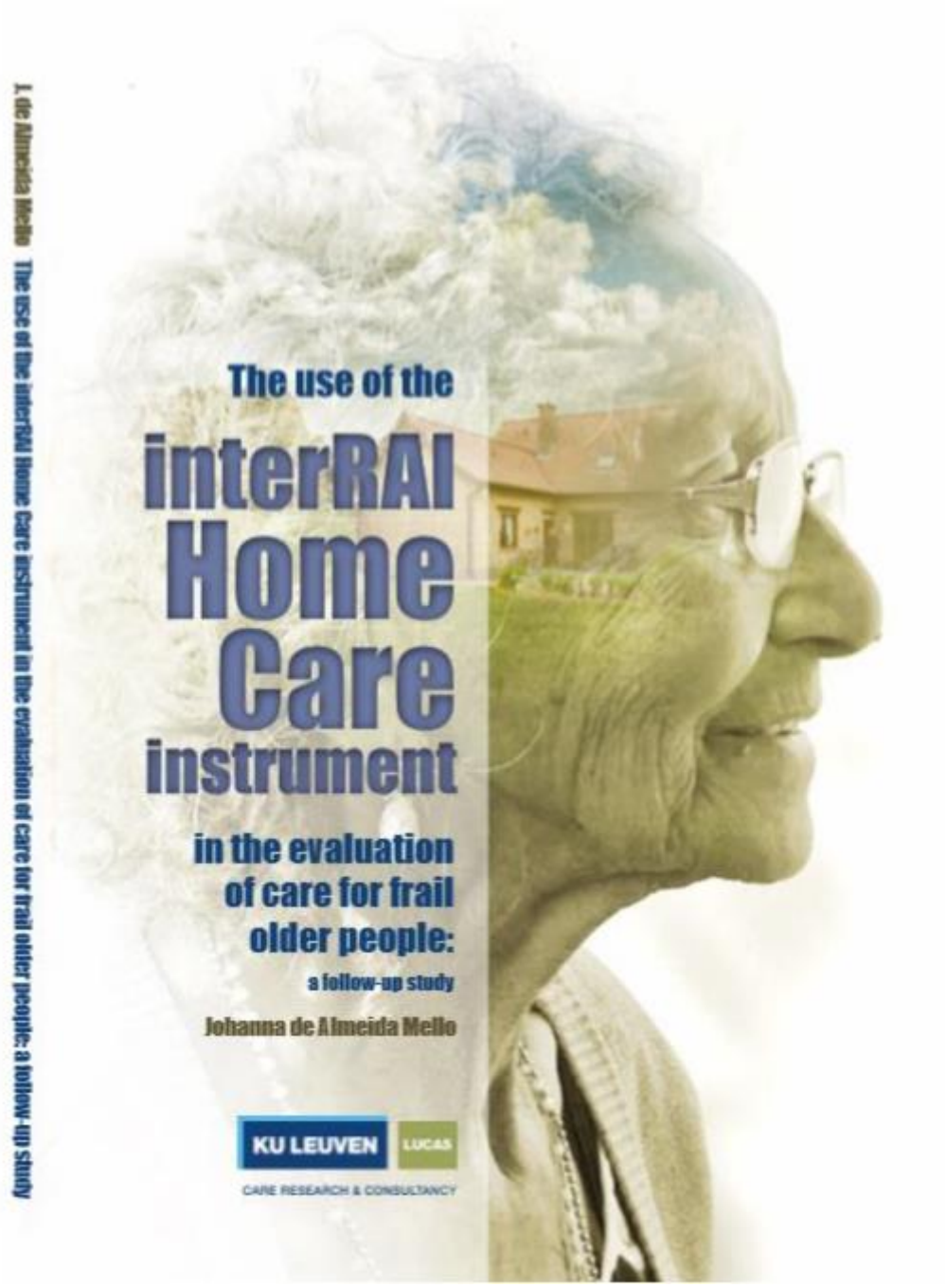
J. de Almeida Mello The use of the interRAI Home Care instrument in the evaluation of care for frail older people: a follow-up Study



The use of the interRAI Home Care instrument in the evaluation of care for frail older people:

a follow-up study

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The use of the interRAI Home Care instrument in the evaluation of care for frail older people: a follow-up study

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I admire the older persons for their wisdom and inner strength. I grew up with my grandma telling us stories and caring for us. She taught us so much about life, and always with a great smile. She baked us the best cookies and bread. She still does! Thank you for all the love and prayers, grandma. Muito obrigada, vovó Flor!

Portrait by Hennie Vervelde

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Summary

Background: The Belgian National Institute for Health and Disability Insurance (NIHDI) launched the third protocol agreement, also known as Protocol 3. This framework has the goal of supporting older persons to stay at home for as long as possible, by guaranteeing access to affordable formal care services, along with improving coordination and integration of care. Under this agreement, several bottom-up innovative home care interventions have been financed since 2010. This doctoral thesis reports some results of this evaluation.

Objectives: As the goal of these interventions is to keep frail older people at home with low burden for the informal caregivers, it is important to identify the determinants of informal caregiver's burden. Another important goal is to analyze which interventions can effectively delay nursing home admission. The following research questions are explored in this PhD research:

1. What is the evidence in the scientific literature for using the interRAI Home Care (HC) instrument to evaluate home care interventions?
2. What are the factors mostly associated with informal caregivers' burden in the population of the study?
3. What is the effect of home care interventions on delaying or avoiding institutionalization of frail older persons?
4. What is the resource utilization of frail older people in the community compared with frail older people going into residential care?

Methods: This is a longitudinal intervention study based on a quasi-experimental design. The study consists of a comparison of the arm receiving several types of interventions with a comparison group of older people living at home and not receiving any intervention. The study includes older people who were at least 65 years old and frail.

Results: The systematic review showed that the interRAI Home Care (HC) was found suitable to be used in this research. The application of this comprehensive assessment instrument made it possible to stratify the study population in levels of impairment as well as to analyze the informal caregiver's burden more in depth than in existing scientific literature in this topic. The RUG-III/HC algorithm, also calculated with items from the interRAI HC instrument, showed to be a useful tool to identify clients eligible for nursing home placement as well as clients who should be receiving interventions in the community.

Conclusion: This PhD thesis shows the added value of the interRAI Home Care (HC) instrument in the evaluation of care of frail older people. This comprehensive assessment enabled the analysis of the determinants of informal caregivers' burden, a common risk factor for nursing home admission, as well as the identification of interventions to allow frail older people to remain at home for as long as possible. By using a standardized assessment such as the interRAI HC, many tools can be available to help organize and coordinate the services, as well as to guarantee continuity of care for the clients. This research can help organizations, service providers and policy makers to plan and deliver interventions according to their client's needs.

Samenvatting

Achtergrond: Het Belgische Rijksinstituut voor Ziekte- en Invaliditeitsverzekering (RIZIV) lanceerde het derde protocolakkoord, ook bekend als Protocol 3. Dit heeft als doel ouderen te ondersteunen om zo lang mogelijk thuis te blijven wonen door toegang tot betaalbare, formele zorg en betere coördinatie en integratie van zorg te garanderen. In het kader van dit akkoord worden sinds 2010 verschillende innovatieve interventies in de thuiszorg gefinancierd en geëvalueerd. Dit proefschrift beschrijft enkele resultaten van deze evaluatie.

Doelstellingen: Aangezien Protocol 3 beoogt om kwetsbare ouderen langer thuis te laten wonen met een zo laag mogelijke zorgbelasting voor de mantelzorgers, is het belangrijk om de determinanten van deze zorglast te identificeren. Een ander doel is te analyseren welke interventies effectief een opname in een woon- en zorgcentrum kunnen vermijden of uitstellen. De volgende onderzoeksvragen worden in deze doctoraatsthesis onderzocht:

1. Wat zijn de bevindingen in de wetenschappelijke literatuur met betrekking tot het gebruik van het interRAI Home Care (HC) instrument om interventies in de thuiszorgsetting te evalueren?
2. Welke factoren zijn het meest geassocieerd met de zorgbelasting van mantelzorgers in de onderzoekspopulatie?
3. Wat is het effect van de interventies op het uitstellen of vermijden van institutionalisering van kwetsbare ouderen?
4. Wat is het niveau van zorggebruik van kwetsbare ouderen in de thuiszorg, vergeleken met kwetsbare ouderen die in een woonzorgcentrum gaan wonen?

Deze thesis beschrijft een longitudinale studie, gebaseerd op een quasi-experimenteel design. De studie bestaat uit een vergelijking van de interventiegroep met een vergelijkingsgroep van thuiswonende ouderen die geen interventie

ontvingen. Alle ouderen in de studiepopulatie waren minstens 65 jaar oud en kwetsbaar.

Resultaten: Op basis van de literatuurstudie bleek het interRAI Home Care (HC) geschikt te zijn om in dit type onderzoek te worden gebruikt. De toepassing van een holistisch beoordelingsinstrument maakte het mogelijk de onderzoekspopulatie te stratificeren in afhankelijkheidsniveaus en de zorgbelasting van de mantelzorger grondiger te analyseren dan in reeds bestaande wetenschappelijke studies. Het RUG-III/HC algoritme, ook gebaseerd op het interRAI HC instrument, bleek een nuttig hulpmiddel te zijn om cliënten te identificeren die in aanmerking zouden moeten komen voor residentiële zorg en cliënten die interventies in de thuiszorg zouden kunnen blijven ontvangen.

Conclusie: Dit proefschrift toont de meerwaarde van het interRAI HC instrument in de evaluatie van de zorg voor kwetsbare ouderen. Het interRAI HC maakte het mogelijk de determinanten van de zorgbelasting voor mantelzorgers te analyseren. Zorgbelasting is een van de meest voorkomende risicofactoren voor opname in woon- en zorgcentra. Bovendien werden interventies geïdentificeerd die als doel hebben kwetsbare ouderen zo lang mogelijk thuis te laten blijven. Het gebruik van een gestandaardiseerd instrument faciliteert de organisatie en coördinatie van zorg en waarborgt de zorgcontinuïteit voor de cliënten. Dit onderzoek kan organisaties, dienstverleners en beleidsmakers helpen om interventies te plannen en te verlenen op basis van de behoeften van de cliënten.

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Chapter 1

General introduction

Background

Community Care

Staying at home for as long as possible can be a suitable alternative for older people because it is preferable to stay in a familiar environment than moving into residential care [1-5]. Several studies have shown that institutionalization may be associated with adverse outcomes such as depression, lower quality of life, an increase in the use of medication and a rise in mortality [6-11].

Due to the high costs of residential care, policy makers are keen to foster community care. In 1994, the World Health Organization defined home care as "an array of health and social support services provided to clients in their own residence. The assumption is that these coordinated services may prevent, delay or be a substitute for temporary or long-term institutional care" [12]. A more recent definition of home care defines it as "a phenomenon in which care is provided by professionals to people in their own homes with the ultimate goal of not only contributing to their life quality and functional health status, but also to replace hospital care with care in the home for societal reasons". In this definition, home care covers a wide range of activities, from preventive visits to end-of-life care [13]. According to the 2009 WHO-report, an appropriate balance between care settings for older persons' care is necessary, including supported self-care and home-based services. The report emphasizes the need for specific interventions to help maintain older people at home and to prevent long-term institutional care [14].

Community care in Belgium

In 2013, a total of 274000 people aged 65 years and over were receiving long-term care (13.3%) and 100.800 of them were receiving nursing care at home (4.9%) [15]. A total of 125.000 older people (5.9%) were receiving care in nursing homes and by 2025 this number will have increased up to 149.000, according to population

prognoses with an 'optimistic' home care scenario (large increase in home care capacity) [16]. The Belgian National Institute for Health and Disability Insurance Care (NIHDI) finances care services at home, which are provided to a variety of older persons and by different types of organizations and professionals [17]. Frail older people often have complex needs and several health and social care providers may be involved in their care simultaneously (e.g. physician, home nurse, physiotherapist, occupational therapist, etc.). In addition, older people may receive assistance by a social worker as well as domestic care (help with IADL such as food preparation, housekeeping, groceries services, etc.).

The Belgian health system is a broad system. Health care for community dwelling frail older people is provided by a mix of family practitioners, self-employed nurses and nurses employed by not-for-profit organizations. Care can also be provided by other care professionals working in an independent practice (i.e. physiotherapists, occupational therapists, psychologists, etc), or employed by for profit or not for-profit private organizations or by Public Centers for Social Welfare [19]. Practically all services are subsidized. The Belgian health system is primarily funded through social security contributions and taxation, but there are also out of pocket contributions by patients. The system is based upon the principles of equal access and freedom of choice [18]. Moreover, the overall goal of long-term care policies in Belgium is to provide universal access to affordable and high-quality care services [19].

The Belgian care sector is mainly regulated and financed by two public authorities: the federal and the regional governments. The federal government is responsible for the regulation and the financing of the compulsory health insurance, paid by contributions and taxes. As a result, health care requiring the intervention of medical doctors, paramedical and nursing staff is organized at the federal level. The regional governments are responsible for other aspects of care for older people, such as aid for IADL and ADL at home and social care. This responsibility has increased in the

past years, since regional governments currently also regulate a wide range of issues related to LTC services: certification of facilities such as nursing homes, day care centers and rehabilitation facilities, integration and coordination of services at the local level, quality monitoring systems, etc.

In general, the Belgian LTC system can be characterized as a mixed system with extensive and diverse publicly financed formal care services. The system is also characterized by freedom of choice. Based upon this freedom and according to circumstances, frail older people may move from one setting to another (e.g. from home to hospital and then back to their home or for a short period or permanently into residential care). A coordinated follow-up of frail older people is essential for creating, updating and evaluating the care plans at different times and by different care professionals working in these settings. Therefore, integrated care becomes an important element of quality, as well as continuity of care.

Long-term residential care in Belgium comprises assisted living, care homes and nursing homes [20, 21, 22, 23]. Eligibility for long-term care in the community and for residential care depends on the degree of care dependency and is evaluated using the 6 items of the Belgian Katz ADL (Activities of Daily Living) scale, adjusted with 2 items about cognitive performance (disorientation in time or space) [24]. Even though this eligibility criterion exists, it is mostly applied for the funding of residential care. The admission to a nursing home can still be granted to a client with low care dependency and it may still happen that older persons are admitted 'too early' into residential care, so, at low care levels.

As in most European countries, long-term care policies in Belgium aim at allowing frail older people to remain in their homes for as long as possible and at avoiding early nursing home admission [25]. In recent years, the Belgian government launched a third protocol agreement between the different competent ministries,

also known as Protocol 3. The goal was to define a common policy framework for long-term care. This framework is based on the following principles: supporting older persons to live at home independently for as long as possible; supporting informal caregivers; guaranteeing access to affordable formal care services and improving coordination and integration of care [26]. Under this protocol, the interRAI Home Care instrument was chosen as the main instrument for the evaluation of the interventions.

The interRAI instruments

The interRAI instruments are a set of standardized, evidence-based and internationally validated assessment instruments. These were developed by interRAI, which is an international collaborative of scientists, clinicians and policy makers to improve the care and quality of life of vulnerable persons. Currently, 87 researchers and clinicians from 35 nations are fellows of interRAI (2017).

The Resident Assessment Instrument for nursing homes (RAI 1.0), also called the Minimum Data Set or MDS, was the first assessment developed by interRAI. It dates back to 1987. The first version of this instrument was implemented in all nursing homes in the USA from 1992 on [27, 28]. Since then, several other instruments have been developed for different care settings. The latest generation of the interRAI instruments (the interRAI Suite) shares a common language across settings, with some specific items adapted to specific care settings. All core items are the same and this enables information sharing and the transfer of data across organizations and settings. This feature enhances continuity of care (29) so that professionals can follow the clients' information through their care trajectories (e.g. from community care setting to residential care setting or to acute care setting and so on). The interRAI Suite also provides a set of common outcomes which can be useful for care planning (30, 31, 32). After completing the interRAI assessment, embedded algorithms produce scales which have been internationally validated with existing gold standard scales (e.g. interRAI Cognitive Performance Scale x Mini-Mental State

Examination, interRAI Depression Rating Scale x Hamilton and Cornell scales). The Client Assessment Protocol (CAPs) are also generated automatically after an assessment is completed and they are a useful tool to identify the factors that may lead to adverse outcomes and that need to be addressed by the care professionals. The main goal of the CAPs is to provide information to help develop a care plan for the client (33). A report of the OECD (2012) showed that the interRAI instruments enable integrated eCare and allow high quality data sharing between organizations and settings [34]. The use of the interRAI Suite provides standardized tools that can assure a minimum high quality standard in the gathering of information and in the care planning [33].

Moreover, the Suite of interRAI instruments provides tools for benchmarking by offering adjusted quality indicators. These interRAI quality indicators use aggregated data to identify the prevalence or incidence of outcomes in organizations and makes it possible to measure and compare quality of care. Moreover, these quality indicators can also emphasize changes in clinical status as a result of an intervention. To calibrate the quality measures, the indicators are risk-adjusted using some inclusion and exclusion criteria (e.g. people in palliative stage of illness are often excluded because of their deteriorating health situation which is often not due to quality issues), as well as for some related factors (e.g. quality indicator for falls is adjusted for locomotion levels). Quality indicators are very useful for quality improvement, as well as for public reporting and benchmarking and can be used in the future for cross-national comparisons (34).

Another feature of the interRAI instruments is the Resource Utilization Groups (RUGs) system, which enables the classification of clients in groups based on their case-mix. Each client is allocated into a RUG group in which a case-mix index will show the relative use of resources (cost) for caring for this client (35). The RUGs system has proven to be robust across countries and it is used in the United States, Canada, Iceland and Finland as a basis for funding of long-term care (34). Recently

the RUG-system has also been validated as a case-mix system for persons receiving home care (36).

The interRAI instruments in Belgium

In 2003, the Belgian government decided that a comprehensive geriatric assessment instrument was one of the necessary tools in order to maintain or improve the quality of care for older persons in Belgium. This instrument had to meet the following conditions: (1) international validation; (2) adaptable to different contexts of care; (3) give a holistic view of the older person's situation; (4) provide the necessary input to create an adequate care plan; (5) promote collaboration in a multidisciplinary team; and (6) promote continuity of care. Subsequently, four potentially suitable instruments were tested during the INTERFACE project [37]. The interRAI suite of instruments came out as the best option.

Based on the conclusions from the INTERFACE project, the interRAI Suite of instruments was tested as to feasibility in Belgium. Firstly, between 2006 and 2009, three instruments were tested in three different settings: in the community setting (the interRAI Home Care instrument - HC), in the residential setting (the interRAI Long-Term Care Facilities instrument - LTCF) and in the acute care setting (interRAI Acute Care - AC) [38, 39, 40, 41].

In 2010, the interRAI HC was implemented as a mandatory evaluation instrument for innovative home care interventions under the Protocol 3 agreement. The interventions were considered to be innovative in the Belgian home care context because they were not yetfunded by the health insurance and they were not part of regular community care. The interventions under this evaluation have used the interRAI HC instrument since 2010.

Moreover, in the period between 2012 and 2015, the interRAI Palliative Care (interRAI PC) instrument was tested in Belgian nursing homes [42]. A screener instrument – the BelRAI Screener - was also developed for the Belgian home care

setting consisting of four short modules from the interRAI HC instrument, and one module from the interRAI Mental Health instrument. This short screening instrument determines whether a person should have a full interRAI HC assessment based on a certain cut off value [43]. The BelRAI Screener will also be used as a decision aid to check whether care dependent people would be entitled to an extra financing for their care.

