of administrative tasks in favor of patient-related activities, reducing their time pressure –or 'objective burden' – and frustration [1, 7-12]. Integrated working is assumed to contribute to a positive work environment by fostering inter-disciplinary collaboration and communication, and to increase job satisfaction by providing more opportunities for professional development and patient-centered care [10-15]. However, less favorable impacts may be equally plausible. Integrated care might hold considerable infringements upon the work, autonomy and identity of professionals, and its introduction might cause organizational upheaval, conflicts, deteriorating relationships and professional dissatisfaction [8, 16-18]. Moreover, integrated working might actually hamper workflows and thus increase objective burden [9-11]. Common integration mechanisms, such as multidisciplinary meetings and a shared information system, are typically placed on top of existing structures rather than replacing them, resulting in duplication and inefficiency and making coordination among professionals increasingly time-consuming [10, 11]. In addition, integrated working may require professionals to take on additional tasks alongside their day-to-day activities. For instance, the active recruitment of patients may increase patient flows, and collecting and documenting additional patient information involves actions that were not previously required [10, 19]. As well, integrated working requires professionals to learn new tasks and to absorb them into existing routines, which is likely to demand additional inputs of time [1, 7, 16-19].

The perceptions and experiences of professionals in the integrated care context have been well documented over the years [6, 7, 9, 11-13, 16-18]. Reports on integrated working often describe professionals experiencing increased time demands, intensive workloads and productivity problems [20-25]. Similarly, studies suggest that integrated working causes a shift towards more non-patient related activities, such as administrative tasks and team meetings [26-28]. Whilst the concerns regarding integrated working thus seem justified, the current evidence is largely based on self-report and qualitative data. Understanding the objective impacts of integrated care on professionals requires detailed data from formal administrative systems [29]. Such data are, however, extremely sparse in the literature, as a result of which little is known regarding the objective burden of professionals delivering integrated care.

The present study aimed to fill this gap by performing a comprehensive analysis of professionals' time investments during the first 12 months of integrated working. The research setting was the Walcheren region of the Netherlands, where an intervention was implemented that specifically targeted independently living frail elderly patients (and their informal caregivers). This 'Walcheren Integrated Care Model' was designed in accordance with the evidence at the time of implementation in 2010. In conjunction with the implementation of the intervention, a geriatric care network was created that included a hospital, a mental health organization, allied health practices and patient, informal caregiver and volunteering associations. Representatives of the network partners, municipalities, and social care and welfare agencies formed a formal steering group was responsible for the planning and implementation of the intervention. The regional health insurer provided an experimental financial module to reimburse all intervention-related costs to participating primary care practices. The present study was part of a large-scale evaluation of the Walcheren Integrated Care Model. The following research question was used: What is the impact of the Walcheren Integrated Care Model on the objective burden and job satisfaction of professionals?

METHODS

STUDY DESIGN AND SELECTION

The medical ethics committee of the Erasmus Medical Centre Rotterdam reviewed and approved the study protocol (No. MEC-2013-058). This study involved a quasi-experimental design with a control group. The experimental group consisted of 3 primary care practices located in eastern Walcheren that provided care according to the intervention, and the control group consisted of 5 primary care practices located in northern, southern and western Walcheren that provided care as usual. Control practices had not been involved in the intervention's development and did not use any of the intervention components. The selection of control practices continued until the control and experimental group consisted of a similar number of frail elderly patients.

Inclusion criteria of patients were age (≥75) and frailty. Frailty was measured with the Groningen Frailty Indicator, a validated and widely used screening instrument [30]. Practices provided the names and contact information of the patients that met the inclusion criteria. Patients were subsequently mailed an information leaflet, the screening instrument, an informed consent form and a postage paid envelope. The researchers identified frail elderly patients based on their screening scores (≥4) and provided their names to the intervention practices. Control practices remained uninformed regarding the frailty of their elderly patients during the evaluation period. Exclusion criteria for patients were being on a waiting list for a nursing home and having a terminal illness with a life expectancy of less than 6 months.

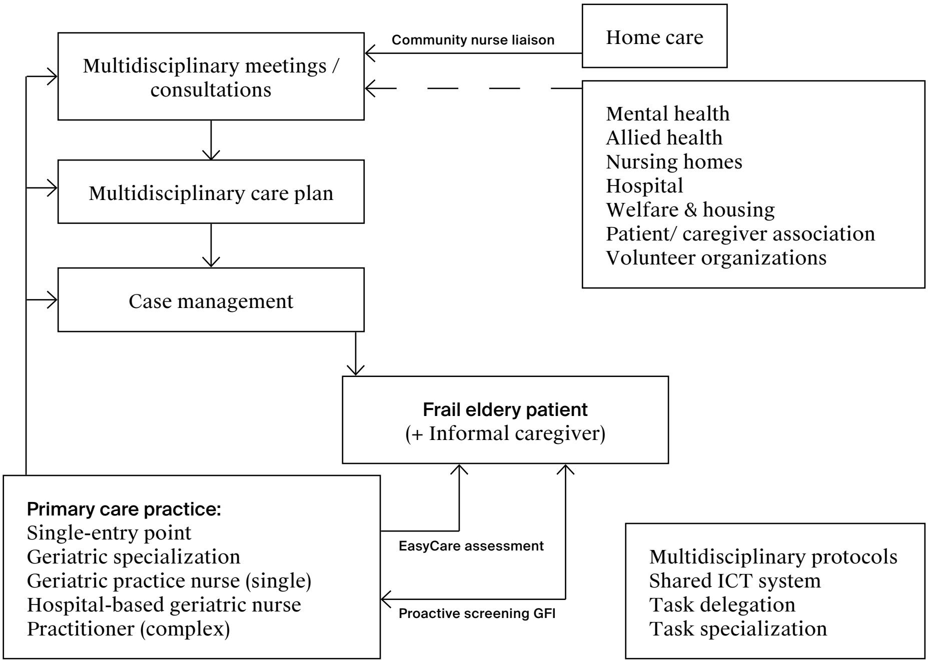
INTERVENTION

Care as usual in the Netherlands can be described as reactive. Patients usually consult with their general practitioner on their own initiative. Care and curative services can only be accessed through referral of their general practitioner [31]. Communication and information-exchanges between primary, secondary and tertiary professionals is typically bilateral and ad hoc. The aim of the Walcheren Integrated Care Model was to address these issues in the care for frail elderly patients in the community using the following components: a single entry-point, proactive screening, comprehensive needs assessments, case management, multidisciplinary group meetings, care plans and protocols, a shared information system, and task specialization and task delegation (*Figure 1*). The primary care practice functioned as a ***single entry point*** for frail elderly patients, their informal caregivers and professionals. All elderly patients (75+) were ***proactively screened***. Frail patients (frailty score ≥ 4; range 1–15) were visited by a case manager, who performed a ***comprehensive assessment*** of needs of patients and their informal caregiver(s) using an evidence-based assessment tool [32]. The results of the assessments were subsequently discussed in a ***multidisciplinary group meeting*** chaired by the general practitioner. The core team consisted of the general practitioner, a case manager and a community nurse employed by the home-care organizations. Home-care organizations provide various services in the patient's home, ranging from around-the-clock supervision and/or specialized nursing care, home rehabilitation, home meal services, personal care and domestic assistance, using small community-based teams of general and specialized nurses and domestic helpers. The community nurse acted as a liaison for home-care professionals by relaying their wishes, observations and suggestions to the intervention team. This arrangement aimed to better utilize the unique information and signaling-function of home-care professionals, owing to their close proximity to patients and informal caregivers.

Other professionals relevant to the patient's care trajectory, such as a hospital geriatrician, a nursing home doctor, a physiotherapist, a social worker or psychologist, could attend team meetings. The team formulated a ***multidisciplinary care plan*** in consultation with the patient and informal caregiver(s), after which tasks were assigned to the appropriate professionals according to ***multidisciplinary care protocols. Case management*** involved ensuring access to the appropriate services and planning, coordinating and monitoring care delivery. A specialized practice nurse performed 'single-disease' case management, whereas a hospital geriatric nurse-specialist performed 'complex care' case management. The care plan was periodically evaluated in a multi-disciplinary meeting, the frequency of which ranged from once a month to once a year, depending on the patient's condition.

The entire process was supported by ***task delegation***, task ***specialization*** and a ***shared information system***. Tasks relating to care coordination, patient monitoring and maintaining patient records were transferred from general practitioners to case managers. Geriatric specialization of general practitioners was a precondition for participation in the intervention. Postgraduate education programs for general practitioners in the Netherlands do not typically include geriatric care. Supplementary training was thus required to ensure that sufficient geriatric knowledge was available at intervention practices. Specifically, general practitioners gained insight into the associations between diseases and the daily functioning of frail elderly

FIGURE 1. The Walcheren Integrated Care Model



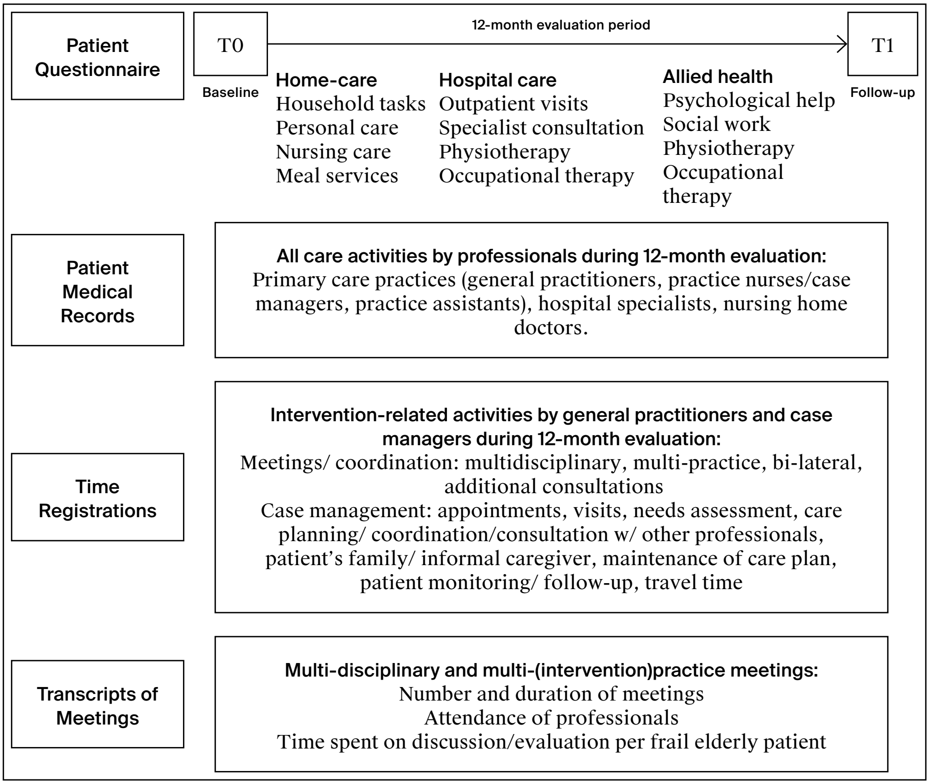
patients, and how to provide an integrated response to their needs by reshuffling tasks between primary, secondary and tertiary care. Case managers also received training in geriatric care, and completed courses on case management and the use of the evidence-based instruments. As well, a hospital geriatrician was available to intervention practices for consultation on complex cases. The shared information system allowed professionals to access and make adjustments to the care plan of a particular frail elderly patient.

DATA COLLECTION AND INSTRUMENTS

OBJECTIVE BURDEN

Data regarding the objective burden of professionals were collected from patient medical records, transcripts of multi-disciplinary meetings, time registrations of professionals and patient questionnaires. Written informed consent was obtained from all participating frail elderly patients. A total of 1845 frail elderly patients were approached, of which around 80% responded. Whilst 33% (n = 464) was subsequently identified as frail, a loss to follow-up of 19% between T0 and T1 resulted in a study population of 377 frail elderly patients, of whom the medical records were subsequently analyzed (see [33] for further details). The medical records were extracted on location from the information systems of the 8 participating primary care practices. These data involved all care activities related to the delivery of care to each frail elderly patient over a 12-month period by general practice professionals (general practitioners, practice nurses, practice assistants and case managers), hospital specialists and nursing home doctors (*Figure 2*). Additionally, transcripts of multi-disciplinary meetings were used to determine which professionals had attended and the amount of time spent per frail elderly patient. General practitioners and case managers of intervention practices provided time registrations of intervention-specific activities, i.e., multi-disciplinary meetings, bimonthly joint meetings with all intervention practices, additional meetings with other primary care providers and hospital specialists, and bi-lateral meetings between general practitioners and case managers. Case managers also provided time registrations of activities relating to case management: making appointments/visiting patients, needs assessment, formulation of care plan, patient monitoring, follow-up visits/calls, care planning/coordination and travel time. The standardized registration forms were faxed to the researchers on a monthly basis. Finally, participating frail elderly patients were mailed a questionnaire at baseline and 12 months later regarding their use of home-care (domestic helpers, home-care nurses), allied health services (occupational-/ physiotherapist, social worker, psychologist) and hospital care services.

FIGURE 2. Objective burden data collection



Objective burden was differentiated into patient-related (visits, consultations) and non-patient related activities (meetings, prescriptions, referrals, administrative tasks) and linked to standardized time-units (Box 1). For primary care practice professionals, these time-units were based on the consensus among the general practitioners. For hospital specialists, time-units were obtained from the *Dutch Manual for Economic Evaluations* [34]. Time-units for patient-related activities of allied health professionals were obtained from professional associations and insurance companies. However, information regarding their non-patient related activities was unavailable.

BOX 1. Standardized time units in minutes per patient

Primary care practice professionals	*Patient-related*		*Non-patient related*	
	Consultation by phone	5	Mail processing	0.5
	Consultation	10	Repeated prescription	3
	Double consultation	25	Consultation with general practitioner	5
	Visit	10	Consultation other practice	5
	Double visit	25	Consultation nursing home	5
	Visit (+30 min.)	35	Consultation specialist	5
	Other activities	0.5	Other consultations	0.5
Hospital specialists	*Patient-related*		*Non-patient related*	
Academic hospital	Outpatient consultation	15	Administration	5
General hospital	Outpatient consultation	10	Administration	3
Allied health professionals	*Patient-related*		*Non-patient related**	
	Duration of session	30	-	
	Duration of session	60	-	

**Not available. Other activities= injections, glucose measurement, urine checks; other consultations= patient's family, other professionals*

JOB SATISFACTION

Data regarding the job satisfaction of professionals were collected with questionnaires that were distributed 18 months after implementation of the intervention (i.e., after all eligible elderly patients had been included). For privacy reasons, home-care organizations distributed the questionnaires to their own employees. Allocation of home-care professionals to the control or experimental group was based on their responses to additional items in their questionnaires regarding the location(s) at which they were (most) active as care providers. Employees of primary care practices were mailed a questionnaire and were allocated based on their affiliation to either a control or experimental group practice. As allied health and hospital professionals operate regionally, they could not be allocated to a group and were therefore excluded from the questionnaire study. The questionnaire was pilot-tested by a panel of 5 professionals (1 general practitioner, 3 registered nurses and 1 domestic helper). Based on their feedback, a case description of a frail elderly patient was included. The case helped determine whether respondents were actually involved in the care for frail elderly patients. Respondents were asked to indicate whether they recognized the case in their daily work; if not, they did not have to fill out the questionnaire.

Job satisfaction was measured with the 'Job Satisfaction Scale', which has been validated in the healthcare setting reaching a high reliability ($\alpha = 0.86$) [35]. Its 10 items address a range of intrinsic and extrinsic dimensions of job satisfaction and consist of a 7-point Likert scale from 1 (extremely dissatisfied) to 7 (extremely satisfied). Items regarding background variables included: age, gender, number of working hours per week, current professional role and number of years of experience in this role [35, 36]. The questionnaire was designed according to the 'post-then-pre' principle, in which baseline and follow-up measurements are performed simultaneously [37].

ANALYSIS

In regard to objective burden, the time investments of all professionals were aggregated for each patient, and described using means, standard deviations and percentages. Within- and between-groups analyses were performed using paired or independent t-tests, McNemar's test, Wilcoxon signed ranked test, Chi Square tests and Mann Whitney U-tests. Linear regression analyses were used to examine the extent and direction of potential associations between time investments, frailty and the intervention. The internal consistency of the job satisfaction scale was checked using Cronbach's alpha, and missing values were imputed using the Expectation Maximization Method. All variables were described using means, standard deviations and percentages. The variable 'current professional role' was transformed into the dichotomous variable 'employed by primary care practice' to account for the central role of primary care practices in the development and implementation of the intervention. The new variable was included as a predictor in subsequent linear regression analyses. Regression analyses involved baseline scores (model 1), control variables (model 2) and the intervention (model 3). All models and effects were considered significant if $p < 0.05$.

RESULTS

PROFESSIONAL QUESTIONNAIRE

Six hundred and twenty-six questionnaires were sent, of which 196 were returned. A total of 16 respondents were excluded due to their uninvolvement in the care to frail elderly patients (n = 10) or because they could not be allocated to the control or experimental group (n = 6). This amounted to 180 respondents and a response rate of 29%. The majority of respondents were female and employed by a homecare organization, most of which working as domestic helpers (Table 1). The average age of respondents was 44 years. They worked around 21 hours per week and had been in their current positions for approximately 9 years. Whereas the experimental and control group were equal in terms of gender, age, years in current position and hours per week, the percentage of practice nurses/case managers and general practitioners was significantly higher in the experimental group.

JOB SATISFACTION

The internal consistency of the Job Satisfaction Scale was sufficient with values $\alpha = 0.82$ (T0) and $\alpha = 0.75$ (T1). Regression analyses showed that the intervention did not significantly affect job satisfaction (Table 2). Several control variables showed effects on separate dimensions of job satisfaction. Most notably, the number of work years negatively impacted the professionals' satisfaction with the responsibilities ($p = 0.004$), physical conditions ($p = 0.013$), opportunities to use one's own skills ($p = 0.013$), general work situation ($p = 0.002$), freedom of methods ($p = 0.007$) and number of work hours ($p = 0.002$). Age reduced professional satisfaction with colleagues ($p = 0.001$) but increased satisfaction with physical conditions ($p = 0.005$), the possibility to use personal skills ($p = 0.037$) and the number of work

TABLE 1. Questionnaire response and description of study population

RESPONSE (*n/n*)	**PROFESSIONALS** (*n*=180)	**CONTROL GROUP** (*n*=120)	**EXPERIMENTAL GROUP** (*n*=60)
Primary care (*28/48*)	General practitioner*	3	7
	Practice nurse /case manager*	3	5
	Practice assistant	5	5
Home-care (*152/578*)	Domestic helper	85	36
	Registered nurse	24	7
Control variables	Women (%) Men (%)	97% 3%	90% 10%
	Age (*M, SD*)	44.6 (12.7)	43.7 (11.6)
	Years in current position (*M, SD*)	9.1 (8.3)	8.4 (7.6)
	Hours per week (*M, SD*)	20.8 (9.6)	22.3 (11.5)

**p< 0.05; M=mean; SD=standard deviation*

hours (*p* = 0.016). Professionals employed by practices were more satisfied with the responsibilities (*p* = 0.044) and variation in their work (*p* = 0.020). Baseline scores were a predictor for all dimensions of job satisfaction (*p* < 0.001).

OBJECTIVE BURDEN

There was no significant difference between the control and experimental group in the mean total time investment and patient-related time investment of all professionals combined (Table 3). The mean non-patient related time investment of all professionals was, however, significantly higher in the experimental group than in the control group (t(375) = –21.947, *p* = 0.000). The mean of total time investments (t(375) = –3.149, *p* = 0.002) and non-patient related time investments (t(375) = –9.464, *p* = 0.000) of professionals of primary care practices (excluding case managers) were significantly higher in the experimental group, whereas no differences in patient-related time investment were observed. Similarly, the mean total time investment (t(375) = –6.231, *p* = 0.000) and mean non-patient related time investment (t(350) = –18.477, *p* = 0.000) of general practitioners was significantly higher in the experimental group, but there was no significant difference in their patient-related time investment. Practice assistants in the control group had significantly higher mean total (t(226.450) = 4.371, *p* = 0.000), patient-related (t(229.267) = 3.492, *p* = 0.001) and non-patient related (t(227.954) = 4.184, *p* = 0.000) time investments than practice assistants in the experimental group. Conversely, practice nurses in the experimental group had significantly higher mean total (t(318.930) = –3.573, *p* = 0.000), patient-related (t(305.667) = –3.327, *p* = 0.001) and non-patient related (t(349.917) = –3.437, *p* = 0.001) time investments than practice nurses in the control group. Finally, there were no significant differences between the experimental and control group in the time investments of hospital specialists, home-care professionals and allied health professionals.

Regression analyses were performed to examine the contribution of the intervention and patients' frailty to each type of time investment (Table 4). Frailty showed significant relationships with total, (*p* = 0.000), patient-related (*p* = 0.000) and non-patient related (*p* = 0.008) time investments of all professionals combined, whereas the intervention only showed significance on non-patient related time

TABLE 2. Linear regression analyses with job satisfaction scores (T1) as dependent variable, and baseline scores (T0), control variables and the intervention as independent variables

		PREDICTORS																				
		BASELINE			GENDER			AGE			NO. HOURS			NO. YEARS			PRACTICE			INTERVENTION		
Dimensions (1-7)	Adj.R^2	B	SE	β	B	SE	β	B	SE	β	B	SE	β	B	SE	β	B	SE	β	B	SE	β
Responsibility	.15	0.32	0.06	**.36**	0.01	0.31	.00	0.01	0.01	.07	0.00	0.01	.01	-0.03	0.01	**-.24**	0.37	0.18	**.16**	-0.07	0.13	-.04
Variation	.27	0.53	0.07	**.51**	0.36	0.31	.09	0.01	0.01	.08	0.01	0.01	.05	-0.01	0.01	-.09	0.44	0.19	**.17**	-0.07	0.13	-.04
Colleagues	.40	0.43	0.05	**.52**	0.09	0.30	.02	-0.02	0.01	**-.23**	0.01	0.01	.10	-0.01	0.01	-.09	0.30	0.18	.11	-0.02	0.13	-.01
Physical conditions	.59	0.69	0.05	**.73**	-0.21	0.28	-.05	0.02	0.01	**.16**	-0.01	0.01	-.06	-0.02	0.01	-.11	0.25	0.17	.09	0.21	0.12	.09
Skills	.54	0.77	0.06	**.73**	-0.19	0.31	-.05	0.01	0.01	**.13**	0.00	0.01	.01	-0.02	0.01	**-.16**	0.29	0.19	.09	0.10	0.13	.04
General situation	.23	0.45	0.07	**.44**	-0.01	0.01	-.02	0.01	0.01	.08	0.00	0.01	.03	-0.03	0.01	**-.25**	0.25	0.20	.10	0.17	0.14	.09
Freedom	.39	0.46	0.04	**.63**	-0.04	0.19	-.02	0.01	0.00	.14	0.00	0.01	.05	-0.02	0.01	**-.20**	-0.02	0.12	-.01	0.08	0.08	.06
Appreciation	.61	0.76	0.05	**.77**	0.38	0.27	.08	0.01	0.01	.06	0.01	0.01	.07	-0.00	0.01	-.03	0.14	0.16	-.05	-0.07	0.12	-.03
Remuneration	.82	0.92	0.03	**.92**	0.08	0.24	.01	-0.00	0.01	-.03	-0.00	0.01	-.02	0.00	0.01	.02	-0.06	0.15	-.02	-0.04	0.10	-.01
Hours	.75	0.84	0.04	**.86**	0.10	0.21	.02	0.10	0.00	**.11**	-0.00	0.01	-.02	-0.02	0.01	**-.14**	0.21	0.13	.07	-0.05	0.09	-.02
Total satisfaction	.37	0.53	0.05	**.61**	-1.26	1.80	-.05	0.02	0.03	.04	-0.01	0.04	-.02	-0.07	0.05	-.10	-1.06	1.07	-.07	-1.02	0.76	-.08

Adj.R^2 = Adjusted Explained Variance; B=Unstandardized Coefficient; SE=standard error; β = Standardized Coefficient (Bold= p<0.05). Bold=p<0.05. All reported regression models were significant (p<0.001)

TABLE 3. Mean and Standard Deviation of professionals' time investments in minutes per frail elderly patient over the 12-month evaluation period for the control and experimental group

	CONTROL GROUP (N=193 PATIENTS)						EXPERIMENTAL GROUP (N=184 PATIENTS)					
	TOTAL		PATIENT-RELATED		NON-PATIENT RELATED		TOTAL		PATIENT-RELATED		NON-PATIENT RELATED	
Type of professional	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
All professionals	11547	15733	11517	15726	30	41	12926	14439	12576	14433	**350**	194
Home-care	10989	15490	-	-	-	-	11833	14265	-	-		-
Allied health	369	907	-	-	-	-	352	1054	-	-		-
Hospital specialist	23	24	18	19	5	6	23	29	18	22	5	7
Primary care practice*	**165**	159	140	130	**25**	40	**212**	129	146	103	**66**	45
Case manager	-	-	-	-	-	-	230	281	115	140	115	151
General practitioner	**86**	76	83	73	**3**	7	**136**	81	86	66	**51**	34
Practice assistant	**52**	86	**32**	65	**19**	35	**24**	25	**15**	20	**9**	10
Practice nurse	**27**	47	**25**	40	**2**	9	**49**	69	**43**	63	**6**	12

**Excluding case managers. M= Mean; SD= standard deviation. Bold = $p<0.05$*

TABLE 4. Linear regression analyses with total, patient-, and non-patient related time investments as dependent variables, and frailty and the intervention as independent variable

		TIME-INVESTMENTS											
		TOTAL				PATIENT-RELATED				NON-PATIENT RELATED			
Type of professionals	Predictor	Adj. R^2	B	SE	β	Adj. R^2	B	SE	β	Adj. R^2	B	SE	β
All professionals	Frailty	0.12	2802	393	**.346**	0.12	2792	393	**.345**	0.02	10	4	**.089**
	Intervention	0.12	665	1466	.022	0.12	348	1467	.012	0.58	317	14	**.751**
Primary care practice	Frailty	0.02	10	4	**.134**	n.s.	-	-	-	0.02	3	1	**.110**
	Intervention	0.04	44	15	**.151**	n.s.	-	-	-	0.20	41	4	**.432**
General practitioner	Frailty	0.04	8	2	**.176**	0.03	6	2	**.169**	0.01	2	1	**.080**
	Intervention	0.12	49	8	**.294**	0.02	1	7	.011	0.49	47	3	**.699**
Practice assistant	Frailty	0.00	2	2	.060	0.00	1	1	.047	0.00	1	1	.060
	Intervention	0.05	-29	7	**-.220**	0.03	-18	5	**-.177**	0.04	-11	3	**-.211**
Practice nurse	Frailty	0.00	0	2	.010	0.00	0	1	-.001	0.00	0	0	.059
	Intervention	0.03	22	6	**.182**	0.02	18	5	**.171**	0.03	4	1	**.172**
Home-care	Frailty	0.11	2720	389	**.341**	-	-	-	-	-	-	-	-
	Intervention	0.11	152	1449	.005	-	-	-	-	-	-	-	-
Hospital	Frailty	n.s.	-	-	-	n.s.	-	-	-	n.s.	-	-	-
	Intervention	n.s.	-	-	-	n.s.	-	-	-	n.s.	-	-	-
Allied health	Frailty	n.s.	-	-	-	-	-	-	-	-	-	-	-
	Intervention	n.s.	-	-	-	-	-	-	-	-	-	-	-

Adj.R^2 = Adjusted Explained Variance; B=Unstandardized Coefficient; SE=standard error; β = Standardized Coefficient (Bold= $p<0.05$); n.s.= regression model not significant. Note: Values of B and SE are rounded up investments ($p = 0.008$). Frailty was significantly associated with total ($p = 0.009$) and non-patient time investments ($p = 0.018$) of primary care practice professionals, and the intervention with their total ($p = 0.003$) and non-patient related ($p = 0.000$) time investments. For general practitioners, frailty was related to total ($p = 0.000$), patient-related ($p = 0.001$) and non-patient related time investment ($p = 0.031$). The intervention showed significance on total ($p = 0.000$) and non-patient related time investment ($p = 0.000$) of general practitioners. No relationships were found between frailty and the time investments of both practice assistants and nurses, whilst the intervention showed significance in all 3 categories of time investment for both types of professionals ($p \leq 0.001$). These effects were negative for practice assistants and positive for practice nurses. Frailty was significantly associated with home-care professionals' total time investments ($p = 0.000$).

Overall, frailty explained little variance, whereas contribution of the intervention was considerable in non-patient related time investments of all professionals, general practitioners, and primary care practice professionals (from 1–2% of variance explained to 58%, 49% and 20%, respectively).

DISCUSSION

The aim of this study was to determine the impact of integrated working on professionals' objective burden and job satisfaction in the context of an intervention targeting frail elderly patients in the community. To our knowledge, this study is the first to use data from formal administrative systems to do so. The results demonstrate that professionals delivering care according to the Walcheren Integrated Care Model spent significantly more time on non-patient related activities than professionals delivering usual care, whereas no differences were found in time spent on patient-related activities. As well, professionals' job satisfaction was not affected by the intervention.

These findings confirm a major concern among scholars and professionals regarding the impacts of integrated working. It is widely believed that patient-centered care requires additional coordination activities on top of regular practice routines [8-10, 16-18]. Leutz [10] noted that 'integration costs before it pays', and many in his wake have noted that the up-front investments of integrated care are unavoidable, whereas the future pay-off is uncertain [2, 9, 10, 11, 38]. The transition towards integrated working is also believed to be a long-term process from which no short-term efficiency gains can realistically be expected [26]. The present study confirms that this is indeed the case, at least in the first 12 months of integrated working. However, given enough time, integrated working may prove beneficial, as it increasingly becomes a practice routine [11-13, 38].

In the present study, professionals from practices that delivered integrated care spent more time on non-patient related activities than professionals from practices that delivered usual care. Whilst this finding may not be surprising considering the additional intervention- and case management-related activities, it does raise questions regarding the long-term sustainability of integrated care. General practitioners already face considerable workloads, to which the responsibility of integrating care for specific patient subgroup only adds [10]. As well, intervention-related activities may supplant existing workloads of general practitioners and their staff. Professionals may feel compelled to work overtime at increasing personal cost just to maintain progress in the intervention [27]. Consequently, integrated care may cause staff burnout and retention problems, affecting its sustainability in the long run [7, 11, 27, 29]. Several authors have therefore called for better support of practices developing integrated care to offset the detrimental impacts on staff, for instance by providing additional financial and human resources [13, 18, 22, 38-42].