Since 2017, other interRAI instruments are being tested in Flanders: the Mental Health instrument, the instrument for Rehabilitation therapies and the instrument for Child care. Moreover, a social supplement for the interRAI Suite is being created.

In order to be able to use the interRAI instruments in Belgium, several steps were taken:

1. Translation of the instruments into the three official languages (Dutch, French and German);
2. Adaptation of the instruments and manuals to the Belgian care settings;
3. Development of a secured website allowing professional caregivers from several disciplines to fill out the instruments in a multidisciplinary way. This secure website is interconnected with the Belgian e-Health platform to allow direct access to several disciplines of caregivers (physicians, nurses, physiotherapists, occupational therapists, social assistants, etc.).
4. Development of a wiki-site containing all the information professional caregivers and researchers might need in order to understand the BelRAI instrument thoroughly. This website also contains information about the outcome variables of the instruments (CAPs, scales, etc.). The wiki-site serves as an online manual for professional caregivers in their day-to day use of the BelRAi instruments and their applications.
5. Adaptation of the CAPs to the Belgian care setting so that they can aid professionals to build a care plan for their clients.

In Belgium, the interRAI instruments can be electronically transferred across settings in a way that the data can follow the client (e.g. from the home care setting to the nursing home). This allows for information sharing across settings and across professionals to ensure continuity of care and to facilitate multidisciplinary collaboration. Another feature of the BelRAI system is that professional caregivers can observe the evolution of their clients' outcomes individually or in groups [33].

Innovative home care interventions in Belgium – Protocol 3

In July 2009, the Belgian National Institute for Health and Disability Insurance (NIHDI) launched a first call for interventions of innovative care and support for frail older persons. This call for projects was a result of an agreement between the federal and the regional authorities having competencies in the organisation of care for older people [44, 45]. Through this agreement, called Protocol 3, a large budget which was going to be used for the extension of nursing home capacity was partially allocated to finance and evaluate alternative forms of home care and support of care in the community during a period of four years. The aim of the call was to identify effective interventions which could avoid institutionalization of frail older people. Other objectives were to maintain a good quality of life for the older person as well as low informal caregiver's burden. In order to evaluate these interventions a consortium of universities was created consisting of the Université Catholique de Louvain, KU Leuven, Universiteit Antwerpen and Université de Liège. From April 2010 onwards, 64 selected projects received financing. These projects planned interventions targeting diverse groups of frail older people, involving a variety of professionals and organisations in several contexts. A second call for projects was launched in March 2014, and the new projects (all of them involving case management interventions combined with other services) started in September 2014. Protocol 3 can be considered a large-scale program of multiple bottom-up interventions with the goal of keeping frail older people at home longer.

Since the beginning of the evaluation process, the projects have been grouped into homogeneous types in order to allow for comparisons. This classification was part of an implementation analysis. Only interventions delivered on a permanent basis by a project were retained for the classification and were grouped following an operational typology [46]. To ensure that interventions were described thoroughly and correctly, a qualitative research based on a normative approach was conducted [47]. This research used yearly questionnaires, interviews and case-studies in order to track features of the interventions such as frequency of the delivered services, skills of personnel, turnover, use of best practices, tailored service design and linkages with other organizations in the community. The costs of the interventions were also assessed.

Based on this extensive study, interventions were grouped into single and multi-component interventions according to the key services provided to the older persons. The classification yielded the following types of interventions:

1- Single interventions:
    a. Occupational therapy (home adaptations and advice about assistive devices)
    b. Psychological support
    c. Day care
    d. Night care (either offered exclusively to one frail older person with full supervision or to several frail older persons)
2- Multi-component interventions:
    a. Case management with psychological support and occupational therapy
    b. Case management with occupational therapy and physiotherapy

c. Case management with several rehabilitation services (occupational therapy, physiotherapy, psychotherapy and night support) in a short-term residential setting
d. Case management with occupational therapy at home for older persons with visual impairment

Study aims

This doctoral research is part of the Protocol 3 project. As the goal of these interventions is to keep frail older people at home longer with good quality of life and low burden for the informal caregivers, it is important to evaluate the client's entire situation. For this purpose, it is essential to capture as much information as possible using a thorough instrument in the evaluation.

The main goal of the research is to evaluate whether home care interventions are effective at avoiding or preventing early nursing home admission of frail older people. This is an important goal since residential care can be very costly and older people usually prefer staying in their home environment. In order to attain this goal, the study consisted of the following parts:

1. An overview of interventional studies using the interRAI HC instrument

The first study in this thesis is a systematic review about how the interRAI HC instrument was previously used in research to evaluate interventions in home care. By analysing published research with the interRAI HC, we can learn about advantages and disadvantages of using this instrument, as well as learn from existing knowledge on this type of evaluation.

2. The identification of the determinants of informal caregiver's burden using the interRAI HC instrument

The second study was performed to explore informal caregiver's burden as it is known to be one of the risk factors of nursing home admission of frail older people. This study was based on a new perspective by combining two frameworks: the Role Theory and the Stress Process Theory as recommended in Bastawrous (2013). This was only possible because a comprehensive assessment was used, the interRAI HC, allowing for the testing of several determinants from both theories present in the instrument. The interRAI HC can measure the situation of the informal caregiver (relation to the client, co-habitation or not, types of care activities, etc.) as well as the possibility to continue giving care.

3. The effectiveness of home care interventions in delaying or avoiding nursing home admission of frail older people

This study was performed to evaluate the effect of innovative interventions in home care to keep frail older people at home. Identifying the most effective interventions is essential to make policy decisions. Our study not only aimed at analysing whether interventions had an effect on nursing home admission but also to identify for which type of population they were effective.

4. The description of the case-mix of home care clients and comparison with clients in residential setting

This final study in this thesis explored the case-mix of clients receiving home care interventions and compared their case-mix with clients being admitted into nursing homes. As interventions in our study were designed to keep frail older people at home, clients receiving these interventions should have a similar case-mix as clients in residential care. This study can help to determine eligibility to residential care and to help interventions to tackle the right risk clients.

List of Abbreviations

CAPs: Client Assessment Protocols

interRAI HC: interRAI Home Care instrument

RUG: Resource Utilization Groups

CIN-IMA database: National Health Insurance database

OECD: Organisation for Economic Co-operation and Development

IADLP: Instrumental Activities of Daily Living Performance scale

ADLH: Hierarchical Activities of Daily Living scale

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Outline

The following chapters describe and answer each of the research questions of our study:

Chapter 2 - Protocol of the research (background, methods, research questions and discussion).

Chapter 3 - Systematic review of evaluations of home care interventions using the interRAI HC instrument.

Chapter 4 - Determinants of informal caregiver's burden.

Chapter 5 - Results of the evaluation of home care interventions in preventing or delaying nursing home admission of frail older people.

Chapter 6 - A comparison between the RUG III case mix of community care clients and older people admitted into nursing homes

Chapter 2

Research protocol: Interventions to delay institutionalization of frail older persons: design of a longitudinal study in the home care setting

This chapter is an adaptation from:

de Almeida Mello, J., Van Durme, T., Macq, J., Declercq, A. (2012). Interventions to delay institutionalization of frail older persons: design of a longitudinal study in the home care setting. *BMC Public Health*, *12*: 615.

Introduction

This chapter consists of the protocol of the PhD research which serves as a basis for this thesis. The protocol is an adapted version of a previously published paper describing the global Protocol 3 research project (de Almeida Mello et al, 2012). The reason why only the adapted version is included in this chapter, is the fact that three of the research questions of this thesis are different than the ones in the published protocol. This was mainly due to the use of a comparison group in this thesis from a registry database (IMA – Intermutualistisch Agentschap). This comparison group was used to match the clients in the study with clients living at home not receiving interventions, in order to analyze the effect of the interventions on the risk of nursing home admissions. The global protocol uses mainly a control group created for the research but this control group was not yet available in the first years of the research.

The research questions of this PhD thesis protocol are:

1- What is the evidence in the scientific literature on the use of the interRAI Home Care instrument for evaluating home care interventions?

2- What are the factors mostly associated with informal caregivers' burden in the study population?

3- What is the effect of home care interventions on delaying or avoiding institutionalization of frail older persons?

4- What is the resource utilization of frail older people in the community compared to older people being admitted to nursing homes?

In the protocol, each research question is described, as well as the methodology used to answer these questions. Each research question of the protocol relates to institutionalization of older persons. The interRAI Home Care instrument enabled us to evaluate aspects of the situation of frail older people linked to their risk of institutionalization (such as informal caregiver's burden, ADL and IADL problems, cognitive decline, etc). The goal was to apply the interRAI HC in this evaluation, showing its applicability for research in community care and for policy making.

De Almeida Mello et al. BMC Public Health 2012, 12:615
http://www.biomedcentral.com/1471-2458/12/615

BMC Public Health

STUDY PROTOCOL Open Access

Interventions to delay institutionalization of frail older persons: design of a longitudinal study in the home care setting

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Abstract

Background: Older people usually prefer staying at home rather than going into residential care. The Belgian National Institute for Health and Disability Insurance wishes to invest in home care by financing innovative projects that effectively help older people to stay at home longer. In this study protocol we describe the evaluation of 64 home care projects. These projects are clustered according to the type of their main intervention such as case management, day care, night care, occupational therapy at home and psychological/psychosocial support. The main goal of this study is to identify which types of projects have the most effect in delaying institutionalization of frail older persons.

Methods/design: This is a longitudinal intervention study based on a quasi-experimental design. Researchers use two comparison strategies to evaluate intervention - comparison between older persons receiving the interventions and older persons who are still at home but who do not receive any intervention and between older persons in the study population and older persons who are going into residential care. Projects are asked to include clients who are frail and at risk of institutionalization. In the study we use internationally validated instruments such as the interRAI Home Care instrument and the Zarit Burden Interview-12. These instruments are filled out at baseline, at exit from the project and 6 months after baseline. Additionally, caregivers have to do a follow-up every 6 months until exit from the project. Criteria to exit the cohort will be institutionalization longer than 3 months and death. The main analysis in the study consists of the calculation of the relative risk of definitive institutionalization.

Discussion: This research will provide knowledge on the functional status of frail older persons who are still living at home. This is important information in order to characterize the population at risk of institutionalization, as well as to explore the determinants for informal caregivers' burden. The identification of effective home care interventions in delaying institutionalization will be useful to inform and empower home care providers, policy and related decision makers to manage and improve home care services.

Research protocol: Interventions to delay institutionalization of frail older persons: design of a longitudinal study in the home care setting

Background

Older people usually prefer staying at home rather than going into residential care [1, 2, 3]. Several organizations and professionals provide care for older people at home. In 1994, the World Health Organization defined home care as "an array of health and social support services provided to clients in their own residence. The assumption is that these co-ordinated services may prevent, delay or be a substitute for temporary or long-term institutional care" [4]. A more recent definition of home care defines it as "a phenomenon in which care is provided by professionals to people in their own homes with the ultimate goal of not only contributing to their life quality and functional health status, but also to replace hospital care with care in the home for societal reasons". In this definition, home care covers a wide range of activities, from preventive visits to end-of-life care [5]. According to the 2009 WHO-report, an appropriate balance between care settings for elderly care is necessary, including supported self-care and home-based service. The report emphasizes the need for interventions to help maintain older people at home and to prevent long-term institutional care [6].

In the literature, several studies can be found about predictors for home care use. The most predominant determinants are age, living arrangement, number of informal caregivers, income, medical diagnosis and functional status [1, 7]. Moreover, randomized controlled trials have shown that targeted home care can contribute significantly to reduce hospital admission, to delay institutionalization and to improve quality of life [8, 9, 10].

The Belgian National Institute for Health and Disability Insurance (NIHDI) wishes to invest in community care by financing innovative home care interventions that effectively help older people to stay at home longer. In this study, the effects of these interventions are examined as to whether they keep frail older people longer at

home, avoiding or delaying nursing home admission [11, 12, 13, 14, 15]. These interventions might not be considered to be innovative in other countries. The term 'innovative' in the context of this research is defined as interventions which are not yet financed by the Belgian care insurance NIHDI. These interventions can be seen as alternatives or add-ons to the standard home care services which are already funded (respite care, nursing care at home, physiotherapy, etc.).

The main goal of this study is to identify which types of interventions have the most effect in delaying institutionalization of frail older persons.

Methods

This is a longitudinal intervention study based on a quasi-experimental design [16]. Due to some constraints, a randomized controlled trial is impossible to realize. The constraints are mostly practical and ethical, since all frail older people who wish to benefit from an innovative project cannot be denied access to it. In addition, researchers cannot have a total control of the intervention since projects are delivering the services in the 'real world'. Projects may organize their intervention according to their specific types of services. Non randomization and variety of projects impose a thorough description and follow up of target population and intervention content. Two comparison strategies will be used to evaluate the interventions: comparison of the arm receiving the intervention with older people living at home and not receiving any intervention (comparison group) and a comparison with older people who are being institutionalized.

Sample size considerations

Using an effect size of 0.50, a two-sided significance level of 0.05 and a power of 85%, 75 participants are needed in each group. We expect each organization to include at least 45 participants per year because this is the minimum size of case load projects reported at the beginning of their activities. The clusters of projects will have then a larger sample size than indicated by the sample size calculation.

Study population

The study will include older people who are at least 65 years old and who are living at home. Projects are asked to include only clients who are frail and at risk of institutionalization. Frailty can be measured in the study with two different scales and caregivers are allowed to choose between them. One of these scales is the Edmonton Frail Scale [17, 18] with a cut-off point of 6. Another scale is an adapted version of the Katz scale for Belgian home care and residential care [19]. Older people with a Katz score equal to A, B or C will be included [20]. Clients who have been diagnosed with dementia by a geriatrician, neurologist or psychiatrist may also be included in the study.

Data from 64 innovative projects will be analysed in this research. Due to the fact that the projects vary in the scope of the intervention they provide, these projects will be clustered according to the type of their main intervention: case management, day care, night care, occupational therapy at home, psychological/psychosocial support, or case management combined with other interventions.

Each project has to collect data on at least 75% of their total client population in order to ensure representativeness. This means that caregivers have to fill out assessments for at least 75% of clients benefiting from their projects.

Ethical approval and informed consent

This observational study was approved by the Belgian Privacy Commission and by the Ethics committee of the Belgian Universities - Université Catholique de Louvain and KULeuven with dossier number B40320108337. A formal procedure was implemented so that caregivers could fill out the questionnaires on a secured website.

For this study, older persons are asked to sign an informed consent agreement. In case they are not capable of signing this document, a family member or a legal

representative will sign it on their behalf, as stipulated by Belgian law [21]. Clients do not undergo the intervention because of the research. The research however evaluates the effects of the intervention. Clients have the right not to participate in the research and they may withdraw their consent at any time. In that case, all data for this person is removed. Their consent or refusal to consent does not affect their participation in the intervention. All data are anonymized and analyzed according to the rules of the Belgian Privacy Commission [22].

Research questions

The aim of the study is to answer the following research questions:

1- What is the evidence in the scientific literature of the use of the interRAI Home Care instrument for evaluating home care interventions?

2- What are the factors mostly associated with informal caregivers' burden in the study population?

3- What is the effect of home care interventions on delaying or avoiding institutionalization for frail older persons?

4- What is the resource utilization of frail older people in the community compared to older people being admitted to nursing homes?

Instruments

interRAI HC instrument

The interRAI HC instrument is an internationally validated instrument consisting of several domains such as cognitive functioning, ADL, social and psychological wellbeing, health status, environmental characteristics, etc. The use of a comprehensive geriatric assessment such as the interRAI HC is essential for this type of research in order to have an in-depth view of the client's health and functional

status [23, 24, 25]. The follow up of these characteristics will give insight in the evolution of the client's situation and will enable researchers to show the effect of the interventions. In the study we use the validated Belgian version of this instrument named the BelRAI HC.

WHO-QOL-8

The WHO defines Quality of Life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (26). The WHO-QOL-8 scale measures the perceived overall quality of life of the clients. It is derived from the WHO-QOL-Bref and contains each of the domains: physical and psychological health, social relations and environment [27]. This scale was designed for use when researchers need a short and concise instrument to measure quality of life. It is a self-report instrument, so it has to be filled out by the clients themselves.

Zarit Burden Interview 12 (ZBI-12)

In the international literature caregiver burden is perceived as a multidimensional response to stressors associated with care giving. These stressors may be physical, psychological, emotional, social and financial [28, 29]. In this research we use a shorter version of the original 22-item scale Zarit Burden Interview [30]. This scale contains 12 items with a score from 0 to 4. The total score can vary from 0 to 48 and the higher the total score, the higher the caregiver burden. The short form of the scale was chosen, in order not to put a heavier weight on the burden of the caregiver and to increase the response rate.

An ad-hoc economic questionnaire

This questionnaire was created to measure the time spent by the informal caregiver in the care for the frail older person and to make an inventory of the types of tasks performed by the informal caregiver as well as some of demographics (age of informal caregiver, educational level, work status, etc). This questionnaire also

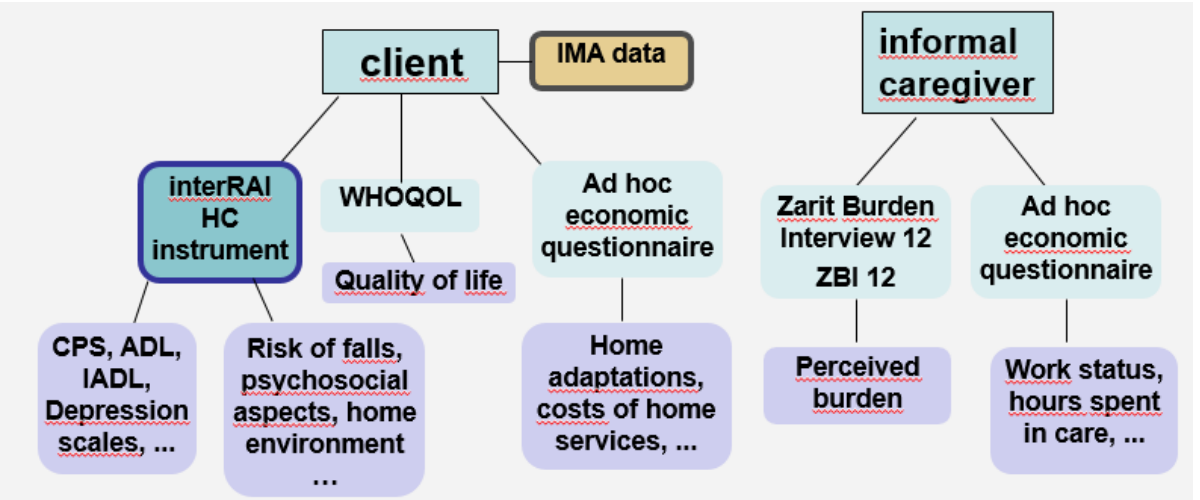
makes an inventory of the costs of staying at home for the older person and of the amount of social care hours they receive at home.

Other sources

The study uses additional data from a national registry database: the CIN-IMA (National Health Insurance database). The CIN-IMA is an official database from the Belgian government, which contains all administrative information about reimbursed healthcare consumption (doctor's visits, hospitalization cost, residential care admissions and costs, usage of prescribed medication, nursing costs, physiotherapy and speech therapy costs).