Intervention practice assistants had lower time investments than their counterparts in the control group, whereas the opposite pattern was observed in practice nurses. These small but significant effects suggest a transfer of certain tasks from assistants to practice nurses due to integrated working, perhaps signifying a process of task-redistribution that may persist well beyond the 12-month evaluation period. No significant difference in time spent by home-care professionals was observed between the experimental and control group, which likely reflects their lack of direct involvement in the intervention. Relatively little is known about the extent to which home-care professionals should be involved in integrated care for the frail elderly. Service users often report strong bonds with their home-care worker [43], which, in itself, may be ample justification for their involvement. However, home-care professionals are typically less qualified than primary care practice staff, which may hamper collaboration and the development of a common understanding of care for frail elderly patients [44].

Job satisfaction remained unchanged by the intervention. As the majority of respondents were home-care professionals, integrated working may have had little impact outside the practices at which it was implemented. Job satisfaction is largely insensitive to changes in the organization of care delivery, particularly if the work itself remains much the same [36]. The lack of effect on job satisfaction can also be interpreted as a positive result when considered in conjunction with the observed increase in objective burden. Professionals are typically skeptical towards new ways of working due to the additional time investments implied [23]. Non-patient related time investments in particular have been linked to low job satisfaction [14]. However, the use of different populations and data collection methods in the present study allows no definitive conclusions regarding an association between objective burden and job satisfaction in the integrated care context.

STRENGTHS AND LIMITATIONS

The main strengths of this study are the collection of objective data from formal systems in combination with information from other sources, and the use of a validated measure of job satisfaction. The main limitation was the relatively low response to the professional questionnaire. One explanation is that only a subset of potential respondents was actually involved in care for frail elderly patients. As well, recall over an 18-month period may not be entirely accurate. The ‘pre-then-post’ design can lead to socially desirable responses, although this seems to be outweighed by its advantages, i.e., a minimum time investment for respondents and reduced risk of response shift bias [37]. Self-reporting methods such as time registration forms are prone to inaccuracy, but are the only means of documenting intervention-related activities that are not documented elsewhere. Moreover, these forms provided only a fraction of objective burden data, the bulk of which was derived from patient medical records.

RECOMMENDATIONS FOR RESEARCH AND PRACTICE

Future research should focus on long-term impacts of integrated working on the objective burden and job satisfaction of professionals. Of particular interest is whether the initial time demands diminish over time and if the benefits for professionals, most notably job satisfaction, become apparent. Interactions between job satisfaction and objective burden could be examined by collecting data on both outcomes from a single population of professionals. Ideally, these data are collected over multiple years to determine how integrated working affects the process of task distribution over time. A longitudinal approach allows in-depth analyses of the contribution of separate integrated care components to objective burden. Furthermore, future research should address the role and involvement of homecare professionals in integrated care models for frail elderly patients.

This study begs the question whether the general practitioner should invariably be the 'chief integrator' and single-entry point. As the gatekeepers to the health system, general practitioners seem optimally positioned to lead integration efforts in the Netherlands. The central role of general practitioner is, however, not universal, and other professionals may be better equipped to drive integrated care efforts in other countries. Still, regardless of the setting, integrated care for the frail elderly is a complex undertaking that involves patients with complex care demands. It is therefore recommendable that the final responsibility of these initiatives rests with a medical doctor. Finally, integrated care is unlikely to produce short-term efficiency gains whilst almost certainly placing additional burden on professionals. Integrated care planning and practice should therefore be based on realistic expectations.

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FORMAL and INFORMAL CARE for COMMUNITY-DWELLING FRAIL ELDERLY PEOPLE over time: A COMPARISON between INTEGRATED and USUAL CARE in The NETHERLANDS

CHAPTER VII

Janse, B., Huijsman, R., Looman, W.M., Fabbricotti, I.N.
Health & Social Care in the Community, 2017; 00:1–10.

ABSTRACT

While integration has become a central tenet of community-based care for frail elderly people, little is known about its impact on formal and informal care and their dynamics over time. The aim of this study was therefore to examine how an integrated care intervention for community-dwelling frail elderly people affects the amount and type of formal and informal care over 12 months as compared to usual care. A quasi-experimental design with a control group was used. Data regarding formal and informal care were collected from frail elderly patients (n = 207) and informal caregivers (n = 74) with pre/post-questionnaires. Within-and between-group comparisons and multiple linear regression analyses were performed. The results showed marginal changes over time in the amount of formal and informal care in both integrated care and usual care. However, different associations between changes in formal and informal care were found in integrated and usual care. Most notably, informal caregivers provided more instrumental assistance over time if formal caregivers provided less personal care (and vice versa) in integrated care but not in usual care. These results suggest that integrated care does not necessarily change the contribution of formal or informal care, but changes the interaction between formal (personal care) and informal (instrumental) activities. Implications and recommendations for research and practice are discussed. Trial registration: Current Controlled Trials ISRNT05748494.

WHAT IS KNOWN ABOUT THIS TOPIC

- Community-based frail elderly care is a co-production between formal and informal caregivers;
- This co-production can be conceptualised as “complementation,” “supplementation” and “substitution”;
- Integrated care models are expected to result in new configurations of formal and informal care.

WHAT THIS PAPER ADDS

- Integrated care did not increase formal or informal care contributions over time, but resulted in a different pattern of associations between formal and informal care types in comparison to usual care;
- The associations in integrated care particularly involved formal personal care and informal instrumental assistance;
- Common conceptualisations of formal–informal care interactions may be less applicable to integrated care settings.

INTRODUCTION

Countries worldwide are struggling to provide care to the growing number of frail elderly people while being under economic pressure to reduce healthcare costs [1]. Frail elderly people have multiple physical, psychological and social problems that render them in need of a wide range of services over an extended period of time [2]. Health policy is increasingly directed towards replacing expensive institution-based elderly care with community-based services and informal care [3]. As a result, the greater part of frail elderly care is currently provided in the patients' private homes by paid professionals –or *formal* caregivers– and unpaid *informal* caregivers, such as spouses, children or close friends [4, 5]. In response, new care models for frail elderly people aim to coordinate formal and informal care, often through the development of integrated care arrangements [6, 7].

The concept of integrated care commonly refers to a coherent and co-ordinated set of health and social services from a range of organisations, provided to individual patients by both formal and informal caregivers [8,9]. The underlying rationale is that a single caregiver is unable to meet all care demands of frail elderly patients, and that all caregivers, both formal and informal, must therefore combine their efforts in a co-ordinated manner [10]. This requires a degree of collaboration and communication between formal and informal care that is often lacking in community-based elderly care [5]. Integrated care for frail elderly people typically involves a more active role of informal caregivers in the planning and delivery of care [11]. More frequent interactions between formal and informal care are assumed to foster the trusting relationship needed to "renegotiate" the division of care activities [3,12]. Ideally, a new configuration of tasks emerges that is more in accordance with the needs, abilities and preferences of the frail elderly and informal caregivers. This allows formal caregivers to shift their focus from filling gaps in informal care to supporting caregivers in performing their care tasks [13,14]. Support may involve (temporary) changes in the amount or type of tasks of informal caregivers at risk of overburdening, for instance by relieving them of their most demanding care tasks in favour of light household work, minor personal care tasks or companionship [15,16]. However, formal and informal caregivers' care goals and views regarding the services needed may also prove irreconcilable [7]. For instance, formal caregivers may fail to recognise the contribution of informal caregivers, whereas informal caregivers may have little confidence in the abilities of formal caregivers [6]. Moreover, integrated care may be used as a pretext to impose care services on frail elderly people. A growing distrust of formal care may cause informal caregivers and elderly patients to isolate themselves from services altogether [17].

The literature on elderly care has traditionally regarded formal and informal care as discrete entities, the interplay between which has long been neglected [18]. However, the collaboration between formal and informal caregivers of community-dwelling frail elderly people has since become a burgeoning field of inquiry. Recent studies have, for instance, identified the main determinants of formal and informal care use among elderly patients [13,19] and have described "mixed" elderly care networks in terms of composition and task division [20,21]. Others have shown how different health policies affect formal–informal care collaboration, and the importance of stable and long-term relationships among formal and informal caregivers in delivering consistent and high-quality community-based elderly care [22-25]. However, the current evidence is mostly based on cross-sectional research that ignores the temporal dynamics of community-based care for frail elderly people. Also, these dynamics have rarely been investigated in the context of integrated care, as a result of which empirical and theoretical literature in this area is limited. A number of authors have nonetheless noted that the increased involvement of informal caregivers in integrated elderly care can be expected to lead to higher informal care contributions over time [9,16,26].

With "integration" becoming a central tenet of community-based elderly care [27], a better understanding of its impacts on formal and informal care over time is needed. The present study therefore explored the impact of an integrated care intervention for community-dwelling frail elderly people on the amount and type of formal and informal care over a 12-month evaluation period. The intervention, the "Walcheren Integrated Care Model" (WICM), was implemented in the Walcheren region of the Netherlands early 2010 and was designed in accordance with the evidence at that time. The following research question was formulated: How does integrated care for frail elderly people affect the amount and type of formal and informal care over time as compared to usual care?

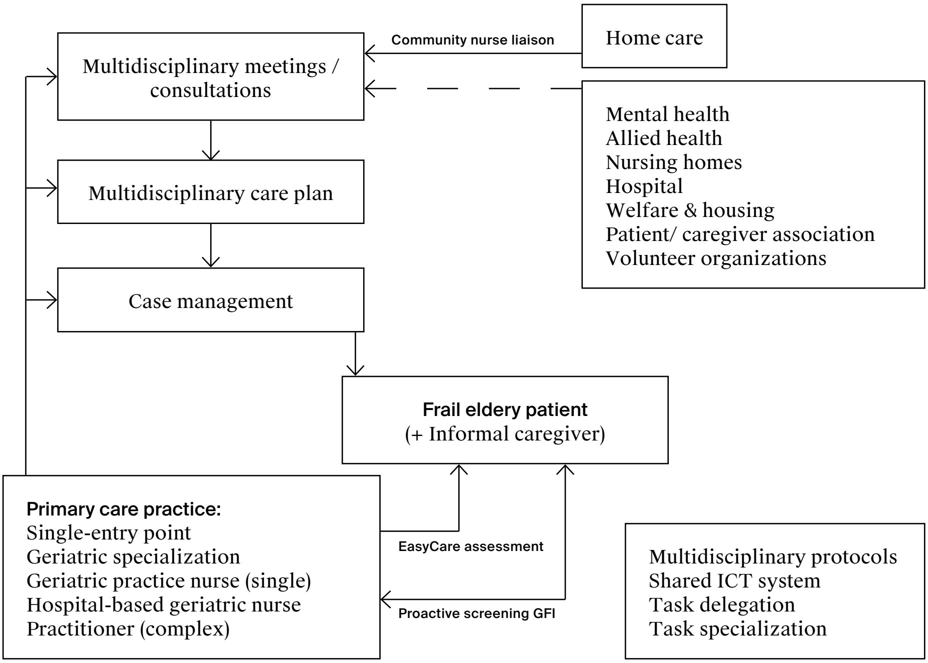
THEORY

Community-based elderly care is a co-production of formal and informal care, the interplay between which is typically conceptualized in terms of "complementation," "supplementation" and "substitution." Complementation refers to the segregation of activities based on each caregiver's particular abilities, with informal caregivers performing non-skilled care tasks (e.g. light household/personal care activities) and formal caregivers performing technical and skilled tasks (e.g. nursing care) [28,29]. Supplementation is the transfer of informal care tasks to formal caregivers if the informal caregiver is at risk of overburdening, often involving (temporary) respite of emotionally and/or physically demanding tasks, such as lifting, helping with bathing, (un) dressing and toileting [30]. Substitution occurs when an increase of a particular type of formal care corresponds with a decrease of its informal counterpart or vice versa [31]. Complementation and supplementation are seemingly in line with integrated care aims such as informal caregiver involvement and support, describing situations in which formal and informal providers jointly manage the overall care load by (respectively) dividing or sharing tasks [13,31].

INTERVENTION

Care as usual in the Netherlands can be described as fragmented and reactive. Elderly patients usually consult with their general practitioner (GP) on their own initiative. GPs are the gatekeepers to the Dutch healthcare system, and care and curative services are only accessible through their referral. Communication and co-ordination between primary, secondary and tertiary care is typically ad hoc. Caregiver support services (e.g. respite care, psychosocial counselling, educational/training programmes) are similarly fragmented across municipal agencies, home care and voluntary/informal care organisations [32]. The WICM consisted of multiple components that aimed to provide integrated and proactive care to community-dwelling frail elderly patients (Figure 1), a detailed description of which can be found in the research protocol [33]. Primary care practices (PCPs) served as single entry points for frail elderly patients and formal and informal caregivers. GPs proactively screened elderly patients (≥75) for frailty using the "Groningen Frailty Indicator" (GFI), assessing physical, cognitive, social and psychological functioning [34]. Patients with a score of ≥4 were considered frail. A case manager subsequently performed a comprehensive assessment of needs of the frail elderly patient and the informal caregiver (if present) using the evidence-based EASYcare instrument [35]. These assessments were then discussed in a multidisciplinary intervention team consisting of the GP, the case manager and the community nurse. The latter represented home care and acted as a liaison by relaying the observations and suggestions of home-care personnel to the intervention team. The aim was to better utilise the information and unique perspective of home-care professionals working in close proximity to patients and their informal caregivers. Other formal caregivers relevant to the patient's care trajectory, such as a hospital geriatrician, a nursing home doctor, a physiotherapist, a social worker or psychologist, could attend the multidisciplinary team meetings. A multidisciplinary patient care plan was then formulated, which also included suggestions for informal caregiver support services. The division of formal and informal care tasks was explicitly discussed and, if necessary, changed in accordance with the preferences and abilities of patients and informal caregivers. Care activities were assigned to the appropriate formal caregiver according to multidisciplinary care protocols. Case management in the WICM involved linking patients and informal caregivers to the appropriate services and ensuring their admittance to these services; care planning and delivery; and monitoring the progress of the care plan. The entire care trajectory was supported by a shared ICT system, task delegation and task specialisation.

FIGURE 1. The Walcheren Integrated Care Model



METHODS

DESIGN AND PARTICIPANTS

The medical ethics committee of the Erasmus Medical Centre Rotterdam reviewed and approved the study protocol (No. MEC-2013-058). This study involved a quasi-experimental design with a control group and before and after measurements with questionnaires [33]. The experimental group consisted of three PCPs (six GPs) located in eastern Walcheren delivering integrated care. The control group consisted of five control PCPs (five GPs) located in northern, southern and western Walcheren delivering care as usual. The potential study population consisted of all elderly patients and their informal caregivers of practices in the experimental and control group. The inclusion criteria for elderly patients were being 75 years or older, not being on a waiting list for a nursing home, not being terminally ill with a life expectancy of less than 6 months, and frailty (GFI score ≥4). Informal caregivers were defined as partners, family, close friends or neighbours who provide non-professional and unpaid care.