Figure 1 provides an overview of all the instruments completed during the Protocol 3 evaluation process and their main outcome variables.

Figure 1: Instruments used in the Protocol 3 evaluation



Data collection

Professional caregivers are asked to fill out the interRAI Home Care instrument. They also fill out the WHOQOL and an ad-hoc economic questionnaire by interview and the main informal caregivers fill out the ZBI-12. These questionnaires are completed at inclusion of the frail older person in the project (baseline), at exit from the project and 6 months after baseline. Additionally, if the clients stay longer than 6 months in the project, caregivers have to do a follow-up every 6 months until exit from the project. Follow-up of the clients happens from March 2011 until July 2013. The follow-up period varies between 6 to 36 months. Criteria to exit the cohort are institutionalization longer than 3 months and death. Follow up also ends for clients who left the projects.

Professional caregivers are instructed on how to fill out the questionnaires during a 2-day training and a follow-up training of 1 day. They fill out the interRAI HC based on observation and on interview of the older person and of the main informal caregiver.

For the analysis, the interRAI-data will be linked with data from the national database CIN-IMA (Inter-mutuality Agency), consisting of data on national health service consumption reimbursed by NIHDI. This data will be added to the analysis for the clients receiving interventions.

The “permanent sample” of people over 65 extracted from the CIN-IMA database will serve as a control group for our study population. By using this database we will be able to compare older persons who are receiving interventions with older persons who are not receiving them (comparison group). In this database we will select clients who are still living at home and have the same levels of impairment as the intervention group.

Analyses

- Research question 1 - What is the evidence in the scientific literature on using the interRAI Home Care instrument to evaluate home care interventions?

In order to answer this research question, a systematic literature review will be performed to explore whether the interRAI HC instrument can bring an added value to the evaluation of home care interventions.

The aim of this systematic review will be to identify interventional studies using the interRAI HC instrument and to report the advantages and disadvantages of the use of this instrument for evaluating interventions. Moreover, based on the results of the systematic review, we can gain insight on which variables to use in our evaluation study.

In the context of our study, this systematic review can be very useful in order to evaluate how other researchers applied the interRAI HC instrument on their research. Moreover, this review could help researchers in the future to choose the main variables they might need for which type of evaluation they wish to perform. Secondly, the review will report the results of these interventional studies and the advantages and disadvantages of the use of the interRAI HC in this type of research.

- Research question 2 - What are the factors mostly associated with informal caregivers' burden in the study population?

As informal caregivers are often involved in most of the care for frail older persons, they play an important role in helping them stay at home. It is therefore important to tackle problem situations which may cause burden. In our research, we have a particular interest in the factors predicting burden, since burden is one of the risk

factors of institutionalization (31, 32). The goal of our analysis is to make an in-depth exploration of the determinants of burden by using a new perspective: combining the Stress Process Model (33) with the Role Theory (34).

- Research question 3 - What is the effect of home care interventions on delaying or avoiding institutionalization of frail older persons?

To answer this research question, the main outcome variable in the study is the relative risk of institutionalization at six months. The relative risk of institutionalization of clients receiving interventions (intervention arm) will be calculated compared to clients not included in any interventions (comparison arm). This analysis will be performed by means of a Poisson regression using software STATA 11. The interventions will be evaluated as to having a positive effect on delaying or avoiding institutionalization or not. Additional analyses for the risk of death at six months will be performed. This is the main analysis of the Protocol 3 protocol study, identifying which interventions can have an effect on keeping frail older persons at home at six months of follow-up.

- Research question 4 - What is the resource utilization of frail older people in the community?

The interRAI RUG-III case-mix system is an internationally validated algorithm, which groups clients according to their resource utilization. The comparison between the resource utilization of clients living in the community and clients being admitted to nursing homes can provide information about the differences and similarities in the profiles of these clients and on the reasons for institutionalization.

Innovative home care interventions can only be effective if they target the right clients. The right clients are the ones at risk of institutionalization. By applying the RUG-III to compare these clients with clients at the entry point in residential care, researchers can gain important information about their needs and resource utilization. This is relevant information in order to create policies for the eligibility of

clients for home care interventions, as well as for residential care, and for planning staff and resources in community and residential care.

Main variables

In order to answer the four research questions, the variables shown in Table 1 will be used. Frequencies will be calculated for categorical variables and means and medians with confidence intervals for continuous variables. All the statistical analyses in the study will be performed with the software Stata 11.1.

Table 1- Main variables

General information	Civil status	InterRAI HC	Qualitative
	Age	InterRAI HC and IMA	Continuous
	Gender	InterRAI HC and IMA	Dichotomic
Socio-economic status	Financial difficulties	InterRAI HC	Dichotomic
	Living status	InterRAI HC	Qualitative
Primary caregiver's burden	Zarit Burden score	ZBI-12	Ordinal (0 to 48)
Functional status	Katz score	IMA	Qualitative
	interRAI ADL hierarchy scale	InterRAI HC	Ordinal (0 to 6)
	interRAI IADLP scale	InterRAI HC	Ordinal (0 to 48)
	interRAI CPS2 scale	InterRAI HC	Ordinal (0 to 6)
Outcome variable	Admission to residential care	IMA	Dichotomic

Longitudinal analyses will be performed to answer the third and fourth research questions. The main outcome variable is the admission to a nursing home in the first six months of follow-up.

The ADL hierarchy scale is a measure of a person's functional performance. It is based on the concept of early, middle and late loss of ADLs and consists of 4 items from the interRAI instruments: personal hygiene, toilet use, locomotion and eating. The scores vary from 0 to 6 and the higher the score, the greater the dependency [35, 36].

The IADLP scale or the Instrumental Activities of Daily Living scale is based on a sum of eight items about IADL: meal preparation, housework, managing finances, managing medications, phone use, shopping and transportation. The scale ranges from 0 to 48, with higher scores indicating greater difficulty in performing these activities (37).

The cognitive performance scale (CPS2) is an internationally validated scale that describes a person's cognitive status. The scores vary from 0 to 6 and the scale consists of 5 items from the interRAI HC instrument: skills for daily decision-making, making oneself understood, short-term memory recall, procedural memory and eating impairment. Higher scores indicate a greater degree of cognitive impairment. Several studies have shown a significant correlation between the CPS scale and the Mini-Mental State Examination (MMSE) [38, 39].

Stratification of the study population

Due to the diversity in degree of impairment of the study population and due to the fact that some interventions target particular types of older people, the study sample will be stratified on the basis of cognitive and functional status. For the stratification, the following interRAI outcome measures will be used: the IADLP scale, the ADL scale and the CPS2 scale. Sub-groups of the total population will be constructed based on

the type of impairment clients present and on the outcome to be measured. Stratification will improve the accuracy and robustness of the statistical analysis.

Discussion

This paper describes the study protocol of a longitudinal quasi-experimental research to evaluate the effect of innovative projects in delaying institutionalization of frail older persons.

A major strength of the study is the period of 3 years, which allows researchers to obtain a large sample size and several measurement points for a number of clients. Another major strength is the availability of the national database IMA to enable researchers to have a large comparison group and to have data on health services and medication consumption of the study population. In addition, the use of international validated instruments such as the ZB-12 and the interRAI HC will make further cross-national comparisons possible in future research.

Some limitations of the study are due to the lack of randomization in the allocation between projects and due to the fact that not all variables collected in the study population will be found in the comparison group. This limitation will be overcome by using a large registry database as a comparison group and by matching the common variables between both groups.

Conclusion

This research will provide knowledge on the functional situation of frail older persons who are still living at home and will allow researchers to make comparisons with older persons who are being institutionalized. The identification of effective projects in delaying institutionalization will be useful to inform and empower home care providers and policy makers to manage and improve home care services.

Abbreviations

WHO: World Health Organization

NIHDI: National Institute for Health and Disability Insurance

WHO-QOL-8: World Health Organization Quality of Life instrument 8

ZBI 12: Zarit Burden Interview - 12 items

interRAI HC: interRAI Home Care instrument

RUG III/HC: Resource Utilization Group III Home Care

IMA: Inter-Mutuality Agency

CIN-IMA: CIN-IMA database – health consumption database of the Inter-Mutuality Agency

ADL: Activities of Daily Living

CPS2: InterRAI Cognitive Performance scale 2

IADL: Instrumental Activities of Daily Living

MMSE: Mini-Mental State Examination

DRS: interRAI Depression Rating Scale

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Competing interests

The authors declare that they have no competing interests.

Authors' contributions

dAMJ, VDT, MJ and DA are involved in the study design and critically reviewed and approved the final manuscript. dAMJ drafted the manuscript. All authors read and approved the final manuscript.

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Chapter 3

Evaluations of home care interventions for frail older persons using the interRAI Home Care instrument: a systematic review of the literature

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Review Article

Evaluations of Home Care Interventions for Frail Older Persons Using the interRAI Home Care Instrument: A Systematic Review of the Literature

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Abstract

Background/Objectives: This systematic review describes the use of the interRAI Home Care (interRAI HC) instrument, an internationally validated comprehensive geriatric assessment, as a base for the evaluation of home care interventions. Because of the evidence base of the instrument and its widespread use, researchers can make a thorough evaluation of interventions in home care and can also have insight in international comparisons. The aim of this systematic review is to identify research that evaluates interventions in the home care setting using this comprehensive geriatric assessment and to describe these evaluations and report the results of the use of this instrument.

Design: Two independent reviewers constructed a comprehensive list of Medical Subject Headings, which was designed for 5 explicit categories: (1) interventions; (2) evaluation; (3) home care; (4) interRAI HC; and (5) older person. A systematic literature search was then performed in the main electronic databases Web of Science, EMBASE, MEDLINE, Cochrane, PsycInfo, and CINAHL for the years 1990 to 2013.

Measurements: Studies were described and the following information was extracted from the articles: mean age and proportion of gender of participants; sample size; location of the study; goal of the study; main findings; main limitations; and results of the evaluation of the interRAI HC instrument.

Results: A total of 349 articles were identified. Eighteen studies met our inclusion criteria describing 18 interventions in home care evaluated with the interRAI HC instrument.

Conclusions: This systematic review can help researchers to plan evaluation of interventions in home care. The interRAI HC instrument proves to be a comprehensive tool to measure outcomes and can serve as an evaluation instrument for interventions. It can also be used as an intervention itself, when caregivers use the tool and its outcome measures to implement a care plan.

Evaluations of Home Care Interventions for Frail Older Persons Using the interRAI Home Care Instrument: A Systematic Review of the Literature

Background

Population aging is perceived as a major challenge for care systems worldwide. The main drivers of public spending on health care for people of 65 years and older are hospital admissions and admissions to long-term care facilities. High quality community care is expected to be a cost-effective solution with a positive effect on the sustainability of health care systems. Usually, interventions in community care vary according to population needs and policy aims. Because frail older persons usually have complex and changing health needs, home care services should be adapted to them [1-3]. This implies the necessity of gathering knowledge on physical, psychological, and social health situation of frail older persons. By means of a comprehensive geriatric assessment (CGA), a suitable evaluation can be made of all essential needs of older persons and their informal caregivers, in order to be able to determine what services are necessary to meet their needs [4-6].

The interRAI assessment instruments are comprehensive geriatric assessment tools, which have been internationally validated in different care settings (community care, residential care, palliative care, acute care, and so on). These instruments have common items and sections making transfer of information across settings possible as well as some specific items according to the setting. The interRAI instruments have often been used in research, as well as in service development and as a base for care and quality improvement [7-9].

The RAI Home Care instrument 1.0 was first developed in 1994. Initially, it was designed to be compatible with the RAI LTCF for the residential setting, already implemented in American nursing homes. This instrument was then revised in 1999, and the version RAI Home Care 2.0 was created. In 2007, after further validations and revisions to be compatible with the other assessment systems, the instrument was named interRAI Home Care (interRAI HC) suite. The interRAI HC suite continues to undergo validity by the interRAI consortium to meet the changing needs of older

persons in the community care setting [10,11]. The assessment items include measures in the following areas: personal information, cognitive performance, communication, hearing, vision, mood and behavior, social functioning, physical functioning, continence, disease diagnoses, service utilization, medications, health conditions and preventive health measures, nutrition, skin condition, informal support services, and environmental aspects. The instrument provides outcome measures [interRAI scales and clinical assessment protocols (CAPs)] to help create a care plan for the older person, and these outcome measures also undergo continuous validation [12-16].

This systematic review describes the use of the interRAI HC instrument (versions 1.0, 2.0, and suite) as a base for the evaluation of home care interventions. Because of the evidence base and widespread use of the instrument, researchers can make a thorough evaluation of interventions in home care and can also have insight in international comparisons. The aim of this systematic review is to identify articles that evaluate interventions in the home care setting using this CGA, to describe these evaluations, and report the results of the use of this instrument. Studies in which the use or implementation of this instrument is viewed as an intervention in itself, are also included. The review can help researchers to determine the type of evaluation they need to perform and to determine whether this CGA can bring an added value to the research.

Methods

Literature Search Strategy and Study Selection

Two independent reviewers constructed a comprehensive list of Medical Subject Headings, which was designed for 5 explicit categories: (1) interventions; (2) evaluation; (3) home care; (4) interRAI HC; and (5) older person (Table 1). A systematic literature search was then performed by the same researchers in the

main electronic databases Web of Science, EMBASE, MEDLINE, Cochrane, PsycInfo, and CINAHL for the years 1990 to 2013. The study followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for reporting systematic reviews [17]. Titles and abstracts of all articles were examined by 2 independent reviewers. Studies were included if they described an intervention in the home care setting, which was evaluated by means of the use of the following interRAI instruments for the community setting: RAI HC versions 1.0, 2.0, or the interRAI HC suite. From now on we will simply mention interRAI HC instrument as referring to all of the versions because the differences between the contents of these versions can be considered compatible among themselves[18]. Only peer-reviewed articles are included in this review. Inclusion criteria are (1) the instrument used is the interRAI HC instrument; (2) articles about older persons; (3) articles describing interventions in the home care setting; and (4) articles published in English.

Table 1 Medical Subject Headings (MeSH) Search Terms*

Search category	**MeSH terms**
Intervention	Intervention studies, Therapeutics , Preventive Health Services
Evaluation	*Evaluat*, Rate*, Assess*, Apprais*, Impact, Effect**
Home care	Community Health Services
interRAI Home Care	Needs assessment, Comprehensive Health Care , *RAI, RAI HC, interRAI Home Care, interRAI HC, MDS[a],* Instruments (MeSH), Questionnaires (MeSH), Geriatric assessment (MeSH)
Older persons	Aged

* For a detailed table with MeSH terms, keywords and explosions of the search strategy, please contact the authors.

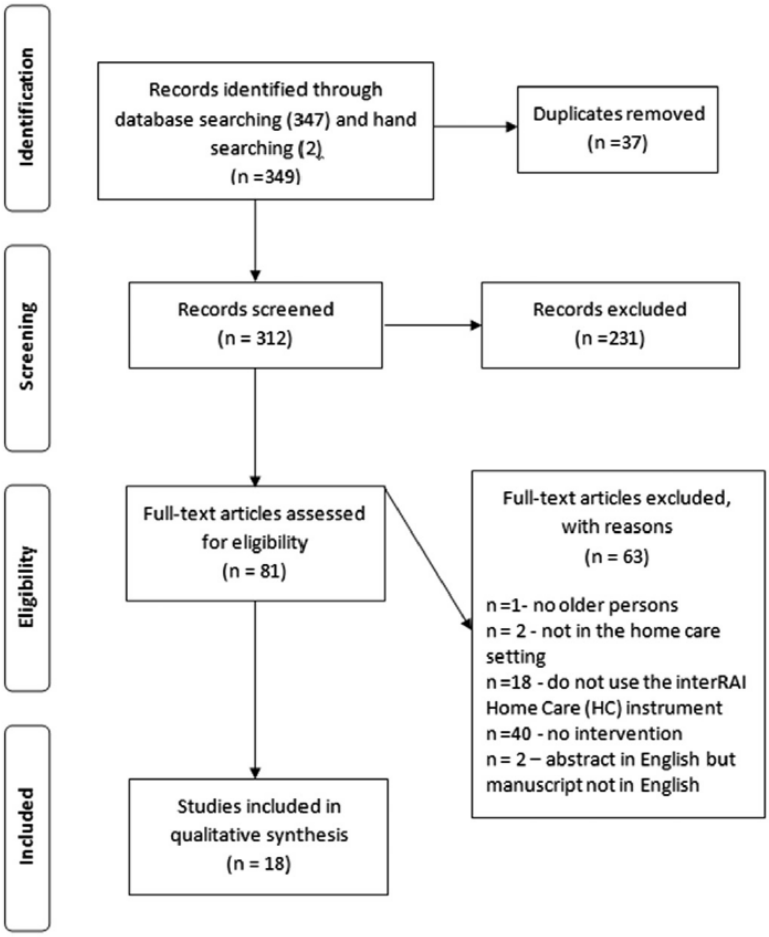
[a] MDS used to be the abbreviation of Minimum Data Set – name formerly given to the interRAI assessments in the decades of the 80s and 90s.

The full text of potential articles was reviewed and the following data were extracted from the studies: (1) author, year; (2) study design; (3) mean age and proportion of gender of participants; (4) sample size; (5) main outcomes; (6) location; and (1) author, year; (2) goal of the study; (3) main findings; (4) main limitations; (5) results.

Results

The original literature search performed by 2 independent reviewers identified a total of 347 articles and 2 additional articles were identified through manual searching (Figure 1). Thirty-seven duplicates were removed, resulting in 312 articles that were screened for inclusion. Subsequently, 81 full-text articles were assessed for eligibility and 18 articles met all inclusion criteria, describing 18 interventions in home care evaluated with the interRAI HC instrument.

Figure 1 Prisma Flow Diagram



Description of Interventions

This section highlights the design features of the studies presented in Table 2. All studies evaluate an intervention in home care using the interRAI HC instrument as an evaluation tool. After carefully reading the articles and selecting the studies, researchers put them into categories based on the type of the intervention they

describe. Three types of interventions were identified: comprehensive geriatric assessment alone, comprehensive geriatric assessment and case management, and comprehensive geriatric assessment in integrated care system. Two other articles did not belong to these categories and described other types of interventions evaluated with the interRAI HC instrument.

The first category consists of studies that show the implementation of a comprehensive assessment instrument (interRAI HC) or a single assessment process as the pure intervention and report the results of this implementation.

The second category consists of studies that describe the evaluation of case management interventions using the interRAI HC as a tool for care planning, case finding, or for care coordination.

The third category describes the evaluation of interventions that involve the use of the interRAI HC as a case management tool but in a more integrated care system. In this case, the care plan is applied to the practice using multidisciplinary teams and integrated services.

Table 2 Summary of studies evaluating Home Care interventions

Author, Year	Intervention	Study design	Age, Mean ± SD Gender (female %)	N	Location
Landi et al., 2001 [19]	Comprehensive geriatric assessment	Single-blind randomized controlled trial with one year follow-up	Intervention: 77.4 ± 9.1 68.2% Control: 77.1 ± 9.5 67.0%	187	Two Heath Districts of the Health Care Agency of Bergamo, Italy
Brown et al. 2009 [20]	Assessment implementation	Randomized controlled trial	Intervention: 81.0 66.0% Control: 81.0 65.0%	311	Bay of Plenty area, New Zealand
Miller et al., 2004 [21]	Implementation of a single assessment process	Observational study	Age: not reported Gender: not reported	89	National Service Framework, England
Roberts et al., 2006 [22]	Single assessment process by nurses	Prospective descriptive study	85.0 58.0%	863 (124 in-depth assessments)	Southampton, England

Stolle et al., 2011 [23]	Implementation of comprehensive geriatric assessment	Cluster randomized controlled trial	78.9 64.7%	484	Germany
Sorbye et al., 2009 [24]	Implementation of common assessment instrument	Comparative study	82.3 74.0%	4010	11 European countries (Denmark, Finland, Sweden, Norway, Iceland, England, Italy, France, The Netherlands, Germany and the Czech Republic)
Igarashi et al., 2009 [25]	Screening by preventive care managers	Quasi-experimental study	Intervention: 80.5 ± 8.9 75.3% Control: 81.2 ± 8.2 69.6%	150	Two cities in Japan (names not mentioned in article)
Diwan et al., 2004 [26]	Care-planning implementation	Observational study	75.0 68.0%	169	Michigan, USA

Chi et al., 2006 [27]	interRAI HC as a case finding instrument	Cluster randomized controlled trial with 1 year follow-up	73.6 ± 5.5 57.4%	925	Hong Kong
Thomas et al., 2007 [28]	Assessment and care plan	Single randomized controlled trial	Intervention group1: 80.7 ± 4.3 62.4% Intervention group2: 80.4 ± 4.4 72.6% Control: 80.7 ± 4.5 67.4%	520	Canada
Shugarman et al., 2002 [29]	Home care services	Comparative study	75.2 ± 11.6 69.1%	527	Michigan, USA
Marek et al., 2006 [30]	Nurse care coordination	Quasi-experimental study	Intervention: 77.0 ± 8.1 82.0% Control: 77.3 ± 7.9 77.0%	85	Missouri, USA
Leung et al., 2001 [31]	interRAI HC instrument in case management	Observational study	74.5 ± 7.2 43.1%	130	Hong Kong

Landi et al., 1999 [32]	Integrated home care services	Longitudinal study	77.5 ± 11.7 71.3%	115	Vittorio Veneto, Italy
Landi et al., 2001 [33]	New integrated care model	Longitudinal study	77.4 ± 9.7 58.5%	1204	Pieve di Soligo, Bergamo, Orvieto en Lecce, Italy
Marek et al., 2005 [34]	Community-based care with nurse coordination (Aging in Place program)	Quasi-experimental study	Intervention: 72.0 ± 10.9 71% Control: 72 .2 ± 10.6 68.0%	156	Missouri, USA
Fries et al., 2004 [35]	Telephone screening in home care	Comparative study	Age: not reported Gender: not reported	23595	Michigan, USA
Zhu et al., 2007 [36]	Implementation of machine learning algorithms	Comparative study	76.3 ± 13.9 68.9%	24724	Ontario, Canada

Comprehensive Geriatric Assessment Alone

Comprehensive geriatric assessment [19]

This article evaluates the impact of the implementation of the interRAI HC instrument on the functional status and hospitalization rates of frail older persons. It is a single-blinded randomized control trial with a 1-year follow-up conducted in 2 districts in Italy. Independently of the group assignment, all eligible patients received case management and care planning. In the intervention group, the case manager assessed the clients with the interRAI HC instrument right after inclusion. The clients in the control group received a conventional geriatric assessment.

Assessment implementation [20]

This article evaluates the effect of the accurate identification of older persons' needs by the implementation of a comprehensive geriatric assessment on health service use and costs. This is a randomized controlled trial in 1 area of New Zealand. Participants in the control group were screened with an instrument called Needs Assessment and Service Co-ordination, whereas the intervention group was assessed by the interRAI HC instrument. The range of services available was identical for both groups and all services prescribed and used were reported. These services and costs were then compared.

Implementation of a single assessment process [21]

This article describes the effects of the implementation of a single assessment process in order to raise assessment standards and promote consistency across the country. The study was carried out in 6 general practitioners' (GPs) surgeries in England. The answers given by clients about their health and social care needs to questions in a contact assessment were compared with answers given by the nurse in the interRAI HC instrument.

Single assessment process by nurses [22]

The aim of this study was to examine the effect and the resources needed for the implementation of a single assessment process and to use the outcome variables of this assessment (CAP) in the care plan. For each CAP, the nurse assessed the situation of the older person including the measures already in place and verified agreement of any action with the patient and the main caregiver.

Implementation of comprehensive geriatric assessment [23]

This article describes a cluster randomized controlled trial for the evaluation of the implementation of the interRAI HC instrument in 69 home care services in Germany. The team of the home care services in the intervention group received training on filling out the instrument and were given support and advice. Baseline data were collected before the training and after a period of 13 months.

Implementation of common geriatric assessment instrument [24]

This study aims at making cross-national comparisons from 11 European countries for home care systems and quality of care and for clients' outcomes through the implementation of a common assessment instrument the interRAI HC. Data is collected by trained professionals at baseline and after 6 and at 12 months. In this review, we include an article which is an overview of all 27 articles produced in the study. This overview contains the main results of each sub-study as well as an overall discussion.

Comprehensive Geriatric Assessment and Case Management

Screening by preventive care managers [25]

This article reports the evaluation of an intervention consisting in the use of the interRAI HC instrument and on constructing a care plan based on the assessment. Evaluation uses a quasi-experimental design in 2 Japanese cities: city A - intervention

group and city B - control group. Two aspects of the client's health were examined: maintaining self-care and having a balanced diet. The skills of the preventive care managers were assessed both objectively (quality of the care plans) and subjectively (self-rated confidence). Comparisons of the care plans in both groups were made 6 months after baseline.

Care planning implementation [26]

This article examines how case managers identify and respond to home care clients' needs in Michigan using the interRAI HC instrument. Two coders were asked to review each client's chart and to make writings about problem and impairment areas as well as client's needs. Thereafter, they examined the output of the interRAI HC instrument (CAPs) triggered by 23 algorithms and evaluated whether there was correspondence between the charts and the triggered CAPs.

interRAI HC as a case finding instrument [27]

The aim of this study was to test whether the utilization of the interRAI HC instrument as a case finding tool had a beneficial impact on the older person's physical and mental health status. This is a prospective 1-year follow-up study performed in Hong Kong. At baseline, before clients were seen by the GP, an interRAI HC was filled out by trained professionals and the outcome measures (CAPS) were generated. These were given to the physician who could then formulate the treatment on the basis of these outcomes. In the control group, no CAPs were generated and clients were treated according to the GPs usual practice. Comparisons between these outcomes were then made.

Assessment and care plan [28]

This study describes a randomized controlled trial with a 4-year follow-up period in Canada. In intervention group 1, older persons were assessed with the interRAI HC instrument and feedback was given to the clients and their informal caregivers. In intervention group 2, older persons were assessed with the interRAI HC instrument,

and the results of the assessments were shared with the older person and the informal caregiver and they were offered referrals to health and social services, if needed. People in the control group did not receive any type of functional assessment nor advice. Comparisons of the care plan decisions were made for the 3 groups.

Home care and informal caregiver's attitudes [29]

This study uses data from 14 regional agencies in Michigan. The participants of the study come from 2 programs designed to expand the availability of home care to older and disabled people. A baseline assessment was completed at 4 days after start of home care services. Follow-up assessments were completed at 45, 90, and 180 days after baseline. The primary outcome variable of interest is hospitalization after baseline. Other measures of interest are informal caregiver's personal burden and interpersonal burden.

Nurse care coordination [30]

This article examines the effect of a nurse care coordination program for people receiving state-funded home care in Missouri. The design of the study is quasi-experimental and compares clients who only receive home care (control group) with clients receiving home care and extra nurse care coordination (intervention group). Data were collected at baseline, at 6 and 12 months by trained registered nurses.

InterRAI HC instrument in case management [31]

This study aims to evaluate the use of the interRAI HC instrument as a tool for case management in Hong Kong. Data is collected by case managers and the output variables of the instrument are then analysed to categorize the population into groups based on matched levels of impairment and services. The care plan is then developed and communicated to the multidisciplinary team.

Comprehensive Geriatric Assessment in Integrated Care System

Integrated home care services [32]

This article describes a 6-month follow-up quasi-experimental study based on comprehensive geriatric assessment and case management in 1 Italian district. The goal of the study is to compare the rates of hospitalization before and after the home care program was implemented. Older persons received case management and care planning by the community geriatric evaluation unit and GPs. Case managers performed the assessment with the interRAI HC instrument immediately after request of home care and at least 2 other times during a follow-up period of 6 months.

New integrated care model [33]

This article describes a 12-month follow-up quasi-experimental study on the impact of a home care project based on comprehensive geriatric assessment and case management on hospital use and cost. This study was conducted by 4 Italian health care agencies adopting an integrated social and medical care program along with a case management approach. Case managers, usually registered nurses with experience in geriatric nursing, performed the assessment with the interRAI HC instrument immediately after request of home care.

Community-based care with nurse coordination [34]

This comparative study aims to analyze the outcome measures of older people in the community participating in community-based projects with older persons with the same case-mix but who are already institutionalized. This home care project called Aging in Place consists of nurse coordination and Medicare home health services in the state of Missouri. The data of the interRAI HC instrument are collected at baseline and every 6 months over a 30-month period.

Other Types of Interventions

Telephone screening [35]

This study aims to determine the accuracy of a telephone screening system to identify older persons eligible for long-term home care. The study makes a comparison between data from Michigan telephone screens and data from in-person assessments using the interRAI HC instrument. The effectiveness of the telephone screening system is then evaluated.

Machine learning algorithms to guide rehabilitation planning [36]

The goal of this study is to predict which clients have a potential for Activities of Daily Living rehabilitation in home care. Predictions are made by using a support vector machine based on the interRAI HC instrument. The study uses data from 8 home care programs in Ontario and wishes to address the issue that many home care clients who would benefit from rehabilitation services, very often, do not receive them.

Main Results of the Use of the interRAI HC

Table 3 describes the goal of each study, their main findings, and main limitations as well as the number of positive or negative results about the interRAI HC instrument.

Table 3 Summary of goals and results of the studies evaluating Home Care interventions

Author, year	Goal	Main findings	Main limitations	interRAI Home Care: total count of positive (+) or negative evaluation results (-)
Landi et al., 2001 [19]	To evaluate the effect of a new assessment system on the functional status and hospitalization rates of frail older persons.	Significant improvement of ADL and cognitive functioning in intervention group. Intervention group showed significant increase in in-home services compared to control group. Hospital admissions in intervention group happened later than in control group. Less admissions to hospital and reduced length of stay in for intervention group. Total cost expenditures were 21% less in intervention group. Study demonstrate that in-depth evaluation of problematic areas together with structured help for	Small sample size which did not allow for subgroup analysis. Length of hospital stay in both groups appears higher than average in other studies (ex. hospitals in the USA) but population in this study is frail and eligible for integrated home care programs. For this study, all health workers were motivated to fill out the interRAI HC instrument but in the "real world" this can be a problem because staff is not always specifically trained to use the interRAI HC instrument and consequently not motivated.	++++

		implementation of home care interventions with interRAI HC assessment can be a key factor for the success of home care programs.		
Brown et al. 2009 [20]	To estimate the health service use and costs resulting from the introduction of the interRAI HC instrument	Clients assessed with the interRAIHC instrument had higher costs for prescribed services and for delivered services. Costs related to interRAIHC are more associated with preventive and diagnostic services, while in the control group the expenditures are more on disability support services.	Lack of very reliable data on social and personal costs (including privately purchased care) and also hours of care given by informal caregivers.	+++
Miller et al., 2004 [21]	To investigate the usefulness of a questionnaire to identify unmet needs in health and social care.	The interRAI HC instrument is viewed as an advantage because the items can be used as triggers (CAPs) for considering appropriate discharges and referrals. The authors acknowledge the need for primary and secondary care to work together, also on transfer of	Case studies with small sample size.	+++

		information. Therefore the need for a single assessment process, with an electronic basis for a reliable, holistic and consistent assessment. A whole assessment may not be necessary for every patient but a mechanism needs to be in place to trigger those in need for a more in-depth assessment.		
Roberts et al., 2006 [22]	To evaluate the feasibility and benefits of carrying out the single assessment process based on the interRAI HC instrument	People scoring 4 or higher in the Sherbrooke questionnaire were viewed as eligible for a comprehensive assessment (interRAI HC). 52% of participants with interRAI HC assessments triggered CAPs for specific problems or risk areas. An inventory of the time spent for preparation and filling out the instrument was made (2.7h for GPs,	High refusal rate (60%) for the interRAI HC by the participants with a Sherbrooke score higher than 4. These non-responders could not be followed-up and were potentially the most frail and in need of assessment.	+ -

		1h for clerical staff, 3h for the secretary and 2.5 for the nurse).		
Stolle et al., 2011 [23]	To measure the effect of the interRAI HC instrument on clinical and functional outcomes	Results show positive effects of the interRAI HC instrument for ADL and IADL change (but results were not statistically significant). No evidence of improvement for cognitive performance change and quality of life. Institutionalization and hospitalization rates are lower in intervention group but show no significant differences. In the intervention groups, there were more improvement in the documentation of the nursing process (more care plans and these are more up-to-date (but no significant results).	Low number of clients per home care agency participating in the study. Implementation of interRAI HC instrument lasted longer than expected. The way of implementing and using the instrument differed by home care agencies. Some used the instrument and also its outcomes (CAPs, quality indicators, etc) and others did not.	+ -
Sorbye et al., 2009 [24]	To implement a common assessment instrument across countries in order to make	The ADHOC project contributed to partially close the gap of information on users of home care services in	The differences in countries profiles and home care structure has to be taken into account when interpreting results.	+++

	comparisons on quality of care and care outcomes.	Europe. Cross-countries comparisons were made possible on health outcomes, social status and structure of services in Europe. Identification of the most frequent problems related to home care: no therapy available for ADL improvement for people with rehabilitation potential, inadequate pain control and no vaccination against influenza.	The ADHOC project focused primarily on the description of home care services users and systems and is aware that differences in the outcomes can be due to background characteristics.	
Igarashi et al., 2009 [25]	To determine whether the implementation of preventive care management using a version of the interRAI HC instrument improves health-related behaviors of older adults and the skills of preventive care managers	Intervention group shows better results for self-care and for quality of care plans Positive correlation between confidence in assessing client's needs and proficiency in understanding the assessment instrument	Differences between the cities involved in the study may have caused bias	++++

Diwan et al., 2004 [26]	To examine how case managers identify and respond to home care clients' needs.	Many problem domains are not identified by the case managers, especially in the domains of health conditions, continence and sensory performance. Functional areas (ADL), environmental issues, brittle support are often identified by case managers. The social function and depression areas are the ones with the most unmet needs, followed by visual function and communication.	Screening happened for one State and may not be able to be generalized to other populations. Small sample size. The responses examined were those noted in the chart of case managers. It is possible that they made/planned interventions without taking notes but not very likely.	+
Chi et al., 2006 [27]	To investigate the effect of the interRAIHC instrument as a case finding instrument for older clients in Hong Kong	Mood symptoms improved significantly more in the intervention group. IADL deteriorated less in intervention group than in control group. Bowel incontinence deteriorated more in the intervention group.	Authors acknowledge that the period of one year is too short to evaluate changes in health status because some problems are due to chronic diseases. They believe that mood status and behavior are more susceptible to change at a short period of time.	-

		Limited effectiveness of the interRAI HC instrument as a case finding tool	Population was not frail enough at baseline and this made it difficult to show improvement in the population.	
Thomas et al., 2007 [28]	To determine whether frail older people can still stay at home with the help of comprehensive geriatric assessment	Intervention group 2 (who accepted offers of referral from the assessor) were more likely to receive formal home care than the control group. Rates of uptake of home care and institutionalization were very low in the three groups and self-rated health and perceived self-efficacy remained stable and high. Authors think that the interventions in groups 1 and 2 were not effective because of ceiling effects due to the relatively good health of the older persons in the study.	Study should be performed in a more frail population. Authors did not assess whether there was adequate provision of home care or if the provision matched the client's needs. Two outcomes that were not measured were visits to emergency departments and informal caregiver burden.	-
Shugarman et al., 2002 [29]	To investigate the relationship between informal caregiver's attitudes	Informal caregiver dissatisfaction with the current level of support received by the older person is	No data available about date of hospitalization or length of stay.	+

	and the risk of hospitalization of older persons taking part of programs designed to expand the availability of home care to older and disabled people.	significantly associated with hospitalization. Informal caregiver's distress is significantly associated with death.		
Marek et al., 2006 [30]	To evaluate the clinical outcomes of a nurse care coordination program.	At 6 months, no significant differences were found but at 12 months the intervention group had less pain and less dyspnea and functioned at better ADL functioning levels than the control group. Authors believe that at least 12 months are needed to show effect for nurse care coordination of frail older clients.	Small study sample from a single state in the USA. Authors acknowledge the need for larger studies across different states.	+++
Leung et al., 2001 [31]	To evaluate the use of the interRAI HC instrument in the development of care plans by a case manager.	Added value of comprehensive geriatric instrument in categorizing the levels of impairment of clients and link them to necessary services regarding their holistic needs.	Small study sample	++++

		Elimination of problem of multiple assessment because case managers communicated the results of the interRAI HC instrument with the multidisciplinary team.		
Landi et al., 1999 [32]	To examine the effect of a home care program based on comprehensive geriatric assessment and case management on hospital use and costs.	Hospitalization rates reduced from 56% to 46 % ($p<0.001$). Length of stay in hospital declined sharply from 16 ± 11 days to 10 ± 11 days ($p=0.01$), so did total costs of hospital-based care (from $4365 to $2435 – $p<0.001$)).	Findings could reflect a historical trend toward reduced rate of hospitalization and length of stay but this is not likely in a limited time frame.	++
Landi et al., 2001 [33]	To test the effectiveness of the interRAI HC instrument on standardized home care programs with case management. To measure the effects of the utilization of this instrument in hospital use and costs.	Significant reduction of the number of hospitalizations associated with reduction of length of stay. Total 27% cost reduction.	The findings might reflect a historical trend toward a reduced rate of hospitalization and reduction of length of stay, but this is not an expected effect because it is been 5 years since the legislation in Italy has been changed. For this study, all health workers were motivated to fill out the interRAI HC instrument but in the “real world” this can be a problem because staff is not	+++

			always specifically trained to use the interRAI HC instrument and consequently not motivated.	
Marek et al., 2005 [34]	To compare clinical outcomes of older persons at home with older persons already institutionalized.	Participants of the home care project had favorable outcomes compared to the other group. ADL, cognitive functioning and depression improved and then declined at a slower rate than in the comparison group. At baseline, the intervention group had higher incidence of incontinence but after intervention started, incidence became higher at the comparison group.	Individual matching strategy was needed to ensure participants in the two groups were comparable. This matching happened for 82% of the clients in the study. This program was only conducted in one agency and it cannot be generalized.	++
Fries et al., 2004 [35]	To determine the accuracy of a telephone screening system to identify persons eligible for home- and community-based long-term care	The telephone screening is an effective method to avoid the high costs of in-person assessment for non-eligible individuals.	Screening happened for one State and may not be able to be generalized to other populations No study was performed to measure the reliability or validity of the interRAI HC assessment made by phone.	+

		No particular items of the screen are responsible for mismatches, but telephone answers are consistently "more impaired" than in-person assessment answers. Telephone assessment cannot replace in-person assessment for clients who would be eligible for home care.		
Zhu et al., 2007 [36]	To investigate the potential of machine learning algorithms to target older clients for rehabilitation at home care	The support vector machine predicts rehabilitation potential better than the use of the ADL CAP. The results provide a method to improve the prediction value of the ADL CAP to be used in home care so that people who really are in need of rehabilitation, receive his type of services.	Some reservations about the use of these methods include the interpretability of these results and the resulting potential for clinical resistance to a "black box" approach. The authors try to address these issues with clarity in the article.	+

Fourteen studies mention only positive results about the instrument, whereas 4 articles mention 1 negative result each. Eight studies describe the instrument as an effective tool to identify the needs of older people so that it can be used as a tool for preventive care management [19,21,22,25,26,31-33].