DATA COLLECTION AND INSTRUMENTS

Data were collected from frail elderly patients and informal caregivers with questionnaires at baseline (T0) and 12 months later (T1) between February 2010 and September 2011. Trained local interviewers with a background in elderly care visited participating frail elderly patients at home with the questionnaire. Patients were asked whether they received informal (i.e. non-professional, unpaid) care and from whom. If the informal caregiver was present, data were collected through face-to- face interviews; if not, a questionnaire was mailed to them. Data regarding formal care use were collected through patient questionnaires. Formal care involved all home care and day care. Home care was subdivided into household assistance, personal care and nursing care. Household assistance refers to paid domestic help with cleaning, doing laundry and groceries. Personal care includes help with bathing/washing, combing hair, and (un) dressing. Nursing care involves activities that require certain skills, such as giving injections and wound care. Day care refers to all daytime activities and care/support services that are provided within nursing homes and day care centres. Respondents were asked to indicate whether they received each type of formal care (yes/no) and, if so, the mean number of hours during the week of measurement. Additional items were included to account for the influence of the patients' age, sex and degree of disability on care use [16,25,31]. The degree of disability was determined with the Katz-15, a measure of independence in activities of daily living, such as bathing, dressing and toileting [36,37]. A higher sum score indicates more disability in performing daily activities. The Katz-15 showed high internal consistency, with a Cronbach's alpha of $\alpha = 0.80$ (T0) and $\alpha = 0.84$ (T1). Informal caregiver questionnaires included the "Objective Burden of Informal Care" instrument to determine the amount of informal assistance with household activities (e.g. food preparation, cleaning, laundry), personal care (e.g. help (un) dressing, washing/ bathing, toileting) and assistance with instrumental activities of daily living (e.g. help moving outside of the house, finances, administration) [38]. Informal caregivers were asked whether they performed each type of care task (yes/no) and, if so, to indicate the mean number of hours per week (during the week of measurement). The overall subjective burden of informal caregivers was measured with the Self-Rated Burden (SRB) scale. The SRB is a VAS-scale ranging from 0 (not at all) to 100 (too much) on which respondents indicate how burdened they currently feel by their informal care responsibilities. The generic SRB is more feasible and at least as valid as more extensive measures of informal caregiver burden, such as the CRA and SCQ [39]. The Community Services Attitude Inventory (CSAI) was included in the follow-up questionnaire to account for the informal caregivers' attitudes towards formal services after 12 months of integrated working. The CSAI consists of 18 items with a Likert scale from (1) strongly disagree to (4) strongly agree [40,41]. A higher sum score indicates less favourable caregiver attitudes towards formal services [42]. In the present study, the CSAI showed sufficient internal consistency with a Cronbach's alpha of $\alpha = 0.75$. Based on previous research [16,20,30,31], additional items were included to account for the informal caregivers' age, sex, paid employment and relationship with the elderly patient (spouse, daughter/son (in law).

DATA ANALYSIS

All items satisfied our criterion of a maximum of 10% missing data, and therefore none were excluded from further analysis. Missing values of the Katz-15 and CSAI were imputed using the series mean and median respectively. The study population was described using means, standard deviations and percentages. Within-group differences in mean care hours were analysed with paired t tests and chi-square tests. The difference in care hours at T0 and T1 (Δ) was computed for each care type. The Δ scores of the control group and the experimental group were examined using independent t tests, Chi-square tests or Fisher's exact tests. Multiple linear regression analyses were used to further examine the changes in care types over time (Δ hours) in the experimental group as compared to the control group. Regression models were constructed using stepwise selection, which involves the iterative placement and removal of predictors based on their contribution to the model's ability to predict the dependent variable [43]. The stepwise method can be used in exploratory model building, and is advised if a sound theoretical basis is lacking and to reduce the number of potential predictors [44]. Predictors of change in formal and informal care (Δ hours) were selected separately for the control group and the experimental group. Potential predictors were other care types (Δ hours), and background characteristic of frail elderly patients (i.e. age, sex, Δ Katz-15) and informal caregivers (age, sex, relation to the patient (partner yes/no), paid employment during the evaluation period (yes/no), Δ SRB, CSAI). Final regression models consisted of selected predictors for each care type in the control group and the experimental group. Models and effects were considered significant if $p < .05$. All statistical analyses were performed using IBM SPSS Version 24.

RESULTS

RESPONSE AND POPULATION

A total of 446 frail elderly patients were included at baseline, of which 262 received informal care. Between baseline (T0) and 12 months later (T1), 239 patients (53.6%) were lost to follow-up. The majorityof these losses were due to the patient's or their informal caregiver's unwillingness to continue participation (n = 196). Other reasons were the patient's death (n = 23), progressive disability/illness or dementia (n = 12) or long-term admittance to a hospital or nursing home (n = 8). The definitive study population consisted of 207 frail elderly patients and 74 informal caregivers: 115 patients and 39 informal caregivers in the control group and 92 patients and 35 informal caregivers in the experimental group. The average age of participating frail elderly patients was 81 years and the majority was female (Table 1). The experimental group consisted of significantly more women than the control group (*p* = .000). Frail elderly patients reported moderate levels of disability (Katz score ~3) at T0, which had increased significantly at T1 in the total population (*p* = .000) and the experimental group (*p* = .000) but not in the control group. This resulted in a significant difference in disability over time between the control and experimental group (△ Katz: *p* = .013). The average age of informal caregivers was 64 years, and more than half were female. The majority of informal caregivers were sons or daughters (in law), followed by partners. Over two-thirds did not have any paid employment during the evaluation period. Participating informal caregivers reported low to moderate levels of caregiver burden at both T0 and T1. Informal caregivers' attitudes towards community services (CSAI) were significantly more negative in the experimental group than in the control group (*p* = .013). In conclusion, the experimental group consisted of significantly more frail elderly women than the control group, showed a significant increase in disability over time, and significantly more negative informal caregiver attitudes.

FORMAL AND INFORMAL CARE

The total amount of care increased from around 6 hr of care at T0 to 7 hr at T1 (*p* = .029) in the total study population (Table 2). A third of participating frail elderly patients received informal care, averaging around 3 hr per week at T0. This increased significantly over the next 12 months to almost 4 hr per week at T1 in the total study population (*p* = .008), with a corresponding increase in the control group (*p* = .026). The most common types of informal care were household assistance and assistance in instrumental activities, both of which were received by around 30% of frail elderly patients. Instrumental activities constituted a fraction of all informal care hours, which consisted mostly of household tasks. Assistance in instrumental activities ranged between 0.5 and 0.9 hr per week at T0 and T1. However, household assistance increased significantly from 2 to 3 hr between T0 and T1 in the total population (*p* = .005) and in the control group (*p* = .006), but not in the experimental group. Informal personal care was provided to approximately 10% of frail elderly patients and constituted between 0.5 and 1 hr per week. Over half of frail elderly patients received a type of formal care during the 12-month evaluation period, averaging to around 3 hr per week. Household assistance was the main type of formal care, received by the vast majority of patients and accounting for around two-third of the total formal care hours. Between 16% and 18% of patients in the control and experimental group received informal personal care at T0. A (moderate) decrease in the control group and a 4% increase in the experimental group at T1 did not result in a significant difference between groups. The total patient population received around 1 hr of informal personal care per week at T0, which increased to 1.3 hr at T1 (*p* = .037). Only the experimental group showed a corresponding increase (*p* = .005), resulting in a significant between-groups difference (*p* = .006). Finally, relatively small proportions of the frail

TABLE 1. Description of the study population

FRAIL ELDERLY PATIENTS	**TOTAL POPULATION** *(n=207)*	**EXPERIMENTAL GROUP** *(n=92)*	**CONTROL GROUP** *(n=115)*
	M (SD)	M (SD)	M (SD)
Age	81 (4.3)	81 (4.3)	82 (4.3)
Female *n (%)*	141 (68)	**68 (74)*****	**73 (64)*****
T0 Katz (0-15)	3.1 (2.7)	3.0 (2.5)	3.3 (2.8)
T1 Katz (0-5)	**3.7 (3.1)*****	**4.0 (3.4)*****	3.5 (3.3)
△ Katz (-15-15)	0.6 (1.9)	**1.0 (2.3)***	**0.3 (1.6)***
Informal Care T0 *n (%)*	72 (35)	34 (37)	38 (33)
Informal Care T1 *n (%)*	74 (34)	35 (38)	39 (36)
INFORMAL CAREGIVERS	**TOTAL POPULATION** *(n=74)*	**EXPERIMENTAL GROUP** *(n=35)*	**CONTROL GROUP** *(n=39)*
	M (SD)	M (SD)	M (SD)
Age	64 (13.3)	62 (12.6)	66 (13.8)
Female *n (%)*	50 (68)	26 (74)	24 (62)
Relation to patient *n (%)*			
Partner (e.g. spouse)	26 (35)	12 (34)	14 (36)
Daughter/son (in law)	41 (55)	20 (57)	21 (54)
Other (e.g. neighbor, friend)	7 (10)	3 (8)	4 (9)
Paid employment *n (%)*	28 (40)	13 (39)	15 (41)
T0 SRB (0-10)	3.0 (2.5)	3.0 (2.5)	3.0 (2.3)
T1 SRB (0-10)	3.4 (2.6)	3.6 (2.5)	3.2 (2.7)
△ SRB (-10-10)	0.4 (2.6)	0.6 (2.6)	0.2 (2.5)
CSAI sum (18-72)	35.2 (5.3)	**36.8 (5.5)***	**33.7 (4.8)***

**p< 0.05; ***p< 0.001. Significant differences in bold*
M=Mean; SD=standard deviation; T0=Baseline; T1=post-measurement; △=difference score T1-T0; CSAI=Community Service Attitude Inventory; SRB=Self-Rated Burden Scale.

elderly patients in the study population received formal nursing care or day care, with 8%–13% and 3%–6% at T0 and T1, respectively.

REGRESSION ANALYSES

The amount of informal household assistance in the control group (Table 3a) increased if the caregiver was female (*p* = 0.032), and with increasing caregiver age (*p* = 0.000) and burden over time (*p* = 0.018); informal household assistance in the experimental group (Table 3b) increased with informal instrumental assistance (*p* = 0.000), but decreased if the caregiver was female (*p* = 0.007) and with more negative caregiver attitudes towards formal services (*p* = 0.014). Informal personal care increased with informal instrumental assistance in both the control group (*p* = 0.031) and the experimental group (*p* = 0.014). However, in the control group more informal personal care was provided to female patients (*p* = 0.000), whereas in the experimental group more personal care was provided if caregivers held more negative attitudes towards formal services (*p* = 0.017). Also, less personal care was provided in the experimental group if informal caregivers were older

TABLE 2. Formal and Informal Care in the Control and Experimental Group

	TOTAL M (SD)			**EXPERIMENTAL GROUP** M (SD)			**CONTROL GROUP** M (SD)			**GROUPS** ∆
Informal Care	T0	T1	∆	T0	T1	∆	T0	T1	∆	p
Informal Care *n(%)*	72 (35)	74 (36)	2 (1)	34 (37)	35 (38)	1 (1)	38 (33)	39 (34)	1 (1)	-
Total Hours Informal Care	2.8 (6.7)	3.9 (8.8)	**1.1 (5.5)***	2.7 (6.2)	3.7 (8.0)	1.0 (6.1)	3.0 (7.0)	4.0 (9.4)	**1.0 (5.0)***	
Household Assistance *n(%)*	55 (27)	61 (30)	6 (3)	27 (29)	30 (33)	3 (4)	28 (25)	31 (27)	3 (2)	-
Hours Household Assistance	2.0 (5.2)	3.1 (7.4)	**1.1 (5.3)***	1.9 (5.4)	2.7 (6.5)	0.8 (5.2)	2.0 (5.1)	3.2 (8.0)	**1.2 (5.3)***	
Personal Care *n(%)*	18 (9)	22 (11)	4 (2)	7 (8)	7 (8)	0 (0)	11 (10)	15 (13)	4 (3)	-
Hours Personal Care	0.4 (2.2)	0.4 (1.7)	0 (1.5)	0.4 (2.2)	0.4 (1.6)	-0.1 (1.7)	0.4 (2.1)	0.5 (1.7)	0.1 (1.4)	
Instrumental Assistance *n(%)*	55 (27)	51 (25)	-4 (-2)	27 (29)	27 (29)	0 (0)	28 (24)	24 (21)	-4 (3)	-
Hours Instrumental Assistance	0.6 (1.5)	0.7 (1.5)	0.1 (1.5)	0.6 (1.4)	0.9 (1.8)	0.3 (1.8)	0.6 (2.1)	0.5 (1.2)	-0.1 (1.2)	
Formal Care	T0	T1	∆	T0	T1	∆	T0	T1	∆	p
Formal Care *n(%)*	112 (54)	117 (57)	5 (3)	47 (51)	51 (56)	4 (5)	65 (57)	66 (57)	1 (0)	-
Total Hours Formal Care [a]	3.1 (5.1)	3.2 (4.6)	0.1 (4.3)	3.5 (6.1)	3.6 (4.9)	0.1 (4.8)	2.8 (4.1)	2.8 (4.3)	0.0 (3.9)	
Household Assistance *n(%)*	104 (51)	108 (52)	4 (1)	42 (47)	46 (51)	4 (4)	62 (54)	62 (54)	0 (0)	-
Hours household Assistance	2.2 (3.1)	2.2 (2.6)	0.0 (2.9)	2.4 (4.7)	2.2 (2.6)	-0.2 (4.5)	1.7 (1.9)	1.8 (1.9)	0.1 (1.5)	
Personal Care *n(%)*	34 (17)	36 (18)	2 (1)	16 (18)	20 (22)	4 (4)	18 (16)	16 (14)	-2 (-2)	-
Hours Personal Care	1.0 (2.6)	1.3 (3.2)	**0.3 (2.1)***	0.9 (2.2)	1.5 (3.3)	**0.6 (2.4)***	1.0 (3.0)	1.1 (3.0)	**0.1 (1.7)***	0.006
Nursing Care *n(%)*	16 (8)	26 (13)	10 (5)	6 (7)	10 (11)	4 (4)	10 (9)	16 (14)	6 (5)	-
Hours Nursing Care	0.2 (0.7)	0.3 (1.0)	0.1 (1.1)	0.1 (2.4)	0.3 (1.0)	-0.1 (1.2)	0.2 (0.6)	0.2 (0.6)	0.0 (0.8)	
Daycare *n(%)*	6 (3)	12 (6)	6 (3)	2 (2)	4 (2)	2 (0)	4 (4)	8 (8)	4 (4)	-
Hours Daycare	0.3 (2.1)	0.3 (2.3)	0.0 (0.6)	0.0 (1.9)	0.0 (0.8)	0.0 (0.0)	0.4 (2.2)	0.5 (2.9)	0.1 (0.8)	
Total Care Hours[b]	5.9	7.0	1.1*	6.2 (8.6)	7.2 (9.0)	1.0 (7.7)	5.7 (9.0)	6.8 (10.9)	1.1 (5.9)	-

p*<0.05;*p*<0.01; ****p*<0.001 (significant differences in bold). M=Mean; SD=standard deviation; T0=Baseline; T1=post-measurement; ∆=difference score T1-T0; ∆Groups=difference in ∆ (hours) of control and experimental group.* [a]*Home- and daycare combined;* [b]*Total informal and formal care combined*

($p = 0.001$) and more burdened ($p = 0.027$). The amount of informal instrumental assistance in the control group increased with informal personal care ($p = 0.078$), if the caregiver ($p = 0.000$) or patient ($p = 0.011$) was female, if the caregiver was employed ($p = 0.002$) or the patient's partner ($p = 0.000$), but decreased with more caregiver burden ($p = 0.000$) and more negative attitudes towards formal services ($p = 0.010$). In the experimental group, informal instrumental assistance increased with informal household assistance ($p = 0.000$) and personal care ($p = 0.039$), and if the caregiver ($p = 0.001$) or patient ($p = 0.000$) was female, but decreased if more formal personal care was provided ($p = 0.001$).