In several studies where case management and the implementation of the interRAI HC were viewed as the intervention itself, positive results were found [25,26,29-31]. Except in 2 studies, the use of the instrument proved limited effectiveness as a case finding instrument [27,28]. However, authors of those studies think this could be due to the profile of the population in the study that was mostly not frail enough to need a comprehensive geriatric assessment. They believe this may have limited the effectiveness of the instrument.

In 8 studies, authors agree that the interRAI HC helps to create better care plans [19,23,25,26,30-33]. Some studies mention that the use of the interRAI HC can reduce costs by means of reducing hospital admissions and the length of stay in hospitals [19,32,33]. Several articles [19-21,24,29-31,33,34] mention the advantage of standardization of the instrument to be used in a whole country or in several countries as a tool for quality of care and benchmarking. About the usability of the instrument, 7 studies agree that training is necessary and that the implementation of such a comprehensive assessment requires time and effort [19,22,23,25,28,33,35]. Some authors mention the evidence basis of the assessment and the triggers (CAPs) for problems and risk situations as a useful tool to help care planning [19,21,24-26,31-34,36].

Another important advantage mentioned in the studies is that the instrument contributes to more communication between care givers and a closer collaboration of professionals [19,25,30-33].

Discussion

This systematic review identified 18 studies describing interventions in home care using the interRAI HC instrument as an evaluation tool. All studies aimed at evaluating interventions in home care using this comprehensive geriatric instrument, but in 6 of these studies the intervention was the pure implementation of the instrument itself.

In 14 studies, the use of the interRAI HC instrument was evaluated as useful, showing positive results in general (Table 3). In 4 studies, the effectiveness of the instrument could not be proven, although some authors think this was maybe due to the design of the study. In general, authors agree that the interRAI HC instrument can help in the evaluation of interventions and that the standardization of the instrument improves collaboration between professionals and allows for benchmarking.

Interventions in home care described in the articles mostly showed features of case management projects based on the application of a comprehensive geriatric assessment to help professionals make a care plan. Studies showed the effectiveness of the interRAI HC as a case finding instrument and to identify the needs of older persons. The use of this instrument coupled with case management can reduce hospital admissions, length of stay, and thus, reduce costs. The models presented in this review are, however, still not applied at a larger scale. Most interventions are limited to some regions of a country and have not yet been implemented in complete countries. The Aged in Home Care project [24] in 11 countries in Europe was also limited to some areas of each country. A harmonization of the way to collect data in Europe by means of a standardized assessment was pointed out in this article as necessary and useful, but most European countries still seem to have a long way to go.

Nowadays, using the term “integrated care planning” is trending. This can be seen as developing structured multidisciplinary care plans, which describe in detail what the essential steps in the care of patients should be. The inteRAI assessment tools provide evidence of reliability in long-term care settings such as home care and residential care, which can bring improvement in the systematic collection of clinical data for audit and for promoting change in practice as well as a way to achieve integrated care planning and continuity of care [37].

Most studies view home care as a better option for older persons with complex care needs, but also a certain level of autonomy. One study [34] even showed that the clinical outcomes at follow-up for people in the community are better when compared with people with the same case-mix in a nursing home. This points out that enhanced community care with case management for frail older people is a good alternative for institutionalization and that this can provide satisfactory outcomes.

This systematic review can help researchers to plan evaluation of interventions in home care. The interRAI HC instrument proves to be a comprehensive tool to measure outcomes and can serve as an evaluation instrument for interventions. It can also be used as an intervention itself, when caregivers use the tool and its outcome measures to implement a care plan.

Future Research

This systematic review can be a base for future research into effectiveness of home care interventions because it provides an overview of evaluations of home care interventions for frail older people. It is recommended that researchers find the most suitable design for their evaluation, but it is common in home care that constraints can limit the possibility for randomization. The use of a comprehensive geriatric assessment such as the interRAI HC instrument showed to be an asset because it can

measure different dimensions of the whole home care client's situation increasing the possibility for choosing several potential outcome measures. Future research into home care interventions could focus on the use of this instrument for care planning and as a measurement of quality of care.

Limitations

The present study has some limitations that should be considered. Only studies published in English were included, and gray literature was not searched. Furthermore, the current review focused on the interRAI HC instrument and discarded other comprehensive assessment instruments. This choice was based on the knowledge that the interRAI instruments show high validity and reliability and are widely used for evaluation and for care planning in several countries. As a result, other studies not including this instrument were excluded from this review.

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Chapter 4

The determinants of informal caregivers' burden in the care for frail older persons: A dynamic and role related perspective.

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The determinants of informal caregivers' burden in the care of frail older persons: a dynamic and role-related perspective

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Abstract

Background: Research into informal caregivers' burden does not distinguish between different stages of impairment. This study explored the determinants of burden from an in-depth perspective in order to identify which determinants apply to which phases of impairment.

Methods: This was a cross-sectional study including frail older persons aged 65 and above. Instruments used were the interRAI Home Care, the Zarit-12 interview and an ad hoc economic questionnaire. A combination of variables from the Stress Process Model and Role Theory and a sub-group analysis enabled refined logistic analyses.

Results: The study population consisted of 4175 older persons and their informal caregivers. About 57% of them perceived burden. Depressive symptoms, behavioral problems, IADL impairment, previous admissions to nursing homes and risk of falls yielded significant odds ratios in relation to informal caregivers' burden for the whole sample. These determinants were taken from the Stress Process Model. When the population was stratified according to impairment, some factors were only significant for the population with severe impairment (behavioral problems OR:2.50; previous admissions to nursing homes OR:2.02) and not for the population with mild or moderate impairment. The informal caregiver being an adult child, which is a determinant from Role Theory, and cohabitation showed significant associations with burden in all strata.

Conclusion: Determinants of informal caregivers' burden varied according to stages of impairment. The results of this study can help professional caregivers gain a greater insight into which informal caregivers are most susceptible to perceive burden.

The determinants of informal caregivers' burden in the care for frail older persons: A dynamic and role related perspective.

Introduction

Informal caregivers play an important role in maintaining the health, well-being, functional status and quality of life of older people living at home. In addition, they are crucial partners in the care of older persons and may help them to stay at home longer. According to The World Health Organization (2008), cooperation between care professionals and informal caregivers should be the basis of primary care for older persons.

In order to understand how and under what circumstances frail older persons are able to remain at home, it is essential to take the role of their informal caregivers into account. Several studies have shown that informal caregivers' burden, also reflecting the quality of the relationship between the informal caregiver and the client, is a major predictor of institutionalization of older persons. It is also a predictor of the use of institutional services such as hospitalization and respite care (Luppa et al., 2010; Miller, Rosenheck, & Schneider, 2012; Spillman & Long, 2009; Spruytte, Van Audenhove, & Lammertyn, 2001).

Zarit, Reever, and Back-Peterson (1980) were the first to investigate and measure informal caregivers' burden. Later, burden was differentiated into having an objective dimension (e.g. demanding physical help, long hours of care, conflicts) and a subjective dimension (e.g. frustration, fatigue) (Montgomery, Gonyea, & Hooyman, 1985). Subjective burden is viewed as the way in which informal caregiver perceive objective burden (Zarit, Todd, & Zarit, 1986).

The Stress Process Model by Pearlin, Mullan, Semple, and Skaff (1990) views caregivers' burden as a dynamic concept. The model proposes that as impairment progresses, caregivers need to adapt to the evolving needs and changing behavior of

the care receivers. In scientific literature, the Stress Process Model is the main framework for understanding the impact of impairment on informal caregivers' burden from onset up to the later stages of impairment. This model proposes that 'primary stressors' like cognitive decline, behavioral problems, functional impairment and other problems related to older persons have an impact on 'secondary strains' (e.g. relationship between informal caregiver and frail older person) which, in turn, can have an impact on informal caregivers' burden and on well-being. Yates, Tennstedt, and Chang (1999) used this model as a starting point, but also focused on the hours of informal care and overload, and Chappell and Reid (2002) focused on the distinction between burden and well-being.

In a recent article, Bastawrous (2013) recommended combining Pearlin's Stress Process Model with Role Theory (Biddle, 1986) in order to provide conceptual clarity. On the one hand, stress theory captures the subjective and objective domains of burden and allows for important contextual elements (e.g. care recipient impairment). Role Theory, on the other hand, facilitates our understanding of how caregiver burden may differ depending on the informal caregivers' role. Roles can differ between social family roles (e.g. caregiving, marital and parenting roles) and non-family roles (e.g. in the domains of paid work, leisure and friendship). In this theory, role strain proposes that multiple demands placed on the person as a result of having too many roles will have negative consequences such as role overload (not having enough time or resources to manage multiple roles) and role conflict (conflicts in role expectations due to conflicting internal and external role expectations). This may lead to additional burden and psychological distress (Iwata & Horiguchi, 2015; Rozario, Morrow-Howell, & Hinterlong, 2004). Informal caregivers who care for their parents often remain in employment and also have to take care of their own children. Occupying multiple roles may intensify role-related stress because of feeling 'sandwiched' in the middle. Analyzing the contexts in which roles are taking place in the informal caregiver's situation is therefore essential to be able to analyze their burden.

The aim of this paper is to explore the significant determinants associated with informal caregivers' burden according to the different phases of impairment of frail older people.

Methods

This was a cross-sectional study of frail older persons who were at least 65 years old and who were receiving home care interventions. These clients took part in a larger study called Protocol 3, which evaluated home care interventions aimed at keeping frail older persons at home longer. The interventions and their evaluation were described in de Almeida Mello, Van Durme, Macq, and Declercq (2012) and Van Durme et al. (2015). After a 2.5-day training course, professional caregivers were asked to fill out the interRAI Home Care (interRAI HC) instrument, an internationally validated comprehensive geriatric assessment (Hirdes et al., 2008).

Professional caregivers also interviewed informal caregivers using an ad hoc economic questionnaire with demographical and work-related questions (job status and left job to give care) and questions about time spent on care (total hours a week). In our study, the main informal caregiver was considered to be the person most involved in the care for the older person, meaning that they were the most involved with daily tasks or emotional support as well as spending time with the older person. This caregiver did not receive any type of remuneration and was not linked to an organization (e.g. not a volunteer). The objective burden was measured by the number of hours per week spent providing care reported by the informal caregivers. Time spent on supervision was also included. For co-habitants, household work was not considered to be informal care if it did not take any extra time. This measurement of caregiving time was consistent with other studies (Dumont, Jacobs, Turcotte, Anderson, & Harel, 2010; van den Berg, Brower, & Koopmanschap, 2004).

The outcome variable in this study was informal caregiver burden, which was assessed by the Zarit Burden Interview 12 (ZBI12). This is a validated shorter version

of the original Zarit Burden Interview questionnaire and is considered to be a reliable tool to measure self-perceived burden experienced by informal caregivers (Bédart et al., 2001 ; Higginson, Gao, Jackson, Murray, & Harding, 2010). It consists of 12 Likert scale questions with two factorial subscales (for personal strain and role strain). The scores of the ZBI12 range from 0 to 48, with a score of 10 or above indicating that the informal caregiver perceives burden.

To record factors related to Pearlin's model (e.g. functional dependence, cognitive decline, behavioral problems, incontinence), we used the interRAI HC instrument. Other factors (e.g. client's age, gender, marital status and living status) were also recorded by this instrument. Functional performance of the older person was measured by the interRAI Activities of Daily Living Hierarchy scale (ADLH) and Instrumental Activities of Daily Living Performance scale (IADLP) (Morris, Fries, & Morris, 1999). Cognitive status was measured with the interRAI Cognitive Performance scale 2 (CPS2) and depression status was measured with the interRAI Depression Rating scale (DRS) (Hartmaaier et al., 1995; Morris, Carpenter, Berg, & Jones, 2000). These scales are internationally validated and are automatically generated when caregivers fill out the interRAI HC instrument (Vanneste & Declercq, 2014).

Data analysis was performed in two steps using STATA 11.1 software. First, descriptive statistics were calculated in order to illustrate baseline characteristics of older persons and informal caregivers. Subsequently, in order to allow for a more in-depth analysis of the population emphasizing the distinction between differing stages of impairment, as stated in the Stress Process Model, we applied a sub-group analysis to the population of the study (Pocock, Assmann, Enos, & Kasten, 2002 ; Sun, Ioannidis, Agoritsas, Alba, & Guyatt, 2014). The sample was divided into three sub-populations according to exploratory sub-groups based on validated cut-offs of the interRAI scales: mild impairment (older persons with higher impairment only on IADL performance – IADLP (IADLP score ≥ 24 and ADLH score < 3 and CPS2 score < 3)), moderate impairment (older persons with higher impairment on IADL performance

and on ADL functioning (IADLP score ≥ 24 and ADLH score ≥3 and CPS2 score < 3)) and severe impairment (older persons with IADL, ADL and cognitive impairment (IADLP score ≥ 24, ADLH score ≥ 3 and CPS2 score ≥ 3) (Morris et al., 2011). After stratification, bivariate analyses and logistic regressions were performed for the three sub-groups as well as for the whole population in the study.

Potential stressors from Pearlin's model associated with perceived informal caregiver burden were explored for the sample by means of bivariate correlations. The following factors were taken from the interRAI instrument: ADL and IADL impairment, cognitive functioning, communication difficulties, visual problems, hearing difficulties, behavioral problems (wandering, verbal abuse, physically aggressive behavior, socially inappropriate behavior), delirium, depression, risk of falls, bladder incontinence, bowel incontinence, sleeping problems, pain, feeding problems, conflict with family, lack of family support, type of support from informal caregiver, presence of other informal caregivers, previous hospitalizations or admissions to nursing homes and house not adapted to older person. The following elements from Role Theory were added to the analysis: informal caregiver's relation to client, informal caregiver's working status, informal caregiver left (part of) job and informal caregiver cares for other(s). A total of 37 variables were tested for bivariate correlations with informal caregivers' burden.

To analyze the relationship between primary stressors, objective burden, informal caregiver's role and perceived burden, we performed a set of logistic regression analyses. These analyses aimed to describe the pattern of relationships between variables that were revealed as being significant in the bivariate analyses. In the logistic regression, the ZBI12 score (perceived burden) was dichotomized (cut-off score 10, without burden: 0, with burden: 1).

Results

Participants

A total of 4799 older people living at home and who have an informal caregiver were included in the study. The main informal caregiver is considered to be the person most involved in the care for the older person, meaning that they are the most involved with daily tasks or emotional support as well as spending time with the older person. This caregiver does not receive any type of remuneration and is not linked to an organization (e.g. not a volunteer). These informal caregivers were asked to fill out the ZBI12.

Table 1 shows the characteristics of the study population. The average age of clients was 81.4 (67.8% female) and of their informal caregivers was 60.9 years old. Approximately half of the older persons were widowed (50.6%) and 43.2% were married. The majority of the older persons did not live with their informal caregivers (60.7%). The caregivers were most often adult children (56.2%) or spouses (30.0%). About 77% of informal caregivers who were adult children were also active in the work environment. Amongst caregivers who were spouses, only 15.2% were still working. Amongst adult children caring for their parents, 36.9% also cared for others (e.g. child or another parent). This percentage was 8.8% for informal caregivers who were spouses. About 82.8% of the older persons were at least impaired in instrumental activities of daily living (IADL), 54.4% needed at least extensive assistance in ADL and 34.1% showed moderate to severe cognitive impairment. In addition, 28.9% of the older persons had symptoms of depression and almost 13% showed behavioral problems. Informal caregivers reported providing emotional support (94.7%), IADL help (84.6%) and ADL help (51.0%). A total of 4175 informal caregivers filled out the Zarit scale (87% of the total number of clients with an informal caregiver). A non-response analysis showed that the informal caregivers who did not fill out the Zarit scale did not significantly differ according to gender, age, work status and other characteristics from the total population of informal caregivers who filled out the scale. According to the ZBI12 scores, 57.3% of the informal caregivers perceived burden.

Table 1. Older persons' and informal caregivers' characteristics

Characteristic of older persons	*n*	*Percentage*	*95 C.I.*[a]	
			LL	*UL*
Mean age of older persons: 81.4 (*SD*=6.8) Median: 82.0				
Gender				
male	1545	32.2	30.9	33.5
female	3254	67.8	66.5	69.1
total	4799			
Marital status				
married	1457	40.5	38.9	42.1
widowed	1821	50.6	48.9	52.2
single	193	5.4	4.6	6.1
divorced	128	3.6	2.9	4.2
total	3599	(missing: 1200)		
Living status				
non-cohabitation	2874	60.7	59.3	62.1
cohabitation	1863	39.3	37.9	40.7
total	4737	(missing: 62)		
Primary stressors				
IADL dependence ≥24	3402	82.8	81.6	83.9
ADL dependence ≥3	2512	54.4	53.0	55.9
CPS2 scale ≥3	1574	34.1	32.8	35.5
Depression scale ≥3	1339	28.9	27.6	30.2
Behavioral problems present	597	12.7	11.8	13.7

Characteristic of informal caregivers	*n*	*Percentage*	*95 C.I.*[a] *LL*	*UL*
Mean age of informal caregivers= 60.9 (*SD*=13.3) Median: 57.5				
Relation to client				
Adult child	2690	56.2	54.8	57.6
Spouse	1435	30.0	28.7	31.3
Other family member	396	8.3	7.5	9.0
Friend	88	1.8	1.5	2.2
Neighbor	88	1.8	1.5	2.2
Other	89	1.9	1.5	2.2
total	4786	(missing: 13)		
Professional status of informal caregiver				
Retired	1784	47.1	45.5	48.6
Employed	1106	29.2	27.8	30.7
Unemployed	155	4.1	3.4	4.7
Other (housewife, etc.)	743	19.6	18.4	20.9
total	3788	(missing: 1011)		
Type of support given to older person (more than one type possible)				
IADL help	3999	84.6	83.57	85.6
ADL help	2405	51.0	49.6	54.4
Emotional support	4452	94.7	94.0	95.3
Objective burden Time spent on care				
less than 10 hours a week	1752	43.3	41.8	44.9
from 10 to 29 hours a week	1110	29.7	28.3	31.2
more than 29 hours a week	1047	28.0	26.6	29.5
Total	3909	(missing: 890)		

Perceived burden				
Zarit score ≥ 10	2393	57.3	55.8	58.8
Zarit score < 10	1782	42.7	40.3	44.2
Total population with Zarit filled out	4175	(missing: 624)		

[a] Note. *CI* = confidence interval; *LL* = lower limit; *UL* = upper limit.

Bivariate analysis showed that primary stressors from Pearlin's model such as ADL, IADL, depression, cognition, behavioral problems, risk of falls and other factors were significantly positively correlated with the burden experienced by informal caregivers. Moreover, cohabitation and time spent providing care were also positively correlated with informal caregivers' burden. The determinants from Role Theory – caring for others, the informal caregiver being the adult child and the informal caregiver having left part of his/her job – also showed a significant positive correlation. The older person's age and gender (female) were significantly negatively correlated with perceived informal caregiver burden.

Sub-group analysis

In order to allow for a more in-depth analysis and to account for differences in impairment levels as stated in Pearlin's model, a sub-group analysis was performed. With regard to perceived burden, sub-population 3 (severe impairment) differed significantly from the two other sub-populations ($p < 0.001$). Almost 70.0% of the informal caregivers of older persons with severe impairment perceived burden versus 52.8% in the sub-population with mild impairment and 53.1% in the sub-population with moderate impairment. Moreover, older persons with severe impairment showed the highest levels of depression (41.0%), which is significantly higher ($p < 0.001$) than in the two other sub-populations (moderate impairment: 21.8% and mild impairment: 18.2%).

Subsequently, the bivariate analyses were repeated per sub-group of impairment. The burden perceived by informal caregivers was significantly correlated with cognitive impairment, IADL impairment, depression, behavioral problems, time spent providing care (objective caregiver burden), previous admissions to nursing homes or respite care, risk of falls and cohabitation for all three sub-populations. ADL impairment was only positively correlated with perceived burden in the sub-populations with mild and moderate impairment. The fact of the informal caregiver being the adult child was positively and significantly correlated for all sub-groups. Other variables did not correlate with perceived burden in any of the sub-populations.

Logistic analysis

Table 2 shows the odds ratios (OR) of these determinants at .05 level for the whole population and for the three sub-populations. In the logistic models, the significant determinants for the whole population were IADL dependence, depression, behavioral problems, risk of falls, previous admissions to nursing homes, informal caregiver being the adult child, cohabitation and conflict with family. This means that informal caregivers caring for older persons with any of these characteristics were most likely to perceive burden. For instance, behavioral problems were associated with perceived burden (OR: 1.88, CI: 1.31; 2.69). As a determinant from Role Theory, if the informal caregiver was an adult child, perceived burden was more likely to happen (OR: 2.06, CI: 1.63; 2.59). Informal caregivers living with a frail older person were also associated with perceived burden (OR: 1.77, CI: 1.39; 2.26) as well as informal caregivers with conflictual relationship with the older person (OR: 1.71, CI: 1.20; 2.45). Other significant factors were the risk of falls (OR: 1.41, CI: 1.17; 1.69), previous admissions to nursing homes (OR: 1.42, CI: 1.03; 1.96), frail older person with depressive symptoms (OR: 1.11, CI: 1.06; 1.16) and IADL performance (OR: 1.04, CI: 1.02; 1.05).

Table 2. Logistic regressions for determinants of perceived burden of the whole population of the study and the sub-groups of impairment.

	Whole population (*n*=3340)	Mild impairment (only IADL impairment) (*n*=1097)	Moderate impairment (only IADL and ADL impairment) (*n*=1309)	Severe impairment (IADL, ADL and cognitive impairment) (*n*=934)
Cohabitation	1.77 [1.39, 2.26] .000***	1.83 [1.23, 2.73] .003**	1.85 [1.29, 2.66] .001**	1.81 [1.13, 2.89] .013*
IADL dependence	1.04 [1.02, 1.05] .000 ***	1.05 [1.02, 1.08] .000 ***	-	-
Depression	1.11 [1.06, 1.16] .000 ***	-	1.18 [1.10, 1.27] .000 ***	1.10 [1.03, 1.19] .007 **
Behavioral problems	1.88 [1.31, 2.69] .001 ***	-	-	2.50 [1.59, 3.93] .000 ***
Older person shows conflict with family	1.71 [1.20, 2.45] .003 **	-	1.81 [1.03, 3.18] .039*	-
Risk of falls	1.41 [1.17, 1.69] .000***	1.62 [1.20, 2.17] 001**	-	1.51 [1.03, 2.22] .034 *
Previous admissions to nursing homes	1.42 [1.03, 1.96] .032*			2.02 [1.09, 3.73] .024*
Informal caregiver is adult child	2.06 [1.63, 2.59] .000***	1.82 [1.26, 2.61] .001**	1.97 [1.38, 2.80] .000***	2.05 [1.29, 3.27] .002**

*** p < .001 ** p< .01 * p< .05

For the whole population, ADL and cognitive impairment were found to be significant determinants only according to the unadjusted OR, but not when all variables were included in the model. Time spent providing care and the fact that the informal caregiver left their job to care for the older person also proved significant when no other variables were included in the model.

The results of the logistic models were refined by repeating the analyses for each of the three sub-populations. The significant determinants of burden differed between strata. Two determinants were significant for all three sub-groups of impairment: cohabitation and the informal caregiver being the adult child. The latter is an element from Role Theory.

In the sub-group with mild impairment, significant determinants were IADL performance, risk of falls, the informal caregiver being the adult child and being a co-resident. Informal caregivers caring for older persons with risk of falls showed a significant association with perceived burden (OR: 1.62, CI: 1.20; 2.17) as well as being the adult child (OR: 1.82, CI: 1.26; 2.61). Moreover, cohabitation was also associated with a higher chance of perceived burden (OR: 1.83, CI: 1.23; 2.73). Another significant determinant for this sub-group was IADL impairment but with a low OR. (OR: 1.05, CI: 1.02; 1.08).

In the moderate impairment group, the informal caregiver being an adult child was the most significant determinant (OR: 1.97, CI: 1.38; 2.80). Cohabitation (OR: 1.85, CI: 1.29; 2.66) also showed a strong and significant association. Other significant determinants were conflictual relationship with family (OR: 1.81, CI: 1.03; 3.18) and depressive symptoms (OR: 1.18, CI: 1.10; 1.27).

In the sub-group with severe impairment, the presence of behavioral problems was the most significant determinant (OR: 2.50, CI: 1.59; 3.93). The informal caregiver being the adult child also showed a strong association with burden (OR: 2.05, CI: 1.29; 3.27). Other determinants were previous admissions to nursing homes (OR:

2.02, CI: 1.09; 3.73), risk of falls (OR: 1.51, CI: 1.03; 2.22), cohabitation (OR: 1.81, CI: 1.13; 2.89) and depressive symptoms (OR: 1.10, CI: 1.03; 1.19).

In the model for the total population and in the models for the sub-groups of moderate and severe impairment, the value of the explained variance increased by about 36% when adding the variable from Role Theory 'informal caregiver is the adult child'. In the model for the sub-group with mild impairment, the explained variance increased by 33% after adding the same variable. This means that this addition provided more explained variance to the model, which can be considered as an advantage of using this extra variable in the analysis demonstrating an added value of combining the Stress Process Model with Role Theory.

Discussion

This paper explored the associations between several primary stressors, objective burden, informal caregiver's role and perceived burden. Variables examined as potential determinants were based on the Pearlin Stress Process Model and Role Theory. To our knowledge, this is the first paper to combine variables from these two models in order to investigate informal caregivers' burden.

The results were consistent with what has been found in other studies, but they are more refined. Risk of falls, depressive symptoms and behavioral problems have also shown to be significant determinants of burden (Black & Almeida, 2004; Kuzuya et al., 2006; Taylor, Kuchibhatla, Østbye, Plassman, & Clipp, 2008), but our study showed that some determinants only applied to a certain level of impairment. Risk of falls was significant for the groups with mild and severe impairment. Depressive symptoms were significant for the sub-groups of moderate and severe impairment groups. Behavioral problems and previous admissions to nursing homes were only significant for the sub-group with severe impairment. In other words, depending on the level of impairment, the risk of caregiver burden was affected by different determinants. This is consistent with Pearlin's Stress Model, which explains that

burden should be viewed as a process that progresses as impairment increases. The only common determinants for all three populations were the informal caregiver being the adult child, which is an element from Role Theory, and cohabitation.

Most studies analyze burden in a general way for a whole population of older persons. One study worked with a sub-sample in order to analyze informal caregivers' burden, but mostly focused on dementia and non-dementia diagnosis (Balducci, Melchiorre, Quattrini, & Lamura, 2008). By means of sub-group analysis, the population of this study was able to be stratified according to IADL, ADL and cognitive impairment, and we were able to explore the determinants of burden for each level of impairment. Results showed that these determinants indeed differed across impairment levels.

Findings from the current study offer important contributions to the realm of caregiving research. In contrast to prior studies, this research showed that a combination of the Stress Process Model and Role Theory could offer a more in-depth perspective to informal caregivers' burden. These determinants should all be taken into account when developing a more comprehensive model of caregiving, along with the creation and planning of interventions and programs in order to support informal caregivers (Barbosa, Figueiredo, Sousa, & Demain, 2011). As seen in literature reviews and other studies, home care interventions can help decrease informal caregivers' burden (Adelman, Lyubov, Delgado, Dion, & Lachs, 2014; Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012; Pinquart & Sorensen, 2006).

The availability of data from comprehensive geriatric assessments such as the interRAI HC enabled many possible determinants to be explored (e.g. behavioral problems, risk of falls, previous admissions to nursing homes, among others). To our knowledge, no other study has considered so many elements (37) while analyzing informal caregivers' burden. Moreover, in comparison with other large-scale studies on informal caregivers' burden (Onder et al., 2009), this research comprises one of

the largest study samples from one nation. This enabled us to carry out a refined sub-group analysis based on the IADL, ADL and cognitive functioning scales.

Professional caregivers can help prevent or decrease informal caregiver burden by systematically identifying informal caregivers who are at risk of burden, by taking the stages of frail older persons' impairment into account. Providing early interventions to alleviate informal caregivers' burden and informing informal caregivers about the stressors they can expect at differing stages of impairment may help them to be better prepared for upcoming challenges in caregiving.

Strengths and limitations

Strengths of this research were the combination of the Stress Process Model and Role Theory to explore informal caregivers' burden, the large sample size and the use of a comprehensive geriatric assessment enabling the analysis of several potential determinants and a refined stratification of the population.

This study was cross-sectional. Longitudinal data would allow testing the dynamics of the change in informal caregivers' burden according to changes in older person's and informal caregiver's situation. Another limitation is the absence of information regarding the informal caregiver's gender.

Conclusion

Determinants of informal caregivers' burden varied based on stages of impairment. The results of the study add to the literature showing that different determinants apply for different types of impairment. Given the association of cohabitation and informal caregiver being the adult child with perceived burden for all strata of impairment, we can conclude that it is important to take both determinants into account when professional caregivers deal with frail older persons and their informal caregivers. For the other determinants, the associations differed. Risk of falls proved to be a strong determinant for the sub-population with mild impairment, and

admission to nursing homes, depression and behavioral problems proved significant for the population with severe impairment. Conflict with family and depression were associated with burden for the population with moderate impairment. These results enable professional caregivers to gain a greater insight into which informal caregivers are most susceptible to caregivers' burden.

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Disclosure statement

None.

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Chapter 5

Exploring home care interventions for frail older people in Belgium: a comparative effectiveness study

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Clinical Investigations

Exploring Home Care Interventions for Frail Older People in Belgium: A Comparative Effectiveness Study

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Objectives: To examine the effects of home care interventions for frail older people in delaying permanent institutionalization during 6 months of follow-up.
Design: Longitudinal quasi-experimental research study, part of a larger study called Protocol 3.
Setting: Community care in Belgium.
Participants: Frail older adults who received interventions (n = 4,607) and a comparison group of older adults who did not (n = 3,633). Organizations delivering the interventions included participants provided they were aged 65 and older, frail, and at risk of institutionalization. A comparison group was established consisting of frail older adults not receiving any interventions.
Intervention: Home care interventions were identified as single component (occupational therapy (OT), psychological support, night care, day care) or multicomponent. The latter included case management (CM) in combination with OT and psychological support or physiotherapy, with rehabilitation services, or with OT alone.
Measurements: The interRAI Home Care (HC) was completed at baseline and every 6 months. Data from a national database were used to establish a comparison group. Relative risks of institutionalization and death were calculated using Poisson regression for each type of intervention.
Results:: A subgroup analysis revealed that 1,999 older people had mild impairment, and 2,608 had moderate to severe impairment. Interventions providing only OT and interventions providing CM with rehabilitation services were effective in both subpopulations.
Conclusion: This research broadens the understanding of the effects of different types of community care interventions on the delay of institutionalization of frail older people. This information can help policy-makers to plan interventions to avoid early nursing home admission.

Exploring home care interventions for frail older people in Belgium: a comparative effectiveness study

Background

Community care can be a valuable alternative to institutional care for frail older people. Because of the high costs of residential care, policy-makers are keen to foster such initiatives. In addition, most older people prefer to remain at home as long as possible because it allows them to maintain their social networks and live in a familiar environment [1,2]. Several studies have shown that institutionalization may have adverse outcomes such as depression, loneliness, decreased quality of life, increased use of medication, and greater mortality [3-8].

Literature reviews about the determinants of institutionalization identify dementia as one of the strongest predictors [9-11]. Other predictors are aggressive behavior, depression, and incontinence [12,13]. Older age, comorbidity, and a large number of prescribed drugs also increase the risk of placement in a nursing home. Other factors are absence of a suitable informal caregiver and high informal caregiver burden [14,15].

Most interventions are designed to delay institutionalization of frail older people are a combination of various interventions, called multicomponent interventions [16]. Delaying institutionalization is not the only goal. It is also necessary to ensure that quality of life is satisfactory and that informal caregiver burden is sustainable. Many authors recommend the development of interventions in the community that address these issues so that older people can stay at home longer [17-20]. A closer look at such interventions reveals the following effective components: comprehensive geriatric assessment, integrated care plan, care provider identified as case manager, systematic follow-up, day-to-day support services, and educational support [21-23].

To enable and encourage older people to stay at home, countries implement programs specifically designed for them [24-27]. Through the National Institute for Health and Disability Insurance (NIHDI), the Belgian federal government has started funding bottom-up initiatives targeting frail older people living at home. These innovative interventions aim to reduce the risk of institutionalization while maintaining the quality of life of the people concerned and keeping informal caregiver burden low. A consortium of universities has evaluated the effectiveness of these interventions. The study described in this article is part of this evaluation [28]. The larger study (Protocol 3) uses a mixed-methods approach, combining qualitative methods to understand the content and the implementation process of the interventions and quantitative methods to assess changes in outcome and cost. The objective of this article is to examine the effects of home care interventions for frail older people on delaying permanent institutionalization during the first 6 months of follow-up.

Methods

Design

Protocol 3 is a longitudinal intervention study based on a quasi-experimental design [29]. The protocol of the research has been published previously [28]. The study compares outcomes of frail older people receiving home care interventions with those of a group not receiving any intervention (comparison group). The study took place in Belgium between 2010 and 2014, and subjects were followed for 3.5 years. This article reports the initial findings of the evaluation of these interventions.

Setting

The study was conducted in the community, and private nonprofit, private for-profit and public agencies delivered interventions. The Belgian health insurance system funded the interventions. The main aim of these interventions was to delay institutionalization of frail older people.

Sample Selection

Organizations delivering the interventions were allowed to include participants provided they were aged 65 or older, frail, and at risk of institutionalization. Frailty was assessed using the Edmonton Frail Scale or the Katz Scale (Belgian version) [30] or was determined according to a dementia diagnosis. Organizations selected older people in the community based on referrals from their physicians, social services, or nurses providing hands-on nursing care at home. Other referrals came from hospitals or home care organizations. Older people (and their family members) were free to choose which organizations provided the services they needed. A comparison group was created consisting of frail older people not receiving any interventions.

Instruments

Professional caregivers such as nurses, occupational therapists, physiotherapists, psychologists, and social workers delivered the interventions. They completed the interRAI Home Care (HC) instrument, an internationally validated comprehensive geriatric assessment [31] that maps several aspects of a client's situation, such as cognitive functioning, activity of daily living (ADL) and instrumental ADL status, social and psychological well-being, health status, informal care support, and service use, for each participant after a 2.5-day training program. InterRAI HC assessments were completed at the start of the intervention (when the frail older person was first enrolled—baseline) and at several specified time points during the Protocol 3 study. Only the baseline data were used for this article. Frail older people were able to participate in the program as long as necessary and to exit the program at any time. Researchers monitored the interventions for 3.5 years.

The study used additional data from a national registry database: the National Health Insurance database (CIN-IMA), an official database of the Belgian government that contains all administrative information about reimbursed healthcare consumption (doctors' visits, hospitalization, nursing home admissions, use of prescribed medication, nursing, physiotherapy, speech therapy). The main outcome variable for

the study population was permanent institutionalization, which was defined as a stay of 90 consecutive days or more in a nursing home. A secondary outcome variable was death. Both variables were provided in the CIN-IMA database. For privacy reasons (to prevent identification of subjects), only month and year of admission to a nursing home and month and year of death were recorded for the study. Data from the CIN-IMA database were available for all older people included in the analysis, whether or not they received an intervention.

Intervention group

The intervention group consisted of frail older people living at home who met the inclusion criteria. Because of their diversity in degree of impairment and because some interventions target particular types of older people, the study sample was stratified based on cognitive and functional status using a subgroup analysis. Stratification helps improve the accuracy and robustness of the statistical analysis. Two strata were created: older people with mild impairment and older people with moderate to severe impairment. The classification was based on the interRAI Hierarchical Activities of Daily Living scale (ADLH) and the Cognitive Performance Scale 2 (CPS2). These two interRAI scales have scores that range from 0 to 6 and have been previously validated [32,33]. A subgroup analysis based on validated cut-off points from the interRAI scales resulted in the following strata: mild impairment (score <3 on the ADL scale and <3 on the CPS2 scale) and moderate to severe impairment (score ≥3 on the ADL scale or ≥3 on the CPS2 scale). In both subgroups, frail older people with symptoms of depression were also identified (validated cut-off score on the interRAI scale Depression Scale (DRS) ≥3), which allowed for a better evaluation of psychosocial interventions.

Comparison group

Everyone selected for the comparison group was aged 65 or older, lived at home, and was not receiving any of the interventions evaluated in this study. This comparison group was selected from the CIN-IMA database and consisted of frail

older people with a similar risk of institutionalization and similar health care consumption, so the group receiving the intervention and the group not receiving the intervention were comparable. Two sub-groups were also identified in the comparison group: older people with mild impairment (comparison group 1) and older people with moderate to severe impairment (comparison group 2). Given the absence of a variable directly measuring health status in the CIM-IMA database, the use of certain drugs or services was used as a proxy. Extensive analyses were performed, and several scenarios were calculated to find the most suitable variables for matching. These scenarios were based on an analysis with the intervention group using the interRAI scales matched with their health proxy variables in the CIN-IMA database.

First, the stratification of the study population was made by using the interRAI scales ADL and CPS2: mild impairment, moderate and severe impairment. After that, we tested the variables from the IMA in these two subgroups to find out which determinants were the most discriminant between the subgroups and could characterize the clients. The following variables were tested from the CIN-IMA database:

- age,

- level of nursing care (Katz forfeit),

- medication use (to identify some diagnoses such as Parkinson's disease, dementia, chronic obstructive pulmonary disease and diabetes mellitus),

- resource utilization costs (nursing, physiotherapy, speech therapy),

- presence of an informal caregiver,

- financial situation

- living arrangements (living alone or with a partner or family member).