An increase in formal household assistance in the control group (Table 4a) was associated with the patients' increased disability over time (△ Katz: $p = 0.049$) and informal caregiver employment ($p = 0.020$). The negative predictor 'nursing care' was non-significant ($p = 0.150$) in the final regression model. No viable regression model could be constructed for formal household assistance in the experimental group (Table 4b). Formal personal care in the experimental group increased with nursing care ($p = 0.013$), the patients' age ($p = 0.020$) and increased disability over time ($p = 0.040$), but decreased with informal instrumental assistance ($p = 0.011$). No viable model could be constructed for formal personal care in the control group. Finally, nursing care decreased with formal household assistance ($p = 0.096$) and with the patients' disability over time ($p = 0.043$) in the control group, and increased with formal personal care in the experimental group ($p = 0.027$).

DISCUSSION

The aim of this study was to examine the changes in formal and informal care in the context of integrated care for the frail elderly in comparison to usual care over a period of 12 months. Few significant changes were found in the amount of formal or informal care over time in both conditions. Subsequent regression analysis however revealed different associations between formal and informal care types in integrated care as compared to usual care.

Most notably, an inverse relationship between *informal* instrumental assistance and *formal* personal care was found in integrated care but not in usual care. In other words, informal caregivers in the integrated care context provided less instrumental assistance over time if formal caregivers provided more personal care over time, and vice versa. This suggests that informal instrumental assistance and formal personal care may be more sensitive to change in the context of integrated care than other care types (e.g. household activities). It has been argued that certain care activities are routine regardless of care setting, whereas other tasks are more easily 'stimulated' through integrated working [8].

One explanation for the difference found between integrated and usual care may be the explicit attention to the informal caregiver in the WICM. The EASYcare instrument that was used to assess the elderly patients' needs also includes an assessment of informal caregiver needs and burden, the results of which are included in the elderly patient's care plan [35]. In the present study, the care plan may have involved changes in formal and informal care in accordance with the needs, abilities and preferences of frail elderly patients and informal caregivers. However,

TABLE 3. INFORMAL CARE (a) Control group. (b) Experimental group

	Δ HOURS					
	HOUSEHOLD ASSISTANCE		PERSONAL CARE		INSTRUMENTAL ASSISTANCE	
Predictors	B (SE)	95% CI	B (SE)	95% CI	B (SE)	95% CI
(a) Control group						
Informal Personal Care			-	-	.127 (.071)#	-.015 – .268
Informal Instrumental Assistance			.217 (.100)*	.020 – .414	-	-
Patient Sex			1.867 (.431)***	1.01 – 2.720	1.114 (.429)*	.264 – 1.964
Caregiver age	0.339 (.070)***	.200 – .477				
Caregiver Sex	4.059 (1.871)*	.352 – 7.766			1.687 (.437)***	.821 – 2.553
Relation (partner)					1.842 (.449)***	.952 – 2.732
Employment					1.319 (.418)**	.490 – 2.148
Δ SRB	0.748 (.308)*	.131 – 1.353			.281 (.069)***	.145 – .418
CSAI Sum					-.096 (.036)*	-.167 – -.024
Adj. R^2	19.2%		16.8%		35.7%	
(b) Experimental group						
Informal Household Assistance	-	-			.110 (.029)***	.053 – 167
Informal Personal Care			-	-	.182 (.086)*	.010 – .354
Informal Instrumental Assistance	1.042 (.287)***	.472 – 1.613	.236 (.094)*	.050 – .422	-	-
Formal Personal Care					-.313 (.091)**	-.494 – -.132
Patient Sex					2.304 (.554)***	1.2.2 – 3.405
Caregiver Age			-.063 (.019)**	-.100 – -.026		
Caregiver Sex	-4.825 (1.744)**	-8.291 – -.075			1.824 (.527)**	.776 – 2.871
Δ SRB			-.222 (.099)*	-.418 – -.025		
CSAI Sum	-.366 (.146)*	-.657 – -.075	.112 (.046)*	.021 – .204		
Adj. R^2	18.0%		23.5%		36.3%	

#= $p<.1$; *$p<0.05$; **$p<0.01$; ***$p<0.001$. Δ = *difference T0-T1*; B= *unstandardized Beta*; *SE= Standard Error*; *CI=Confidence Interval (lower – higher bounds)*; *Adj.* R^2= *adjusted explained variance.*

TABLE 4. FORMAL CARE (a) Control group. (b) Experimental group

	Δ HOURS					
	HOUSEHOLD ASSISTANCE		PERSONAL CARE		NURSING CARE	
Predictors	B (SE)	95% CI	B (SE)	95% CI	B (SE)	95% CI
(a) Control group						
Formal Household Assistance	-	-			-.082 (.049)#	-.180 – .015
Formal Nursing Care	-.254 (.175)	-.600 – -.093			-	-
Paid Employment	1.109 (.469)*	.180 – 2.038				
Δ Katz	.170 (.085)*	.001 – .338			-.092 (.045)*	-.181 – -.003
Adj. R^2	8.0%		No viable model		5.5%	
(b) Experimental group						
Informal Instrumental Assistance			-.225 (.086)*	-.397 – -.054		
Formal Personal Care			-	-	.080 (.036)*	.009 – .151
Formal Nursing Care			.688 (.272)*	.147 – 1.229	-	-
Patient Age			.084 (.035)*	.014 – .154		
Δ Katz			.139 (.067)*	.006 – .271		
Adj. R^2	No viable model		21.3 %		4.4%	

*#= $p<.1$; *$p<0.05$. Δ = difference T0-T1; B= unstandardized Beta; SE= Standard Error; CI=Confidence Interval (lower – higher bounds); Adj. R^2= adjusted explained variance.*

whether this was the case remains uncertain, as no data were collected regarding patient and caregiver preferences. The emphasis on informal caregiver involvement in the planning and delivery of care in the WICM may have also resulted in the renegotiation of formal and informal care tasks. Informal caregivers may become more aware of their own role in the care process due to integrated working, for instance when discussing the division of care tasks with the case manager [45]. Indeed, such explicit discussions of care activities have been argued to be essential to achieving a distribution of tasks that is more in line with the actual care situation [3,13,21].

This study provides no support for the expectation expressed in the literature that integrated care increases informal care contributions over time 9,16,26. However, the results are similar to a study of integrated care in the nursing home setting [8], in which it was hypothesized that integrated care would result in significant changes over time in the degree and nature of involvement and care activities of formal and informal caregivers. The authors concluded that although the relationships between formal and informal care activities changed over time, 'integrated care did not bring about the expected major changes' [8]. Also, the results do not support the notion that complementation and supplementation are congruent with integrated care aims (i.e., informal caregiver involvement and support). Formal and informal caregivers did not become increasingly complementary or supplementary by either sharing or dividing their care activities, nor is there evidence of substitution of informal care. It seems that the common theoretical models of interaction between formal and informal care may be less applicable to the integrated care context.

STUDY LIMITATIONS

The considerable loss to follow-up increased the risk of selection bias due to the non-response of the frailest elderly participants and the most burdened informal caregivers. Care for these 'frailest-frail' typically involves increasingly intensive services that substitute for informal care [31]. The inclusion of this subgroup (and their informal caregivers) in this study might therefore have yielded different or more pronounced results. Another study limitation may be that the regression models explained considerable proportions of variance in informal care but not of formal care. This indicates that background characteristics of frail elderly patients and informal caregivers are poor predictors of changes in formal care over time. Finally, only including the primary informal caregiver excludes the efforts of other informal caregivers. Primary caregivers may have called upon the broader social network for additional help and support. Any resulting changes in informal care that may have taken place within this broader network are likely to have remained undetected based on data from primary caregivers.

RECOMMENDATIONS

Further research is needed to better understand how the integration of community-based care for the frail elderly affects the dynamics between formal and informal care over time. In this context, the notion that instrumental assistance and personal care tasks are especially sensitive to change due to integrated care deserves further research attention. Future research might also focus on determining whether (elements of) integrated care contribute(s) to the desired outcomes for elderly patients and informal caregivers, by collecting additional data regarding their preferences for care, support and the division of care tasks. Future studies should also attempt to include and retain the 'frailest-frail' elderly patients as participants to adequately determine the impact of progressive disability on the amount and type of care over time. These impacts are likely better captured if the elderly patients' entire care network is taken into account, including all formal and informal caregivers [46]. Furthermore, studies of changes over time in formal and informal care should take additional predictors of formal care into account, such as characteristics and the availability of formal services and caregivers [47].

In conclusion, although the amount of formal and informal care changed only marginally over time, different patterns of associations between formal and informal care were found in integrated care and usual care. The associations in integrated care involved informal instrumental assistance and formal personal care, suggesting that these activities may be particularly sensitive to integrated working. Finally, existing theoretical models may be less applicable to describe formal and informal care in the integrated care context.

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CHAPTER

VIII

INTRODUCTION

Frail elderly care has become the shared undertaking of formal and informal caregivers, requiring a degree of coordination and collaboration that is often lacking in community care settings. Integrated care models are being developed to coordinate the efforts of formal and informal care [1]. Expectations regarding the benefits of integrated care for the frail elderly and their formal and informal caregivers have driven its widespread implementation in the past years. However, despite a wealth of literature indicating that integrated care can indeed improve quality and outcomes for elderly patients [2-5], if and how it might benefit their caregivers has remained uncertain.

The primary aim of this dissertation was therefore to examine whether the expectations of integrated care for formal and informal caregivers are justified by investigating three underlying assumptions, i.e., that integrated care for the frail elderly (1) safeguards informal caregivers against the negative impacts of caregiving; (2) improves the work processes and experiences of formal caregivers; and (3) improves the interaction between formal and informal care over time. These assumptions have been investigated with five research questions in the real-life setting of an integrated care intervention for frail elderly patients, the 'Walcheren Integrated Care Model' (WICM).

This chapter starts with a description of the main findings, followed by a reflection on theoretical and methodological issues. This chapter concludes with recommendations for integrated care research, policy and practice.

MAIN FINDINGS

Research Questions 1 & 2: What are the effects of an integrated care intervention for the frail elderly on the perceived health, objective burden, subjective burden, quality of life and satisfaction with care and support of informal caregivers?

These research questions focused on the assumption that integrated care for the frail elderly safeguards informal caregivers against the negative impacts of caregiving. Our study shows that the WICM significantly reduced the informal caregivers' subjective burden, but it did not affect their objective burden, perceived health, quality of life (Chapter 3) or satisfaction with care and support (Chapter 4). These findings confirm that integrated care for the frail elderly can in fact act as a safeguard against informal caregiver overburdening, but also that this does not necessarily translate to (the perception of) better health or quality of life. Moreover, the study results indicate that integrated care for the frail elderly does not substantially change the amount or type of care provided by informal caregivers, nor does it affect their appraisal of care and support services received.

Research Questions 3 & 4: What are the effects of an integrated care intervention for the frail elderly on the formal caregivers' perception of and satisfaction with integration processes, and their objective burden and job satisfaction?

These research questions focused on the assumption that integrated care for the frail elderly improves the work experiences and processes of formal caregivers. Our study shows that the WICM resulted in significant improvements in formal caregivers' perception of and satisfaction with structural, social, cultural and (elements of) strategic integration (Chapter 5). Formal caregivers providing care in accordance with the WICM spent significantly more time on non-patient related activities than formal caregivers providing usual care (Chapter 6). Contrary to what might be expected, however, the increase in objective burden due to the WICM was not associated with a reduction in job satisfaction. The study findings show that delivering integrated care for frail elderly patients can signify additional workloads for formal caregivers whilst fostering integration processes among them.

Research Question 5: How does an integrated care intervention for the frail elderly affect the amount and type of formal and informal care over time?

The final research question focused on the assumption that integrated care for the frail elderly improves the interaction between formal and informal care. This investigation involved a comparison of the changes in formal and informal care over time in integrated care and in usual care (Chapter 7). The findings indicate that the overall amount of formal and informal care changed only marginally over time. However, the WICM resulted in different dynamics between formal and informal care in comparison to usual care. The observed differences suggest that instrumental and personal care activities are particularly sensitive to change in the context of integrated care. However, common theoretical conceptualizations of formal-informal care interactions appear to be less applicable to integrated care settings.

In summary, the impact of integrated care delivery on objective burden was marginal for informal caregivers and decidedly negative for formal caregivers, whereas the interaction between formal and informal care activities changed over time. Informal caregivers nonetheless experienced considerable improvements in the caregiving situation, whereas the work experience of formal caregivers remained unchanged despite the additional demands of integrated working. The satisfaction with care delivery of informal caregivers was not affected but increased in formal caregivers. It can be concluded that many of the expected improvements were not observed in our study, although important positive impacts have been shown. These findings indicate that integrated care for the frail elderly can be expected to safeguard informal caregivers against some negative impacts of caregiving, but improvements for formal caregivers and formal-informal care interactions should not be readily expected. It can thus be concluded that the assumptions regarding the benefits of integrated care for the frail elderly on formal and informal caregivers are not entirely justified.

THEORETICAL REFLECTIONS

IMPACTS OF INTEGRATED CARE ON INFORMAL CAREGIVERS

In the present study, integrated care reduced the subjective burden of informal caregivers whilst other caregiver outcomes remained unaffected (Chapters 3 & 4). This is inconsistent with previous studies of integrated care reporting improvements in informal caregiver satisfaction but no impact on burden [5,6], but also reporting no impact on caregiver satisfaction and an increase in burden [7,8]. Furthermore, no impacts on informal caregivers' quality of life, objective burden or subjective burden were found in a recent evaluation of an intervention similar to the WICM [9]. The empirical evidence for a beneficial effect of integrated care for the frail elderly on informal caregivers thus remains thin. However, this is partly due to the ongoing lack of research attention to the impacts of integrated care on informal caregivers. Indeed, systematic reviews on the effectiveness of integrated care for the elderly share the conclusion that informal caregiver-related outcomes remain rare in evaluations of these interventions [2,10,11].

Differences in the integrated care models under investigation may explain differences in outcomes for informal caregivers. It may be particularly relevant to consider how and to what extent informal care is involved and supported in some of the most extensively described integrated care models in the literature: SIPA, PRISMA, SWING, PACE and the recent ISCOPE (Table 1). The 'System of Integrated Care for Older Persons' (SIPA), the 'Program of Research to Integrate Services for the Maintenance of Autonomy' (PRISMA) and the 'South Winnipeg Integrated Geriatric Program' (SWING) have all been described as 'patient-focused' models that do not prioritize informal caregiver support [5-7]. The 'Program for All-inclusive Care for the Elderly' (PACE), in contrast, aims to reduce the burden of informal caregivers by engaging them in care planning and by providing education and (additional) household/personal home-care services and respite services (e.g. daycare, inpatient respite care) [8,12]. Similarly, the 'Integrated Systematic Care for Older People' (ISCOPE) model includes the informal caregivers' wishes, expectations and needs in the elderly patients' treatment plans [9]. The PACE and ISCOPE models thus actively pursue more informal caregiver support and involvement, in which they are highly similar to the WICM. Unlike the WICM, however, PACE and ISCOPE yielded no beneficial impacts on informal caregivers [8,9], whereas the 'patient-focused' SIPA, PRISMA and SWING models increased informal caregiver satisfaction with care and either maintained or increased subjective burden [5-7]. These studies thus suggest that integrated care models with explicit aims relating to informal caregivers do not necessarily translate to better outcomes for informal caregivers, and that models lacking such aims may even contribute to higher satisfaction rates among informal caregivers. Nonetheless, the present study shows that a reduction in caregiver burden can be achieved through integrated care.