These variables were tested in several combinations. The best strategy to match the population from intervention group and comparison group proved to be a combination of 4 variables from the CIM-IMA database:

- age,

- combined cost of nursing, physiotherapy, and speech therapy,

- level of nursing care,

- use of medication for dementia.

After the tests, the two subgroups 'moderate and high impairments' were grouped together because of very similar values of the discriminant variables.

For comparison group 1 (older people with mild impairment): people were selected from the CIN-IMA database who scored between the 35th and 65th percentiles for costs of nursing, physiotherapy and speech therapy. These were people aged 79 and older with low to moderate nursing, physiotherapy and speech therapy costs.

Comparison group 2 (older people with moderate to severe impairment) consisted of people aged 79 and older receiving a high level of nursing care (meaning that they were receiving nursing support at home and also required help for several ADLs: Katz=C) or were taking drugs for dementia.

Classification of interventions

To ensure that interventions could be tracked, a qualitative investigation based on a normative approach was conducted in the larger study [34]. This study used annual questionnaires, interviews, and case studies. Researchers tracked features of the interventions, such as frequency of the delivered services, skills of personnel, turnover, use of best practices, tailored service design, and connections with other organizations in the community. The costs of the intervention were also assessed. Based on this study, interventions were also grouped into single- and multicomponent interventions according to the services provided. Only types of

interventions delivered on a permanent basis by an organization were retained. The classification yielded the following types of interventions.

Single interventions: occupational therapy (OT; home adaptations and advice about assistive devices), psychological support, day care, night care (offered exclusively to one frail older person with full supervision or to several frail older people, each with partial supervision)

Multi-component interventions: case management (CM) with psychological support and OT, CM with OT and physiotherapy, CM with several rehabilitation services (OT, physiotherapy, psychotherapy, night support) in a short-term residential setting, CM with OT at home for older people with visual impairment.

Frail older people who met the study inclusion criteria were allowed to take part in the intervention even if they did not receive any nursing care at home. OT (or any other type of intervention) was offered to the person concerned continuously, and the effects of the intervention were evaluated.

Although nurses who coordinated the services for the frail older people they cared for often provided CM, hands-on nursing care was not part of the intervention. In Belgium, daily hands-on care is considered part of regular care. The CM intervention consisted of the coordination itself. Social workers who were trained as case managers also provided some CM.

Nursing care at home during the night was considered to be a night care intervention. Occupational therapists and psychologists delivered OT and psychological support at home. Quite often, frail older people with mild impairment did not receive hands-on nursing care but received OT. This could enable them to live in their own house longer once it was adapted to their needs.

Ethics

The Belgian Privacy Commission and the ethics committee of the Belgian Universities (Université Catholique de Louvain and KU Leuven; B40320108337) approved this study. A formal procedure was implemented so that professional caregivers could complete the questionnaires using a secure website. The older people involved in the study all signed an informed consent form.

Analysis

First, descriptive statistics for age and gender were calculated for the subgroups in the intervention and comparison groups. Second, Poisson regression models for calculation of relative risk of permanent institutionalization and death were constructed. The multivariable models built for the calculation of the relative risk (RR) of institutionalization and death were based on a risk period of 6 months. The risks for both population strata for each type of intervention over this time span were subsequently measured and compared with that of the group not receiving any interventions. A robust form of Poisson regression was used in the analysis to obtain robust standard errors for the parameter estimates, as recommended previously [35]. The analysis was performed using Stata version 11.2 (Stata Corp., College Station, TX).

Results

This study used data from 4,607 frail older people receiving interventions and 3,633 frail older people in the comparison group. A subgroup analysis based on validated cut-off points from the interRAI scales resulted in the following strata: a group of frail older people with mild impairment (n=1,999) and a group of frail older people with moderate to severe impairment (n=2,608).

Table 1: Demographic Characteristics of Sample and Intervention Group According to Type of Intervention Received and of Comparison Group

Intervention	Mild Impairment			Moderate To Severe Impairment		
	n	Age, Average±SD	Female, % (95% CI)	n	Age, Average±SD	Female, % (95% CI)
Intervention group (receiving intervention)	1,999	80.9 ± 6.8	71.3 (0.6–0.8)	2,608	81.6 ± 7.1	66.6 (0.6–0.7)
Comparison group (no intervention)	1,871	82.9 ± 4.5	58.8 (0.5–0.6)	1,762	84.9 ± 5.4	68.5 (0.6–0.7)
Case management						
With psychological support and OT	249	76.9 ± 7.2	65.8 (0.7–0.8)	187	78.5 ± 6.3	63.8 (0.5–0.8)
With OT and physiotherapy	126	82.1 ± 5.9	61.5 (0.5–0.7)	256	82.3 ± 6.5	68.3 (0.6–0.7)
With rehabilitation	832	82.2 ± 6.8	64.5 (0.6–0.7)	464	82.2 ± 6.9	70.7 (0.7–0.8)
With OT for older persons with visual impairment	117	80.5 ± 6.4	70.5 (0.6–0.8)			
With OT alone	302	80.9 ± 6.2	63.2 (0.6–0.7)	426	82.9 ± 6.7	69.0 (0.6–0.7)

OT alone	187	80.6 ± 7.2	72.7 (0.7–0.8)	220	79.9 ± 6.6	63.6 (0.6–0.7)
Psychological support alone	186	77.6 ± 5.9	69.8 (0.6–0.8)	122	79.3 ± 6.9	66.8 (0.6–0.7)
Day care				232	79.3 ± 7.3	60.9 (0.5–0.7)
Night care at home with full supervision				473	83.1 ± 7.5	59.8 (0.5–0.7)
Night care at home offered to several frail older persons				228	82.9 ± 5.7	70.8 (0.6–0.8)

SD=standard deviation; CI=confidence interval; OT=occupational therapy.

Table 1 shows the age and gender distribution of the population according to type of intervention and to subgroup, including the comparison group. For the subgroup with mild impairment, the RR of institutionalization at 6 months was much lower for the interventions providing CM with psychological support and OT (RR=0.1), for CM and OT (RR=0.2), for OT for people with visual impairment (RR=0.1) and for CM in a residential setting with rehabilitation services (RR=0.4) (Table 2). Interventions providing only OT also had a low RR (RR=0.7), indicating that these interventions had a certain level of effectiveness at decreasing the probability of a frail older person being institutionalized. No type of intervention showed a significant effect on risk of death.

For the subgroup of people with moderate to severe impairment, the RR of institutionalization at 6 months was less than 1 for interventions providing CM in a residential setting with rehabilitation services (RR=0.7) and for OT interventions (RR=0.2). These interventions delayed institutionalization of older people with moderate to severe impairment, whereas frail older people receiving night support at home with full supervision had a higher risk of institutionalization than people in the comparison group (RR=1.4). As for risk of death, only day care interventions seem to lower the risk for frail older people with moderate to severe impairment at home (RR=0.3). Frail older people who received night care with full supervision had a higher RR of death than people in the comparison group (RR=2.0).

Table 2: Relative Risk of Institutionalization and Death at 6 Months for Frail Older People in the Intervention and Comparison Groups

Type of intervention	Relative risk of Institutionalization n=1,999				Relative risk of Death n=2,608			
	Mild Impairment		Moderate to Severe Impairment		Mild Impairment		Moderate to Severe Impairment	
	n	RR (95% CI)	n	RR (95% CI)	n	RR (95% CI)	n	RR (95% CI)
Case management								
With psychological support and OT	249	0.1 (0.1–0.7)[a]	187	1.1 (0.5–2.4)	249	No death occurred	187	1.0 (0.4–2.4)
With OT and physiotherapy	126	0.2 (0.1–1.2)	256	0.9 (0.4–1.8)	126	0.7 (0.2–2.0)	256	0.7 (0.4–1.2)
With rehabilitation	832	0.4 (0.2–0.7)[a]	464	0.7 (0.4–0.9)[a]	832	1.2 (0.9–1.8)	464	0.8 (0.5–1.2)
With OT for older persons with visual impairment	117	0.1 (0.1–0.5)[a]			117	0.7 (0.2–2.3)		
With OT	302	0.2 (0.1–0.7)[a]	426	0.9 (0.5–1.8)	302	0.9 (0.5–1.7)	426	0.9 (0.7–1.5)
OT alone	187	0.7 (0.1–0.9)[a]	220	0.2 (0.1–0.6)[a]	187	1.1 (0.5–2.3)	220	0.5 (0.2–1.1)

Psychological support		No institutionalization occurred	122	0.3 (0.1–1.0)	186	0.2 (0.1–1.3)	122	0.6 (0.2–1.7)
Day care			232	0.7 (0.4–1.2)		-	232	0.3 (0.1–0.7)[a]
Night care at home								
With full supervision			473	1.4 (1.1–1.9)[a]			473	2.0 (1.5–2.8)[a]
For several frail older persons			228	0.5 (0.2–1.1)			228	0.7 (0.4–1.4)

[a]P<.001. Controlled for age and gender RR=relative risk CI=confidence interval OT=occupational therapy.

Discussion

This article reports the effects of home care interventions for frail older people in delaying permanent institutionalization during 6 months of follow-up. OT interventions delayed institutionalization of older people with mild impairment and those with moderate to severe impairment. OT consisted mostly of adaptations to the home and recommendations about assistive devices. The goal was to enable older people to improve or maintain their ADLs to the best of their abilities. Intervention studies with OT have not focused on the prevention of institutionalization specifically. They have mostly analyzed other outcome variables such as improvement in functional performance and quality of life and reduction of informal caregiver burden and risk of falls, all arguably related to rate of institutionalization [36-38]. The current study showed that OT interventions can prolong the time that frail older people remain at home, at least over a 6-month period.

Multicomponent interventions such as CM in combination with other interventions were effective for older people with mild impairment and those with moderate to severe impairment. This is consistent with the literature and shows the added value of CM to coordinate care for people with complex needs and to support informal caregivers, provided it is combined with other services. As demonstrated by a meta-analysis [39], preventive home visits with no extra services had no effect on rates of institutionalization, as opposed to CM, which reduced admissions to nursing homes in some studies [40,41]. Another meta-analysis [42] showed significant positive effects in seven of 11 randomized controlled trials and two comparative studies. All programs in this meta-analysis were multicomponent and offered a range of specific, intensive supportive caregiving interventions that were specifically designed to meet the unique needs of frail older people and their caregivers. One of these studies showed no significant positive effects, but subgroup analyses revealed a significant positive effect in favor of people with moderate to severe cognitive decline. Similar results were reported in another meta-analysis in which only multicomponent

interventions had a significant effect on delaying institutionalization of older people with dementia [43].

The current study results showed that older people with moderate to severe impairment who received night support at home with full supervision had a higher risk of institutionalization and death than people in the comparison group. This might be because of comorbidities, which could not be controlled for in the analysis. This intervention did not show an effect in delaying institutionalization, but it may have had an effect on decreasing the burden of informal caregivers by offering respite care during the night. More research is needed to confirm this.

Strengths

Clear strengths of the study included the use of a large population-based sample of older people living in the community, the longitudinal design of the research, and the availability of a comparison group from a reliable database suitable for stratification. In addition, the use of a comprehensive geriatric assessment such as the interRAI HC instrument had advantages, such as the possibility of using several outcome variables to evaluate interventions[44]. The interRAI HC instrument made it possible to stratify the population according to impairment levels.

Limitations

The fact that the study sample consisted of frail older people who had been selected to receive the intervention could be a limitation of the research. This selection was not random, so there may be a bias. Not all frail older people in Belgium participated in the interventions, and not all older people in the general population are as frail as the people in the study. An attempt was made to address these concerns by having two strata in the study population (mild impairment and moderate to severe impairment) and by matching them with a comparison group of people with a similar

health profile from the national health consumption database. Another limitation was the lack of data on diagnosis to control for comorbidities in the analysis.

Conclusion

This research broadens the understanding of the effects that different types of community care interventions have with regard to delaying institutionalization of frail older people. Multicomponent interventions involving CM and other services such as OT and rehabilitation and interventions based on OT services were effective in delaying institutionalization of frail older people. This information can help policy-makers to better plan community care interventions to prevent institutionalization.

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Conflict of Interest

The editor in chief has reviewed the conflict of interest checklist provided by the authors and has determined that the authors have no financial or any other kind of personal conflicts with this paper. Prof. Anja Declercq is a board member of interRAI. We have declared this as a conflict of interest, but we do not believe this to have any influence on the study, even though the interRAI HC instrument was chosen to be used in the evaluation of the interventions.

Author Contributions

dAMJ, VDT, MJ, CS, DA: study concept and design, statistical methods. dAMJ, VDT, MJ, CS, DA, VAC: critically interpretation of results, review of article. dAMJ: drafting the manuscript. All authors read and approved the final manuscript.

Sponsor's Role

The NIHDI played no role in the design, execution, analysis, or interpretation of data, neither did it influence the writing of this article.

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Chapter 6

Targeting frail older people at home to prevent admission to residential care: a case-mix study

This chapter will be submitted as:

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Targeting frail older people at home to prevent admission to residential care: a case-mix study

Introduction

Several countries foster community care as an alternative to residential care (1-6). In Belgium, innovative home care interventions are being funded and evaluated (7). These interventions have the purpose of keeping frail older persons at home with satisfactory quality of life and low informal caregiver's burden. Some of these interventions have proven to be effective in preventing institutionalization in the first six months of follow-up (8). In order to identify which type of clients are able to stay at home and which type of clients are being admitted to residential care, it is essential to understand their profile and the resources they use.

Shugarman et al. (2000) compared the resource utilization of nursing home residents in Ohio with that of community care clients in Michigan. They used the previous version of the interRAI instruments (RAI 2.0), along with the Resource Utilization Groups III (RUG-III) case mix system. The calculation of the RUG-III is based upon the relationship between the clients' clinical profile and the staff time (and therefore cost) involved in the provision of their care (9). The researchers showed that the two samples overlapped in many resource utilization levels, but with different distributions.

In the RUG-III system, clients can be classified into a total of 34 or 44 resource utilization groups (RUGs) with a corresponding Case-Mix Index (CMI) for each of these groups. A CMI is a measure of the relative 'amount' of resources necessary for a client in that RUG-III group compared to a client in another RUG-III group. The CMIs indicate the relative amount of resource (including financing) which is necessary for a client in a certain group compared to a client in another group. Clients in a group of high level of resource utilization will have a higher CMI than a client in a group with low resource intensity. The RUG-III system has been applied and validated

internationally (10-16). This system can be used for management purposes (e.g. determining staff levels) and for payment systems. The RUG-III is used for the residential care setting and is calculated with the items from the interRAI Long Term Care Facilities instrument (interRAI LTCF). The RUG-III/Home Care (HC), which was derived from the RUG-III/LTCF, is the validated version used in the community setting (18,19).

There are seven RUG hierarchical categories in the RUG-III system: Rehabilitation, Extensive Services, Special Care, Clinically Complex, Impaired Cognition, Behavior Problems, and Physical Functioning. These categories are further differentiated into 23 groups according to the resources used (e.g. minutes rehabilitation – speech therapy, physiotherapy or occupational therapy; extensive services, special care or clinically complex care) or health and functional situation (impaired cognition, behavior problems or physical impairment). The secondary split is based on an ADL-index, and further differentiates within these groups. The ADL-index consists of four items: toilet transfer, toilet use, mobility in bed and eating. Higher scores on the ADL-index point to higher ADL impairment. The tertiary split divides some RUG-groups even further based upon the score on the DRS scale, the use of extensive services or the use of nursing rehabilitation (10).

To obtain a detailed profile of frail older persons staying at home, it is essential to understand the health and functional status of these persons as well as the resources they use. The objective of this study is to describe and compare the case mix of a population of frail older people in the community with a group of clients from this population who were admitted to residential care permanently. This allows us to understand the clients' resource utilization in the community setting, as well as to describe the resource utilization of clients leaving the community setting and entering residential care. By understanding the resource use of a frail home care population, organizations can plan interventions better and optimize their services and resources to meet their clients' needs.

Methods

Design

This is a longitudinal study including frail older people who are at least 65 years old and who are living in the community. These clients took part in a larger study called Protocol 3, which evaluated home care interventions aiming at maintaining frail older persons at home longer. All clients were frail and at risk of institutionalization. Frailty was measured with a score of the Edmonton Frail Scale of minimum 6 or the Katz Scale (Belgian version) indicating ADL problems. Clients with a dementia diagnosis could also participate in the study (7). The home care interventions were classified as follows:

Single interventions:

1. case management (low intensity, mainly care coordination).
2. occupational therapy (home adaptations and advice about assistive devices)
3. psychological support
4. day care,
5. night care (offered exclusively to one frail older person with full supervision during the whole night or to several frail older people, each with partial supervision),
6. other interventions (these are classified together because they do not belong to a main type. These comprise assisted living, delivery of medications at home, etc.),

Multicomponent intervention:

7. case management (CM) with rehabilitation services and/or psychological support (all case management interventions combined with other services were grouped together, eg. CM with occupational therapy, CM with psychological support, CM with physiotherapy, etc.).

A control group was also constructed of frail older people receiving hands-on nursing care, which is considered to be regular care in Belgium. The purpose of this control group was to compare the resource utilization of clients in the community receiving the interventions and of clients not receiving any of the interventions in the study.

Professional caregivers (mostly nurses, physiotherapists, occupational therapists and social assistants) received a 2.5-day training on how to fill out the interRAI Home Care instrument (interRAI HC). Assessments were performed at baseline (inclusion of frail older people in the program) and every six-months until the frail older people left the program. The InterRAI HC assessments completed at baseline for clients in community care and at exit for clients leaving community care into residential care were used for the calculation of the RUG-III HC classification system.

Table 1 shows the RUG-III classification categories and their corresponding RUG-groups. There are seven RUG hierarchical categories: Rehabilitation, Extensive Services, Special Care, Clinically Complex, Impaired Cognition, Behaviour Problems, and Physical Functioning. These categories are further differentiated into groups according to the resources used (e.g. minutes rehabilitation – speech therapy, physiotherapy or occupational therapy; extensive services, special care or clinically complex care) or health and functional situation (impaired cognition, behavior problems or physical impairment). The secondary split is based on an ADL-index, and further differentiates within these groups. The ADL-index consists of four items: toilet transfer, toilet use, mobility in bed and eating. Higher scores on the ADL-index point to higher ADL impairment. The tertiary split divides some RUG-groups even further based upon the score on the IADL items.