The question remains, however, why integrated care models for frail elderly people are seemingly unable to benefit informal caregivers as expected. In the PACE studies, for instance, the lack of results was explained by arguing that informal caregivers likely interact less with the intervention than the elderly participants, despite efforts to increase caregiver involvement [8,12]. Another explanation may be that integrated care interventions for frail elderly patients typically target informal caregivers as a homogenous group whilst, in reality, they constitute heterogeneous target populations. In the ISCOPE study it was suggested that the intervention's focus might have been too broad, targeting elderly people in general instead of specific risk factors in both patients and informal caregivers [9]. Similarly, in the present study it was argued that informal caregivers who do not live with the frail elderly patient probably interacted less with (elements of) the intervention and were therefore likely impacted less by it (Chapters 3 & 4). Following this line of reasoning, integrated care may be more effective if it allows a tailored approach to dif-

TABLE 1. Overview of Integrated Care Models and Outcomes for Informal Caregivers

MODEL	COUNTRY	AUTHORS [REFERENCE]	IC INVOLVEMENT & SUPPORT	OUTCOMES	
SIPA	CAN	Beland *et al.* [5]	No	Satisfaction Burden	+ 0
PRISMA	CAN	Hebert *et al.* [7]	No	Burden	+
SWING	US	Montgomery *et al.* [6]	No	Satisfaction Burden	+ 0
PACE	US	Atherly *et al.* [8] Friedman *et al.* [12]	Yes	Satisfaction	0
ISCOPE	NL	Blom *et al.* [9]	Yes	Objective burden Subjective burden Perceived Health Quality of Life	0 0 0 0
WICM	NL	This study [Chapters 3 & 4]	Yes	Satisfaction Objective Burden Subjective Burden Perceived Health Quality of Life	0 0 - 0 0

CAN= Canada; US= United States; NL= the Netherlands. IC Involvement = informal caregiver involvement & support are explicit aims

ferent subgroups of frail elderly patients and informal caregivers, for instance based on specific risk factors, relationship (e.g. spousal vs. non-spousal) and place of residence (e.g. co-residing vs. non-co-residing).

Apart from considering how integrated care models differ in their approach of informal caregivers, it is relevant to look at the elements shared by these interventions to better understand their effectiveness. Case Management (CM) is widely recognized as an effective means of addressing specific needs of both frail elderly patients and informal caregivers in the community setting [13]. CM is therefore a central component of community-based integrated care for frail elderly people [14,15], such as the WICM and the other models described above. Studies in elderly care suggest that CM primarily improves the extent to which informal caregivers cope with caregiving rather than improving the actual care situation. For instance, positive impacts of CM for informal caregivers have been found in terms of increased confidence, caregiving mastery, social support, and ability to continue caregiving, and less unmet needs [13,16]. Similarly, in the present study the actual caregiving situation remained largely unchanged in terms of the amount and type of informal care activities, but the experience of the caregiving situation improved in terms of less caregiving-related problems and more sense of social support and fulfillment (Chapter 3). As the main (or only) point of contact between informal caregivers and the WICM, CM is likely to have played an important role in these outcomes. Off course, whether and how CM contributed to certain study findings remains uncertain due to the lack of qualitative process data in the present study.

The ‘intensity’ of CM in integrated care may also provide an explanation for the limited impacts of many of these interventions. CM is intended to provide individualized care tailored to a specific care situation, and its intensity should therefore reflect the needs of the elderly patients and the informal caregiver(s) [17]. The caseload of case managers is an important component of CM intensity; a large caseload increases time pressure on case managers, resulting in less frequent or irregular follow-up and monitoring (i.e. low intensity CM), whereas a manageable caseload allows regular follow-up and monitoring (i.e. high intensity CM). Recent literature reviews of CM-based interventions for dyads of community-dwelling elderly people and informal caregivers found that low intensity CM – i.e. caseloads of 60+ dyads – is associated with a lack of outcomes [18,19]. Large caseloads likely hinder the proactive approach that integrated care interventions intend, as a result of which care delivery remains reactive and its impacts thus remain limited [18]. In the present study, the 4 case managers of the WICM had an average caseload of 94 frail elderly patients, 65 of which with a primary informal caregiver. The caseloads of these case managers thus appears to have exceeded what can reasonably be regarded as manageable, resulting in infrequent follow-up, ineffective interactions with elderly patients and informal caregivers and, ultimately, suboptimal care and support. Limiting the average caseload has been reported to benefit frail elderly patients and informal caregivers, with 50-60 patients per full-time case manager being suggested as the ideal load [17,20].

IMPACTS OF INTEGRATED CARE ON FORMAL CAREGIVERS

Our study regarding the impacts of integrated care on formal caregivers showed improvements in a range of integration processes, including the coordination of activities and information, the quality of communication and social relationships, and the existence of shared norms, values, goals and interests (Chapter 5). These findings mirror the findings of previous studies that have demonstrated increased mutual trust and respect, more immediate, timely, open and effective communication, and easier access to expertise and information from other disciplines among formal caregivers delivering integrated care [21-25]. The consensus in the literature is that effective integrated care delivery is more than simply implementing integrative structures, such as shared protocols, multi-disciplinary meetings or an integrated information system, as it also requires the successful adoption of these structures in day-to-day practice routines and the development of social and cultural bonds needed to work across professional and organizational boundaries [26-28]. Our findings make visible the operational activities associated with the integration process (e.g. multi-disciplinary coordination, information exchange and teamwork) and the efforts to overcome cognitive, cultural and power differences among formal caregivers delivering integrated care. This study thus confirms the notion that developing integrated care for frail elderly patients is as much a process of social, cultural and strategic integration as it is of structural integration.

This study also suggests that achieving integration in the care delivery process does not necessarily translate to better outcomes for formal caregivers. This is in contrast to the common belief that integration is the perquisite of effective integrated care delivery and associated improvements in formal caregivers' work processes and experiences [29-32]. An explanation for the lack of improvements for formal caregivers in the WICM is idea that achieving integration in one place may lead to fragmentation elsewhere [32]. In other words, while collaboration across professional and organizational barriers is central to integrated care, attaining this goal for certain formal caregivers may signify the creation, preservation and heightening of these barriers for other formal caregivers. Research indicates that despite integration efforts, barriers between health and social care, between generalists and specialists, and between community-based and hospital-based professional groups often remain [33-35]. Deteriorating relationships, negative sentiments and conflicts between collaborating professional groups are described throughout the integrated care literature, with insufficient dialogue, feelings of professional superiority or inferiority, and incompatible professional cultures being cited as important underlying causes [36-38]. Some have also noted that integrated working increases the risk of miscommunication and duplication of information, as new and old means of communication are often used in parallel in integrated care interventions [39]. Moreover, even if integrated care is successfully implemented, too strong a focus on collaboration within this initiative may eventually erode collaboration with formal caregivers outside of it [40].

Our study shows that integrated care delivery signifies an increase in objective burden for formal caregivers (Chapter 6). The additional burden of integrated working primarily involved time spent by GPs and other practice personnel on intervention-related activities, most notably multidisciplinary team meetings and (bi-lateral) consultations with other formal caregivers, whereas time spent on patient care remained unchanged. Other studies, in contrast, suggest that a lack of sufficient personnel and knowledge to adequately meet the demands of integrated working are important causes of increased burden [22,41]. Our study also contrasts the belief that integrated working reduces the formal caregivers' objective burden by relieving them of administrative tasks in favor of patient-related activities [42]. This finding raises questions regarding the long-term sustainability of integrated primary care. GP- practices in the Netherlands are already facing considerable workloads, to which the responsibility for integrating care for frail elderly patients only adds. Commentators have therefore expressed the concern that integrated care delivery may come at increasing personal cost for formal caregivers, causing burnout and retention problems in the long run [43,44]. Moreover, increased time spent on non-patient related activities in particular has been linked to low job satisfaction among formal caregivers [45]. The present study however shows that an increase in time spent on non-patient related activities does not necessarily reduce the job satisfaction of formal caregivers delivering integrated care. Whether and how integrated care affects job satisfaction is nonetheless uncertain due to the inconsistency of the evidence, with studies reporting positive, negatives and no impacts [45-48].

THE IMPACT OF INTEGRATED CARE ON FORMAL AND INFORMAL CARE

Our comparison of formal and informal care in the integrated care and usual care setting suggests that existing theoretical models of interactions are less applicable to the integrated care context (Chapter 7). These models have several shortcomings that put them at odds with the aims of integrated care, i.e., an orientation towards formal care, and their normative and static nature. For instance, 'dual specialization' in practice usually means that formal caregivers perform certain activities while informal caregivers perform the remaining activities (separately) [49]. Whilst dual specialization thus implies that informal caregivers simply perform those tasks that formal caregivers leave uncompleted, it also describes situations in which each formal and informal caregiver does what (s) he does best. Either way, dual specialization refers to a task distribution that is 'formal care-oriented' rather than the result of negotiation and shared decision-making – which are key processes in integrated care delivery. ‘Substitution’ and ‘supplementation’ both refer to a transfer of tasks between formal and informal care, typically in situations where formal and informal caregivers perform the same (household or personal care) activities [50]. However, these models do not explain the underlying motivations for these transfers of tasks, i.e., whether the aim is to provide support or respite, whether it is temporary or permanently; whether it reflects a situation in which formal care imposes services on informal care, or a situation in which informal care increasingly shuts out formal care. Others have critiqued the normative nature of the supplementation model, arguing that it suggests a ‘norm’ for the amount of informal care above which formal caregivers must take action [49,51]. In other words, supplementation requires a standardized amount of informal care that *should* be provided. Standardization of informal care for frail elderly people is, however, problematic as each caregiving situation is unique in their characteristics, history and care trajectories. Standardization also goes against the inherent voluntary nature of informal care, and may therefore reduce the positive experience and sense of fulfilment that many derive from caring for a loved one.

Dual specialization, substitution and supplementation are primarily focused on informal caregiver involvement rather than on the collaboration among equal partners in care. The informal caregiver is either a ‘person of need’ or a ‘resource’ at the background against which formal care is provided. In the integrated care context, however, formal and informal caregivers ideally become co-producers of care [52]. The question arises whether formal and informal caregivers can be expected to be co-producers of care, as they represent two fundamentally different care systems. There are inherent asymmetries and differences in knowledge and skills, monetary compensation and motivation for caring. Some countries have made attempts to bridge these differences between formal and informal care. Germany, for instance, offers long-term informal caregivers a fixed financial compensation, professional training and home visit support [53]. However, the unique perspective and insights into the patient’s needs may be lost if informal caregivers are expected to professionalize. Moreover, a fundamental difference in underlying motivating for caring remains; a career in healthcare is an explicit choice for most, whereas providing informal care often is not. Informal care responsibilities are often thrust upon individuals, who have their own personal, professional and family lives. Considering formal and informal care as co-producers of (integrated) care thus prompts the question whether formal care ‘by choice’ can be equated with informal care ‘by chance’.

The dual specialization, substitution and supplementation models are rather one-dimensional in their focus on the amount and type of care alone. The interactions between formal and informal care for frail elderly patients are however increasingly recognized as a complex and dynamic process that involves not only objective aspects (i.e. “who does how much of what?”), but also interpersonal and relational aspects (e.g. mutual respect and trust, quality of coordination and communication) [52]. It thus seems worthwhile to combine objective, interpersonal and relational aspects to better understand the interactions between formal and informal care. Also, these models do not capture the transformational nature of elderly care over time. Research indicates that the nature and amount of informal care given or received within a family changes in response to the elderly’s needs and abilities, and often involves ‘turn taking’ among several caregivers [54,55]. This latter point is relevant for research if the aim is to capture exchanges over time, as it underlines the need to include not only the ‘primary’ informal caregiver in studies (as was the case in the present study) but the wider support network as well.

Finally, these models do not explain the relationships between formal-informal care interactions and outcomes for patients, informal caregivers and formal caregivers, or how different care settings and models mediate these relationships [55]. To describe care collaborations it is best to take into account that caregivers and (the observations of) their actions are interdependent and subject to change over time. Moreover, care should be described as a process that is negotiated or worked out over time by formal and informal caregivers. The outcomes of these negotiations (i.e. who does what) are impacted by characteristics of the patient, caregivers and the care setting in which they occur. Accordingly, the elderly patients’ ability to age in place can be connected with outcomes for formal and informal caregivers (burden, satisfaction with work/care), personal, network and contextual characteristics, whilst recognizing the central role of negotiations among formal and informal care [55].

METHODOLOGICAL REFLECTIONS AND RECOMMENDATIONS FOR RESEARCH & PRACTICE

STUDY DESIGN

A quasi-experimental design with a control group and pre/post measurements instead of a randomized controlled trial can be regarded as suboptimal. However, randomization in organizational research is often impractical and even undesirable [56]. In the present study, randomization would have meant the reassignment (and thus displacement) of frail elderly participants to other GPs than their own, with whom many patients may have had years of history. Randomization would also require formal caregivers to provide usual care to some elderly patients and integrated care to another subset of patients. Whilst blinding may be considered in this context, it was not possible in the present study as frailty screening was part of the intervention and GPs (and other formal caregivers) needed to know which elderly patient to target.

Nonetheless, a non-randomized study poses challenges in terms of contamination between conditions and the existence of confounding variables [57]. Contamination between conditions may have occurred if GPs or other formal caregivers in the control condition became more attentive to their frail elderly patients or (elements of) proactive and integrated care as a result of their participation in the study. As well, most participating GPs were part of the same (regional and national) professional associations and attended the same meetings and training sessions. GPs from the control condition may have been influenced by ideas from GPs working with the WICM, and over time adopted these ideas into their daily practices. Moreover, the WICM project was initiated in the context of growing interest in proactive and collaborative care approaches for elderly people. Both control and intervention GPs were likely already more aware of the needs of their elderly patients, as policy reports and guidelines on this subject had been issued in 2007 and 2010 by the National GP Association (NHG) and the Dutch Medical Associations

(KNMG) [11]. Finally, non-randomization also means that study results can be subject to contamination of confounding variables. Although control variables were identified with great care for each part of this study, important confounding variables may have been overlooked. For instance, dysfunctional family relations, personality traits and preexisting medical conditions have been proposed as mediating factors for informal caregiver outcomes [58].

A more fundamental objection to using (quasi) experimental study designs to evaluate care models is their reliance on correlation and regression analyses and the underlying assumption of independent observations. Patient care is increasingly considered as a relational process of which the outcomes depend largely on the quality of the relationships between elderly patients and formal and informal caregivers [59]. It can therefore be argued that determining the impacts of any intervention in elderly care requires insight into these relationships and their dynamics over time. Moreover, the relationships between patients and formal and informal providers of care do not exist in a vacuum but are part of a social network in which observations are by definition interdependent [60]. These dynamics may be better captured through analysis of the entire care network rather than through traditional intervention studies. Indeed, there is currently increased attention to include the entire social network in research on community-dwelling frail elderly persons [61]. The dyad of elderly patient and informal caregiver should serve as the starting point, after which other (formal and informal) care providers are incrementally included [60]. Multiple care networks can be mapped in this manner, yielding 'nested' data as the unit of analysis. This network approach can also account for the support from the wider social network beyond the primary informal caregiver. Indeed, the focus on the primary informal caregiver in the present study may have excluded the efforts of other informal caregivers that may have been called upon for additional support. The assistance provided by this broader social network may have acted as a 'buffer' against overburdening of the primary informal caregiver. The impacts of such buffer-effects on caregiver outcomes have likely remained undetected based on data obtained from primary caregivers alone.

Akin to social network analysis is the 'realist evaluation', an emerging approach in the integrated care literature. Realist evaluations involve the generation of hypotheses, data collection and the exploration of intervention outcomes by focusing on the groups that benefitted most and benefitted least of the intervention [13]. Realist approaches acknowledge that integrated care does not necessarily work for everyone, since people and the context in which they are embedded may vary [62]. Realist evaluations may therefore provide insight into the impacts of separate integrated care components and the subgroups that benefit most from them. Such an evaluation may, for instance, help explain under what conditions integrated care delivery reduces caregiver burden and for whom; may shed light on specific elements of case management (e.g. training, consultation, advise, support) that contribute (most) to the competence and coping abilities of informal caregivers, or may help understand the nature and role of formal-informal care negotiation in the delivery of integrated care to frail elderly people. From a realist evaluation perspective, the effectiveness of an intervention is not determined based on outcomes alone but also on the consideration of theoretical mechanisms and the context in which the intervention was implemented [13]. A realist approach recognizes that there are many interwoven variables operating at policy, society, organization, program and clinical levels. For instance, the literature suggests that contextual policy conditions, such as changes in public law, can be counteracting forces in achieving integrated care goals at operational levels [63,64]. This method may therefore be better suited for evaluating complex integrated care interventions than 'traditional' causal, non-contextual methods of analysis.

IMPLEMENTATION PROCESS EVALUATION

Formal and informal caregivers have often been overlooked in the integrated care literature, and their perspectives still constitute important knowledge gaps. The present study provides insight into these 'black boxes' by demonstrating impacts of integrated care for frail elderly patients on formal and informal care. However, the black box of the WICM's implementation remains unopened as no process evaluation could be performed due to financial restrictions. The implementation of complex interventions such as the WICM is a challenging process that may warrant an evaluation in itself [65]. The WICM consisted of multiple interrelated components at multiple levels of care delivery targeting frail elderly patients and formal and informal caregivers, and the nature and extent of these interrelations remains unknown due to the lack of an evaluation of the implementation process. A process evaluation may also help determine the extent to which the intervention is delivered as intended (i.e. 'implementation fidelity') and can explain how and why certain outcomes have come about [66]. In the present study, the suboptimal implementation of the WICM could have resulted in the limited exposure of the target populations to the intervention. Implementation evaluations may also elucidate the interrelations between integrated care structures, processes and outcomes. The present study shows that the implementation of integrated care for the frail elderly is as much a process of social, cultural and strategic integration as it is a process of structural integration (Chapter 5). However, even if multidisciplinary meetings and protocols are implemented successfully, formal caregivers do not necessarily use them (as intended) in their practice routines or establish the social and cultural bonds needed to collaborate effectively across professional boundaries. Combining data regarding implementation fidelity, the actual use of intervention components and integration processes among formal caregivers will likely improve our understanding of how effective and sustainable integrated care can be achieved.

MULTI-PERSPECTIVE EVALUATION OF INTEGRATED CARE

The present study shows that integrated care may benefit informal caregivers, but not necessarily formal caregivers. As well, it is conceivable that achieving better quality and outcomes through integrated care may come at considerable financial cost and additional burden for the caregivers involved. It can therefore be argued that evaluations of integrated care should focus not only on the intervention's target population, but also on formal caregiver, informal caregivers, and managers. There is indeed a growing consensus in the literature that multi-perspective evaluation approaches that include patient, professional, organization and system inputs are needed to fully demonstrate the added value of integrated care [27-30,36,64]. Such approaches may also provide insight into the interrelations between integration processes and outcomes as perceived by all relevant stakeholder groups. Moreover, measuring perceptions of integration and effectiveness at multiple levels allows the comparison and monitoring of the degree of alignment between clinical, organizational and system actors involved in integrated care efforts [67,68]. The instrument developed in the present study has been shown to be a reliable measure of integration from the formal care perspective, and may contribute to the development and further refinement of these multi-perspective evaluation approaches.

FOCUS ON DYADIC RISK PROFILES

Informal caregivers who do not live with the frail elderly patient probably interact less with integrated care models than co-residing caregivers, and are therefore likely to be impacted less by it. Integrated care might be more effective if models include active outreach to non-co-residing informal caregivers – particularly in the early stages of the integrated care process (i.e., needs assessments, drawing up of treatment plan). The frail elderly and their informal caregivers constitute heterogeneous target populations. Integrated care can therefore be expected to be more effective if it is tailored to the subgroups that can be expected to benefit most from proactive intervention and support. Researchers have recently identified 'risk profiles' for frail elderly patients based on physical, mental, social functioning [69], socio-demographic and –economic characteristics (e.g. gender, education, income, social support network) [70] and specific combinations of comorbid conditions [71]. In a similar vein, non-co-residing and non-spousal informal caregivers are among the categories that have been identified as "high-risk", along with those who provide personal care and those working full time [72,73]. For future integrated care research and practice it may be worthwhile to combine the risk categories of frail elderly patients and informal caregivers into so-called 'dyadic risk profiles'; it is conceivable, for instance, that dyads consisting of a non-spousal working primary informal caregiver and an elderly widowed care receiver with cognitive and behavioral problems are more at risk for overburdening and institutionalization than dyads consisting spousal and co-residing primary caregiver and the elderly care recipient are both relatively healthy and functionally independent. Different dyads thus have particular health and support needs, and identifying dyadic risk profiles may enable formal services to focus more on prevention and care that is tailored for a particular care situation. Similarly, integrated care interventions could be designed around the informal caregiver-elderly patient dyad and allow sufficient flexibility to intervene accordingly.

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SUMMARY
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CHAPTER

IX

SUMMARY

Frail elderly people are increasingly being cared for in their own homes by both formal and informal caregivers. Integrated care models are therefore being developed to better coordinate formal and informal care for frail elderly people in communities. However, much remains unclear regarding the impacts of integrated care delivery on formal and informal caregivers. The aim of this dissertation was therefore to investigate the three main assumptions regarding the benefits of integrated care on formal and informal caregivers, i.e., that integrated care for the frail elderly (1) safeguards informal caregivers against the negative impacts of caregiving; (2) improves the work processes and experiences of formal caregivers; and (3) improves the interaction between formal and informal care over time.

These assumptions were investigated in the real-life setting of an integrated care intervention for community-dwelling frail elderly people in the Walcheren region of the Netherlands. This intervention, the ‘Walcheren Integrated Care Model’ (WICM), consisted of the following evidence-based elements: a single entry-point, proactive frailty screening, comprehensive needs assessments, case management, multidisciplinary team meetings, protocols and treatment plans, a shared information and communication system, task specialization and tasks delegation, and the creation of a geriatric care network with a formal steering group.

Chapter 2 of this dissertation describes the research protocol for the larger evaluation study that the present study was part of. The evaluation study involved a quasi-experimental design with a control group, and measurements at baseline and 12 months later. The experimental group consisted of 3 primary care practices providing integrated care to their frail elderly patients in accordance with the WICM. The control group consisted of 5 primary care practices that continued to provide usual care to their frail elderly patients. Chapter 2 describes the process and outcome measures for frail elderly patients and formal and informal caregivers that were used to evaluate the WICM. Data were primarily collected with questionnaires; other data sources included patient records, registration forms and transcripts of meetings.

In Chapters 3 and 4 the assumption is investigated that integrated care for the frail elderly safeguards informal caregivers against the negative impacts of caregiving. A total of 195 informal caregivers participated in this study. **Chapter 3** shows that the WICM significantly reduced the subjective burden of informal caregivers, whilst their objective burden, perceived health and quality of life remained unaffected. These results suggest that integrated care models for the frail elderly can in fact safeguard informal caregivers against overburdening, and that such interventions can be implemented without placing additional time demands on informal caregivers. **Chapter 4** reports the effects of the WICM on the informal caregivers’ satisfaction with care and support services. This chapter first describes the development of a new instrument to measure informal caregiver satisfaction, followed by a description of the Primary Component Analysis that was performed to determine the underlying factor structure of the theoretical dimensions. Subsequent regression analyses showed that the WICM affected none of the resulting scales of satisfaction with care and support. The findings of Chapter 4 suggest that, in contrast to what is often expected, the satisfaction of informal caregivers is largely unresponsive to integrated care delivery.

Chapters 5 and 6 examine the assumption that integrated care for the frail elderly improves the work experiences and processes of formal caregivers. Data regarding the perception of integration processes and (job) satisfaction were collected with questionnaires from 180 formal caregivers 18 months after implementation of the WICM. Data regarding objective burden were collected from the medical records of 377 frail elderly patients, patient questionnaires, time registration forms, and transcripts of meetings. **Chapter 5** describes the development of a second new instrument to measure integration processes and satisfaction therewith from the formal caregivers' perspective. After Primary Component Analysis yielded reliable scales, further analyses demonstrated that the WICM significantly improved structural, cultural and social integration, agreement on goals, interests, power and resources and satisfaction with integration. These findings support the notion that integrated care structures foster integration processes among formal caregivers. **Chapter 6** reports on the impacts of the WICM on the objective burden and job satisfaction of formal caregivers. The results showed that formal caregivers delivering integrated care in accordance with the WICM spent significantly more time on non-patient related activities than formal caregivers delivering care as usual, whereas patient-related time investments remained unchanged in both groups. Moreover, the WICM did not affect the formal caregivers' job satisfaction. Chapter 6 indicates that integrated working can increase the formal caregivers' objective burden in terms of additional intervention-related activities that are largely unrelated to actual patient care, but also that this is not necessarily associated with a reduction in job satisfaction.

The assumption that integrated care for the frail elderly improves the interaction between formal and informal care is investigated in **Chapter 7**. This study involved a comparison of the amount and type of formal and informal care over time in the integrated care context of the WICM and in the usual care context of the control condition. The analyses were based on data regarding formal and informal care use by 207 frail elderly patients over a 12-month period. The findings showed that no meaningful changes in the overall amount of formal and informal care had occurred over time in integrated care in comparison to usual care. However, different dynamics between formal and informal care types emerged in integrated and usual care setting suggesting that instrumental and personal care activities are particularly sensitive to changes through integrated care. Chapter 7 indicates that although integrated care does not directly change formal and informal care contributions over time, it can result in different dynamics between them. In the general discussion in **Chapter 8** the main findings of this dissertation are presented and discussed in the context of the current evidence. It is concluded that integrated care models that include explicit aims for informal care do not necessarily translate to better outcomes for these caregivers. Case management is subsequently identified as a crucial component of integrated care for informal caregivers. It is also noted that achieving integration in the care delivery process does not necessarily benefit formal caregivers, and questions are raised regarding the long-term sustainability of integrated frail elderly care in the primary care setting. A discussion of theoretical models of interactions between formal and informal care subsequently shows the limited applicability of these models to the integrated care context. The methodological limitations of this dissertation are discussed, based on which recommendations for future research are provided.

Chapter 8 concludes with the practice recommendation to tailor integrated care to specific risk profiles for dyads of frail elderly patients and informal caregivers in order to improve the effectiveness of such interventions.

This dissertation shows that integrated care for the frail elderly can be expected to safeguard informal caregivers against some negative impacts of caregiving, but also that improvements for formal caregivers and formal-informal care interaction should not be readily expected. It is concluded that, as yet, most expectations regarding the benefits of integrated care for formal and informal caregivers remain unjustified.

SAMENVATTING

Kwetsbare oudere mensen worden in toenemende mate verzorgd in hun eigen huis door zowel formele als informele zorgverleners. Integrale zorgmodellen worden daarom ontwikkelt om formele en informele zorg voor thuiswonende kwetsbare ouderen beter te coördineren. Er bestaat echter nog veel onduidelijkheid over de effecten van integrale zorgverlening op formele en informele zorgverleners. Het doel van deze dissertatie was daarom om de drie kern assumpties over de voordelen van integrale zorg voor formele en informele zorgverleners te onderzoeken, te weten: integrale zorg voor kwetsbare ouderen (1) beschermt informele zorgverleners tegen de negatieve effecten van mantelzorg; (2) verbetert de werkprocessen en -beleving van formele zorgverleners; en (3) verbetert de interactie tussen formele en informele zorg over de tijd.

Deze assumpties werden onderzocht in de praktijksetting van een integrale zorginterventie voor thuiswonende kwetsbare ouderen in de regio Walcheren in Nederland. Deze interventie, het ‘Walcheren Integrated Care Model’ (WICM), bestond uit de volgende ‘evidence-based’ elementen: een ‘single entry-point’, proactieve screening op kwetsbaarheid, uitgebreide behoefteanalyses, case management, multidisciplinaire team overleggen, protocollen en behandelplannen, een gedeeld informatie- en communicatiesysteem, taakspecialisatie en –delegatie, en de oprichting van een geriatrisch zorgnetwerk met een formele stuurgroep.

Hoofdstuk 2 van deze dissertatie beschrijft het onderzoeksprotocol voor de evaluatiestudie waarvan de huidige studie onderdeel was. De evaluatiestudie behelsde een quasi-experimenteel ontwerp met een controle groep, en voor- en nametingen met 12 maanden daartussen. De experimentele groep bestond uit 3 huisartsenpraktijken die integrale zorg verleenden aan hun kwetsbare oudere patiënten volgens het WICM. De controle groep bestond uit 5 huisartspraktijken die reguliere zorg bleven verlenen aan hun kwetsbare oudere patiënten. Voorts beschrijft Hoofdstuk 2 de proces- en uitkomstmaten voor kwetsbare ouderen en formele en informele zorgverleners die gebruikt werden in de evaluatie van het WICM. Dataverzameling geschiedde met name met vragenlijsten; andere databronnen waren patiëntendossiers, registratieformulieren en notulen.

In Hoofdstuk 3 en 4 wordt de assumptie onderzocht dat integrale zorg voor kwetsbare ouderen informele zorgverleners beschermt tegen de negatieve effecten van mantelzorg. In totaal participeerden 195 informele zorgverleners in deze studie. **Hoofdstuk 3** laat zien dat het WICM de subjectieve belasting van informele zorgverleners significant verlaagde, terwijl hun objectieve belasting, ervaren gezondheid en kwaliteit van leven onveranderd bleef. Deze resultaten suggereren dat integrale zorgmodellen voor kwetsbare ouderen daadwerkelijk bescherming kunnen bieden aan informele zorgverleners tegen overbelasting, en dat dergelijke interventies kunnen worden geïmplementeerd zonder extra tijdsinvesteringen van informele zorgverleners te vragen. **Hoofdstuk 4** rapporteert de effecten van het WICM op de tevredenheid van mantelzorgers met zorg- en ondersteuningsdiensten. Dit hoofdstuk beschrijft eerste de ontwikkeling van een nieuw instrument om de tevredenheid van informele zorgverleners te meten. Daarna volgt een beschrijving van de Primaire Componenten Analyse die werd uitgevoerd om de onderliggende factorstructuur van de theoretische dimensies te bepalen. Lineaire regressie analyses lieten daarna zien dat het WICM op geen enkele schaal van tevredenheid effect had. De resultaten van hoofdstuk 4 suggereren dat, in tegenstelling tot wat vaak verwacht wordt, de tevredenheid van informele zorgverleners niet responsief is op integrale zorgverlening.

Hoofdstuk 5 en 6 onderzoeken de assumptie dat integrale zorg voor kwetsbare ouderen de werkervaringen en -processen van formele zorgverleners verbetert. Data over de perceptie van integratieprocessen en over (werk) tevredenheid werden 18 maanden na implementatie van het WICM met vragenlijsten verzameld onder 180 formele zorgverleners. Data over objectieve belasting werden verzameld uit de medische dossiers van 377 kwetsbare oudere patiënten, vragenlijsten, tijdsregistraties van formele zorgverleners, en notulen van teamvergaderingen. **Hoofdstuk 5** beschrijft de ontwikkeling van een tweede instrument om integratieprocessen en de tevredenheid daarmee te meten vanuit het perspectief van formele zorgverleners. Nadat met Primaire Componenten Analyse betrouwbare schalen werden vastgesteld, liet verdere analyse zien dat het WICM resulteerde in significante verbeteringen in structurele, culturele en sociale integratie, meer overeenstemming van doelen, belangen en middelen, en meer tevredenheid met integratie. Deze bevindingen ondersteunen het idee dat integrale zorgstructuren integratieprocessen tussen zorgverleners bevorderen. **Hoofdstuk 6** rapporteert de effecten van het WICM op de objectieve belasting en werktevredenheid van formele zorgverleners. De resultaten laten zien dat zorgverleners die zorg leveren volgens het WICM significant meer tijd besteedden aan niet-patientgerelateerde activiteiten dan zorgverleners die reguliere zorg verleenden, terwijl patientgerelateerde tijdsinvesteringen onveranderd bleven in beide groepen. Daarnaast had het WICM geen effect op de werktevredenheid van formele zorgverleners. Hoofdstuk 6 laat zien dat geintegreerd werken de objectieve belasting van formele zorgverleners kan verhogen in termen van extra interventie-gerelateerde activiteiten moeten uitvoeren die grotendeels ongerelateerd zijn aan patiënten zorg, maar ook dat dit niet per se gepaard gaat met een vermindering van werktevredenheid.

De assumptie dat integrale zorg voor kwetsbare ouderen de interactie tussen formele en informele zorg verbetert, wordt onderzocht in **Hoofdstuk 7**. Deze studie behelsde een vergelijking van de aard en hoeveelheid formele en informele zorg over tijd in de integrale zorgcontext van het WICM en de reguliere zorgcontext in de controleconditie. De analyses waren gebaseerd op data over het gebruik van formele en informele zorg gedurende 12 maanden. De resultaten lieten geen betekenisvolle veranderingen over tijd zien in de algehele hoeveelheid formele en informele zorg in integrale zorg in vergelijking met reguliere zorg. Echter werden wel verschillende dynamieken tussen formele en informele zorgtypen gezien in de integrale en reguliere zorgcontext, welke suggereren dat met name instrumentele en persoonlijke zorgactiviteiten gevoelig zijn voor veranderingen door integrale zorg. Hoofdstuk 7 laat zien dat hoewel integrale zorg niet direct de bijdrage van formele en informele zorg verandert, het wel de dynamiek daartussen kan veranderen.

In de algemene discussie in **Hoofdstuk 8** worden de belangrijkste bevindingen van deze dissertatie gepresenteerd en besproken tegen het licht van bestaande evidentie. Er wordt geconcludeerd dat integrale zorgmodellen met expliciete doelen voor informele zorg niet noodzakelijkerwijs tot betere uitkomsten voor informele zorgverleners hoeven te leiden. Case Management wordt vervolgens geïdentificeerd als cruciaal component van integrale zorg voor informele zorgverleners. Ook wordt besproken dat het bereiken van integratie in het zorgverleningsproces niet per se voordelig is voor formele zorgverleners, en vragen worden opgeworpen over de bestendigheid van integrale zorg voor kwetsbare ouderen in de eerstelijnsetting op de langere termijn. Uit een discussie van de theoretische modellen van interacties tussen formele en informele zorg blijkt vervolgens de beperkte toepasbaarheid van deze modellen in de integrale zorgcontext. Voorts worden de methodologische beperkingen van deze dissertatie besproken, op basis waarvan aanbevelingen voor toekomstig onderzoek worden gegeven. Hoofdstuk 8 sluit af met de praktijkaanbeveling om integrale zorg toe te spitsen op specifieke risicoprofielen voor dyades van kwetsbare oudere patiënten en informele zorgverleners om de effectiviteit van deze interventies te verbeteren.

Deze dissertatie laat zien dat integrale zorg voor kwetsbare ouderen verwacht kan worden bescherming te bieden aan informele zorgverleners tegen sommige negatieve effecten van mantelzorg, maar dat verbeteringen voor formele zorgverleners en in de interactie tussen formele en informele zorg niet zonder meer verwacht kunnen worden. Geconcludeerd wordt dat de meeste verwachtingen omtrent de voordelen van integrale ouderenzorg voor formele en informele zorgverleners vooralsnog ongerechtvaardigd blijven.

DANKWOORD

Het schrijven van een proefschrift mag dan een solistische bezigheid zijn, de succesvolle afronding daarvan is dat zeker niet. Talloze mensen hebben mij de afgelopen jaren op allerlei manieren geholpen, en een ieder van hen ben ik immens dankbaar. Een aantal personen in het bijzonder ben ik veel dank verschuldigd.

Allereerst mijn promotor Robbert Huijsman en co-promotor Isabelle Fabbricotti. Het promotietraject verliep niet altijd even vlot, en het duurde even voordat we samen de juiste *modus operandi* vonden. Jullie bleven altijd geloven in een goede afloop, ook wanneer ik dat zelf niet deed; dank voor dat vertrouwen. Robbert, door de snelheid en reikwijdte van jouw denken waren onze promotiebesprekingen soms enerverend, maar altijd een bron van nieuwe ideeën en dwarsverbanden. Ik heb inhoudelijk en schrijf-technisch veel van je geleerd, en in de moeilijke momenten wist je mij te motiveren om de schouders eronder te blijven zetten. Isabelle, jouw kritische blik is zowel onverbiddelijk als ongeëvenaard. Je las ieder concept-paper, iedere nieuwe versie, de vele revisies en talloze aanpassingen, en voorzag deze van vlijmscherpe commentaren waarop ik meestal eerst twee weken moest studeren, maar die altijd weer bijdroegen aan een beter stuk. Je hebt me geleerd nooit concessies te doen aan kwaliteit en oog te hebben voor details (*check, check, dubbelcheck!*).

Veel dank ben ik verschuldigd aan de organisaties en zorgverleners die betrokken waren bij het Walcheren Integrale Zorg Model en op enigerlei wijze hebben bijgedragen aan dit onderzoek. Dank aan de Walcherse thuiszorgorganisaties en hun medewerkers voor deelname aan het vragenlijstonderzoek. Dank aan de huisartsen en medewerkers van de controle- en interventiepraktijken voor de gastvrijheid en hulp tijdens de dataverzameling op locatie, maar ook daarna. Bijzondere dank aan Auktje Reiffers van Zorggroep Walcheren voor de prettige samenwerking, en aan Ruben de Kuyper, Jan Kees de Meulmeester, Lenny Tange en Mirése de Boo, die ondanks de drukke dagelijkse praktijk altijd bereid waren om mee te denken over het onderzoek.

Zonder data-assistenten geen data, zonder data geen onderzoek, en zonder onderzoek geen proefschrift. Nanda, Gertrud, Emy, Jannie van S., Patricia en Jannie L., dank voor jullie inzet, en natuurlijk voor de gezelligheid tijdens onze teamlunches!

De oud-collega's van HSMO: de promovendi destijds, Linda, Marie-Louise, Martina, Connie, Marcello, Mahdi, Hanna, en later, Laura, Kirti en Mathilde, dank voor de gezelligheid en koffie wanneer dat het hardst nodig was. Jeroen, Annemarie, Mathilde S. en Joris, dank voor de bemoedigende woorden. Karlijn, als kamergenoten hebben we jarenlang lief en (vooral) leed gedeeld; eindelijk zijn we nu allebei zover. Bijzondere dank aan mijn onderzoeksmaatje Willemijn, voor de (methodologische) steun en gezelligheid de afgelopen jaren. Door jouw planning- en organisatietalent was mijn agendabeheer net iets minder chaotisch.

Jacqueline, na BMG zijn Arnout en jij goede vrienden van ons geworden. Ik ben jullie dankbaar voor de fijne gesprekken en gezelligheid tijdens onze dineravonden en uitjes (Droogvaltocht!), waarvan er hopelijk nog velen zullen volgen.

De jongens van Jaarclub Slagtand, dank voor de afleiding en gezelligheid tijdens borrels, lustrumreizen en weekenden. Musch, ondanks mijn talent voor radiostilte blijf je vanuit Singapore stug contact houden; misschien kunnen we nu eens een keer gaan facetimen. Schlösser, ons dronkenmanspact heeft uiteindelijk stand gehouden; dank dat je mijn paranimf wilt zijn.

Hamid, vrienden sinds de lagere school en door gedeelde Zeeuwse ‘roots’ en muzikale interesses zijn we dat altijd gebleven. Jouw ontwerp van het proefschrift is daardoor extra bijzonder! Ik ben je dankbaar voor je hulp, enthousiasme en vriendschap.

Mijn schoonfamilie, Marijke en Reinko, Lieke, Tom en Nena, en Marloes, dank voor jullie betrokkenheid in al die jaren. Lieke, later begonnen en uiteraard eerder gepromoveerd, dank voor je hulp met het brainstormen over de discussie van het proefschrift.

Lieve ouders, ik ben jullie dankbaar voor jullie onvoorwaardelijke steun en vertrouwen terwijl ik mijn weg probeerde te vinden. David, Annemarie, Ella en Louise An; Sam, Nozomi en Lucas; Thomas en Anne-Marijn, en lieve zusje Sarah; hopelijk zien we elkaar vanaf nu weer wat vaker (ik heb vanaf nu in ieder geval zeeën van tijd)! Sam, met jouw als paranimf sta ik straks een stukje steviger in mijn lakschoenen, dank.

Jack en Cécé, dank voor de nodige en onnodige afleiding tijdens schrijfdagen. Lowa†, jouw schrijf-technische expertise was onmisbaar.

Lieve Ireen, er is niemand aan wie ik meer dank verschuldigd ben dan jou. Een groot deel van onze tijd samen stond in het teken van mijn promotieonderzoek. Ik heb werkelijk geen idee hoe je het hebt volgehouden, de lange nachten, de humeurige stiltes, het afwezige staren in de verte, terwijl er aan dit lijden geen einde leek te komen door de chronisch uitlopende planning. Dank voor je oneindige geduld, begrip en ondersteuning. Ik heb zin in onze toekomst samen met ons lieve meisje.

Livia, jouw geboorte was mijn wedergeboorte. Er zijn geen woorden om te beschrijven hoe dankbaar ik ben dat jij in mijn leven bent gekomen.

ABOUT THE AUTHOR

Benjamin Janse was born in Vlissingen, the Netherlands, on April 18th, 1983. After finishing intermediate general secondary education (MAVO), he graduated higher general secondary education (HAVO) in 2001. After passing the propaedeutic exam 'Applied Psychology' at Fontys Hogeschool in Tilburg in 2003, Benjamin went on to study Psychology at Utrecht University. He finished his clinical internship at Tergooi Ziekenhuizen in Blaricum and an additional research internship at the University Medical Centre Utrecht, after which he graduated in 2009 in Neuropsychology with a Master's thesis on the association between cannabis use and schizophrenic symptoms in adolescents. In 2010 Benjamin started his PhD studies at the institute of Health Policy and Management (iBMG) of the Erasmus University Rotterdam on the evaluation of an integrated care intervention for frail elderly people. At iBMG he became increasingly involved as instructor and thesis supervisor in the Bachelor and Master programs. Between 2015 and 2017, he worked as a senior lecturer for the Master program 'Advanced Nursing Practice' at the Hogeschool Rotterdam.

PHD PORTFOLIO

Name PhD student
Benjamin Janse

PhD-period
2010 – 2017

Promotor
Prof. dr. R. Huijsman

Erasmus Department
Erasmus School of Health Policy & Management

Co-promotor
Dr. I.N. Fabbricotti

TRAINING		
Academic Writing in English	EUR	2010
Basic Didactics for Higher Education	RISBO, EUR	2010
PhD Project Management	Hertz Trainingen	2010
Tutor Skills Problem-Based Education	Institute for Psychology, EUR	2011
Research Methods in Frail Older Subjects	NPO/ ZonWW, Utrecht	2011
Time Management	ICM Utrecht	2012
CEFR English Speech Level C1	EUR	2013
Providing Plenary Education	RISBO, EUR	2013
Media Training for PhD Students	jBMG, EUR	2013

TEACHING		
Academic Writing & Research Skills	Premaster Program HCM. ESHPM, EUR	2010
Integrated Care	BSc. Program ESHPM, EUR	2011–2014
Research Methods & Techniques 4	BSc. Program ESHPM, EUR	2012, 2014
Research Methods & Techniques 1	BSc. Program ESHPM, EUR	2013
Quality of Healthcare	Pre-Master Program HCM ESHPM, EUR	2013
Organizational Sciences	BSc. Program ESHPM, EUR	2013, 2014
Management & Innovation Studies	BSc. Program ESHPM, EUR	2014
Organizational Sciences	Pre-Master Program HCM ESHPM, EUR	2014
Organizational Behaviour	MSc. Program HCM ESHPM, EUR	2014

SUPERVISION & COORDINATION		
Thesis Supervisor / Co-supervisor	BSc. Program ESHPM, EUR	2012-2014
Thesis Supervisor / Co-supervisor	MSc. Program HCM ESHPM, EUR	2013, 2014
Co-coordinator Practical Internships	BSc. Program ESHPM, EUR	2014
Thesis Supervisor	MSc. Program Advanced Nursing Practice, HR	2015–2017
Research Coordinator	MSc. Program Advanced Nursing Practice, HR	2015–2017

SEMINARS & CONFERENCES		
Research Colloquia HSMO	ESHPM, EUR	2010–2014
Conference ‘The Future of Elderly Care’	SBO. WTC, Rotterdam	2010
Seminar ‘MDS National Database’	NPO. Erasmus MC, Rotterdam	2011
Symposium ‘Walcheren Integrated Care Project’	Middelburg	2011
GENERO Symposia	NPO / GENERO	2011–2014
Lustrum Symposium iBMG	ESHPM, EUR	2012
Seminar ‘Frailty Screening’	NPO/ NFU, Utrecht	2012
Intergenerational Brainstorm Sessions ‘Elderly Care 2040’	EUR	2012, 2013
Conference ‘Elderly Care 2040’	EUR	2013
Intergenerational Brainstorm Sessions ‘Elderly Care 2040’	EUR	2012, 2013
Conference ‘Elderly Care 2040’	EUR	2013
International Congress of Integrated Care	IFIC, Berlin	2013
Conference National Program Elderly Care	NPO, Den Bosch	2013

PRESENTATIONS		
Oral Presentation ‘The effects of integrated care on formal and informal caregivers’	Research Colloquium HSMO, EUR	2011
Oral Presentation ‘The effects of integrated care on professionals: a systematic review’	Research Colloquium HSMO, EUR	2011
Poster Presentation ‘Geriatric care chains for frail elderly in Walcheren’ (Fabbricotti IN, van Eede F, Reiffers A, Janse B, de Kuyper R, Looman WM)	GENERO Symposium, Rotterdam	2011
Poster Presentation ‘The effects of integrated care on professionals: a systematic review’ (Janse B, Fabbricotti IN, Huijsman R)	International Congress of Integrated Care, San Marino	2012
Oral Presentation ‘The effects of the Walcheren Integrated Care Model’	Final Symposium, Vlissingen	2013
Oral Presentation ‘Integrated care for frail elderly people’	GENERO Symposium	2013
Poster Presentation ‘The effects of an integrated care intervention on informal caregivers: baseline and one year post-implementation’ (Janse B, Fabbricotti IN, Huijsman R)	International Congress of Integrated Care, Berlin	2013

OTHER RELEVANT ACTIVITIES		
Board Member jBMG	EUR	2010–2012
Organizor PhD Career Event	EUR	2013
Winner 3th Prize ‘Best Poster Presentation’	ICIC, Berlin	2013
Peer Reviewer	BMJ Open	2015
Peer Reviewer	IJQHC	2015, 2016
Peer Reviewer	PLOS ONE	2016
Peer reviewer	BMJ	2016