Table 1 – RUG-III HC groups (Source: Hirdes et al., 2013)

RUG-III hierarchical categories	Definition of RUG-III groups
RB0	Rehabilitation High / ADL 11 - 18
RA2	Rehabilitation Low / ADL 4 - 10 / IADL 2-3
RA1	Rehabilitation Low / ADL 4 -10 / IADL 0-1
SE3	Extensive Special Care 3 / ADL > 6
SE2	Extensive Special Care 2 / ADL > 6
SE1	Extensive Special Care 1 / ADL > 6
SSB	Special Care / ADL 14 - 18
SSA	Special Care / ADL 4 - 13
CC0	Clinical. Complex / ADL 11 - 18
CB0	Clinical Complex / ADL 6 - 10
CA2	Clinical Complex / ADL 4 - 5 / IADL 1-3
CA1	Clinical Complex / ADL 4 - 5 / IADL 0
IB0	Cognitive Impairment / ADL 6 - 10
IA2	Cognitive Impairment / ADL 4 - 5 / IADL 1-3
IA1	Cognitive Impairment / ADL 4 - 5 / IADL 0
BB0	Behaviour Problems / ADL 6 - 10
BA2	Behaviour Problems / ADL 4 - 5 / IADL 1-3
BA1	Behaviour Problems / ADL 4 - 5 / IADL 0
PD0	Physical Function / ADL 11 - 15
PC0	Physical Function / ADL 9 - 10
PB0	Physical Function / ADL 6 - 8
PA2	Physical Function / ADL 4 - 5 / IADL 1-3
PA1	Physical Function / ADL 4 - 5 / IADL 0

Analysis

Data analysis was performed in two steps using SAS 9.4. First, descriptive statistics were calculated describing the demographic characteristics and the health status of the sample of older persons in the community (baseline). Subsequently, the resource

utilization of the whole study population was calculated by means of the RUG-III HC case-mix system, which contains a total of 58 variables from the interRAI HC instrument. This calculation was performed for clients in the community (baseline) as well as for the clients who left the community setting into residential setting permanently (at follow-up).

After calculation of the RUG-III HC, the distributions of the RUG groups and the case-mix indexes (CMI) for both populations were compared using Mann-Whitney test and ANOVA, as well as proportion tests for some interRAI scales (ADLH, IADLP, CPS, DRS) and for the self-report item 'feeling lonely' from the interRAI HC instrument. The use of the interRAI scales can be justified by the fact that they have been internationally validated and are comparable to "gold standard" measures (20, 21, 22). They have become worldwide standards to evaluate clients' current clinical status and to do comparisons across time when longitudinal data is available.

Results

The population of the study consisted of 10,289 frail older people living at home (average age: 81.24 ± 7.06, 69.14% female). About 82% of the population had at least one informal caregiver. Table 2 shows the demographic and functional characteristics of the population at baseline. About 78.2% [77.3; 79.0] of the older persons needed at least extensive assistance in IADL, 49.9% [48.9, 50.9] in ADL and 28.12% [27.3, 28.9] were at least moderately cognitively impaired. Moreover, 27.6% [26.7, 28.5] of the older people presented daily depressive symptoms. Urinary incontinence was frequent in this population (28.5%, C.I. 27.7, 28.4) as well as the incidence of falls in the last 90 days (38.5%, C.I. 37.6, 39.4). From this population,

853 clients (8.29%) left the community setting to enter residential care (average age: 83.73 ± 6.73, 70.29% female).

Table 2: Characteristics of community care clients in the study population

	N=10,289 / Age (±SD): 81.24 ± 7.06 % (*95 C.I.*)[a]
Gender: female	69.14% [68.24; 70.03]
Living alone	55.32% [54.36; 56.29]
Availability of an informal caregiver	82.28% [81.53; 83.02]
IADL Performance scale value ≥ 24	78.18% [77.34; 79.02]
ADLH scale value >=3	49.89% [48.92, 50.86]
CPS2 value ≥3	28.12% [27.25, 28.99]
Depression scale value ≥3	27.60% [26.73, 28.47]
Incidence of falls in last 90 days	38.49% [37.55, 39.44]
Urinary incontinence	28.52% [27.65, 28.39]

[a] 95 *CI* = 95% confidence interval

The distribution of frail older people based on the RUG-III clinical groups is shown in Figure 1. The RUG-III groups were ordered by case-mix indexes from left to right on the X-axis. The lowest resource intensive group was PA1 (Physical Functioning ADL – low levels of ADL and IADL impairment) and the highest was SE3 (Extensive Special Care 3). In other words, the first group on the left used the least resources while the last group on the right used the most. The largest proportion of the community setting population could be found in the PA2 (Physical Functioning ADL – low level of ADL impairment, but high level of IADL impairment) group (13.7%). These are clients with neither major ADL-dependencies (in toilet transfer, toilet use, mobility in bed or eating), nor complex nursing care needs, but who need more than extensive assistance in IADL (meal preparation, managing medications and

telephone use). The second most populated RUG-group in community care was RA1 (Low Rehabilitation, with low ADL and low IADL impairment – 13.4%), followed by CA2 (Clinical Complex – 11.3%), PA1 (Physical Functioning ADL – low level of ADL impairment and no or low level of IADL impairment – 9.1%), IA2 (Cognitive Impairment with low ADL but high IADL impairment – 8.3%) and RA2 (Rehabilitation Medium with low ADL impairment but high IADL impairment– 6.6%). Among the population of clients admitted to residential care, the largest group was the Cognitive impairment category IA2 (with low ADL and high IADL impairment) with 12.9% of the clients. These are clients with cognitive impairment, no major ADL-dependencies (in toilet transfer, toilet use, mobility in bed or eating), but with extensive needs of assistance in IADL. The second most populated RUG-group at the entry point into residential care was RA1 (Low Rehabilitation, with low ADL and low IADL impairment – 12.0%), followed by 10.7% in RA2 (Rehabilitation Medium with low ADL impairment but high IADL impairment) and 9.9% in PD0 (Physical Functioning ADL – high level of ADL impairment).

Figure 1: RUG-III HC Distribution of frail older persons in the community and of people recently admitted to a nursing home

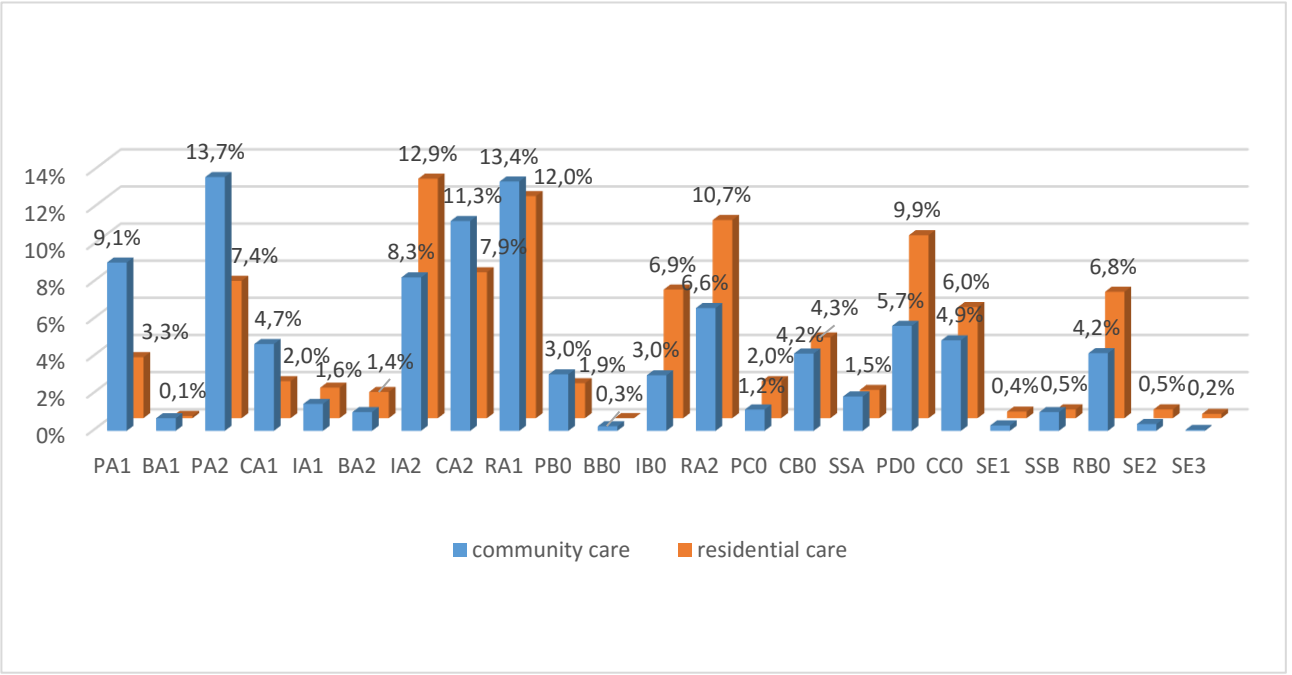

Figure 2 shows the distribution of the case-mix indexes (CMI) for formal care for the whole study population (23). The values on the vertical axis represent the CMI value for the relative resource use of these, also called case-mix. The CMI value gives an indication of the resource allocation for a client compared to another client. The CMI from the RUG III refers to formal care utilization, also considered as staff time. Therefore, a client in a group of rehabilitation (RB0) with a CMI of 3.03 uses approximately 4.9 times more resources (staff time) than a client in the lowest resource group (PA1) with a CMI of 0.61. As the average in the sample of community care clients was 1.36 (SD: 0.69), a client in a sub-group of PA1 (CMI 0.39) used about 45% of the resources (staff time) of an average client in the sample. Additionally, the average value for the CMI for the clients entering residential care was 1.56 (SD: 0.79). As expected, the average value of the CMI for this population was significantly higher than the value for the population in community care (p=0.000 – controlling for initial CMI values of clients entering residential care). Despite of this significant difference, there were clients with high CMI values of resource use and low resource use in both settings, but with different proportions.

Figure 2: RUG-III HC case-mix index (CMI) distribution of frail older persons in the community and of older people recently admitted to residential care

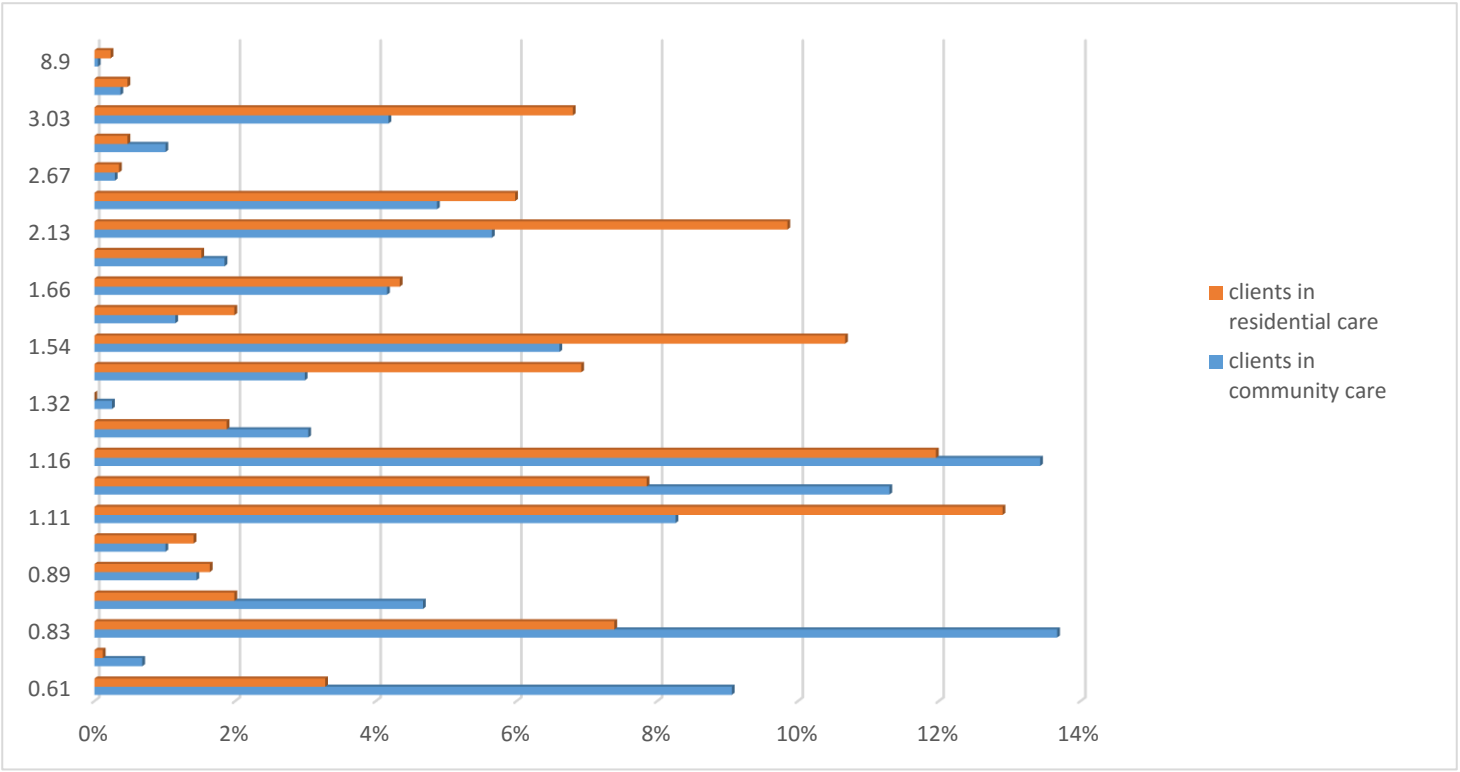

Table 3 shows that, among clients who were being admitted to residential care but who were in low resource utilization groups like Physical Function PA (grouping PA1 and PA2 together), 41.76% (C.I.: 31.43; 52.09) had ADL at least extensive assistance needed for ADL (ADLH score >=3), 79.54% (C.I.: 70.94; 88.14) had at least extensive assistance needed for IADL (IADLP score >=3) and 31.87% (C.I.: 22.11; 41.63) presented mild cognitive problems. Additionally, 37.78% (C.I.: 27.57; 47.99) of the clients had daily depressive symptoms and 36.36% (C.I.: 26.11; 46.61) felt lonely. Therefore, even if these clients were in the lowest RUG group and were being admitted to residential setting, they did need assistance in daily activities and were in need of psychosocial support or felt the need to be in an environment with other people.

In the community care, in the lowest RUG group Physical Function PA (grouping PA1 and PA2 together), 19.99% [C.I.: 18.79; 21.18] had at least extensive ADL needs (mostly daily help for personal hygiene and dressing) and 39.81% [C.I.: 38.29; 41.33] had extensive needs for IADL. In this group, 15.73% (C.I. 14.66; 16.81) of the clients presented mild cognitive impairment (CPS score = 2) and 25.50% [24.20; 26.79] of the clients had daily depressive symptoms (DRS score >=3) or reported that they felt lonely at home (36.44% (C.I. 35.01; 37.87). This means that community clients grouped into the RUG group Physical Function PA would also need formal help if informal help is unavailable or insufficient. For both populations, approximately 33% of the clients had a CMI above the sample average. For the clients in community care who had high resource utilization, since they are still living at home, these resources had to be provided at home, ambulatory in a nearby residential setting, or during a short stay in such a setting. In the community we also find clients with high resource utilization such as SE3 (Extensive Special Care 3) and High Complex Care and high ADL impairment (CC0).

Table 3: Characteristics of the study population in groups PA1 and PA2

	Community care	Residential care	P-value
IADLP score >=24	39,81% [C.I.: 38.29; 41.33]	79.54% (C.I.: 70.94; 88.14)	P=0.000***
ADLH score >=3	19,99% [C.I.: 18.79; 21.18]	41.76% (C.I.: 31.43; 52.09)	P=0.001**
CPS score = 2	15.73% (C.I. 14.66; 16.81)	31.87% (C.I.: 22.11; 41.63)	P=0.000***
DRS score >=3	25,5% [24.20; 26.79]	37.78% (C.I.: 27.57; 47.99)	P= 0.01*
Feels lonely	36,44% (C.I. 35.01; 37.87)	36.36% (C.I.: 26.11; 46.61)	P=0.576

*** p=0.000 ** p=0.001 *p=0.01

Table 4 shows the average CMIs for each type of home care intervention and the control group. As mentioned before, clients in the study population were receiving these interventions to allow them stay at home longer. Clients in the control group were only receiving regular nursing care. The CMI of the clients receiving night care at home were the highest in the study population (1.57) followed by clients receiving occupational therapy (1.47) and clients enrolled in case management interventions with rehabilitation combined or not with psychological support (1.35). Clients in these three types of interventions are at higher resource utilization groups because the RUG system places them in higher groups according to their use of services and therapies. Clients in the control group had an average CMI value of 1.42, which was also above the average in the community setting. Clients with the lowest CMI values

were receiving psychological support at home (1.04), case management with low intensity (1.28), or were enrolled in other interventions (1.18) such as assisted living, delivery of medication at home, etc.. Only clients receiving night care had a similar CMI value of clients admitted to residential care (1.57). In the groups of clients

receiving case management only, or case management with rehabilitation (with or without psychological support) or night care, the CMI of clients being admitted to a residential setting is significantly higher than the CMI of these groups at baseline. This means that at the entry point of residential care, their resource utilization was significantly higher than at baseline and that community care may not have been able to provide the services these clients needed in home care, in which nursing home placement could have been considered a cost effective solution.

Table 4: Average CMI per type of intervention

Type of community care intervention	Total population in community care Average CMI: 1.36 ± 0.69 (N=10,289)	Population admitted to residential care Average CMI: 1.57 ± 0.79 *** (N=931)	P-value
	Average CMI ± SD	Average CMI ± SD	
Case management with rehabilitation (with psychological support or not)	1.35 ± 0.63	1.56 ± 0.82	p=0.000***
Case management only	1.28 ± 0.69	1.56 ± 0.80	p=0.000***
Day care	1.34 ± 0.66	1.49 ± 0.72	p=0.541

Night care	1.57 ± 0.91	1.70 ± 0.63	p=0.001**
Occupational therapy	1.47 ± 0.85	1.64 ± 0.58	p=0.109
Psychological support	1.04 ± 0.43	1.29 ± 0.43	p=0.916
Other interventions (alternative housing, medication delivery, etc.)	1.18 ± 0.58	1.38 ± 0.39	p=0.663
Control group (receiving mainly only nursing care)	1.42 ± 0.77	1.38 ± 0.55	p=0.871

*** p=0.000 ** p=0.001

Discussion

This paper analyzed the resource utilization of a population of frail older people in the community and of a population being admitted to residential care. The CMIs of both groups were compared. In both settings, there was a large variability across the RUG categories with clients in low, medium and high intense resource utilization groups. This finding was also shown in Shugarman (2000), where there was some overlap of the RUG-III categories across two samples but also with large variability across RUG groups. Clients who were very resource intense were also cared for in the community setting (CC0: Complex care group: 27.2% in residential care and 12.0% in community care) and clients who were only minimally resource intense were found in both settings (PA: Reduced physical function ADL: 49% in both settings). There were also very resource intense clients still living at home (a total of 18% in medium and high rehabilitation groups RB and RC). These older people receive home care services, while other people with the same profile are in a residential setting.

A joint report from the OECD and European Union (2013) which presented the RUG distribution of clients in the community and residential settings with samples from 9 countries, also showed an overlap between these two settings. Except for the RUG group 'extensive services', all groups had clients from both settings in almost all countries. Similarly, in our sample there were almost no clients in the highest resource levels (no clients in Rehabilitation High or Very High and a few clients in Extensive Care 3). This is consistent with other previous studies (9, 10, 15), since these clients tend to be in special skilled units in residential care.

We could argue why clients in the lowest group of resource utilization (PA) were targeted by these interventions or were admitted into residential care. The study showed however that many of these clients still have moderate ADL and sometimes high IADL impairment, as well as mild cognitive impairment. Consequently, they are also at risk of institutionalization. Interventions designed to avoid early institutionalization should target this population as well. Clients not having major

ADL, IADL or cognitive problems could still be in need of help because of loneliness or depressive symptoms. This was the case for respectively 36% and 26% of our PA RUG-III group in the community. Engaging these clients in activities and offering psychological support and guidance would be advisable. Supervision and help for clients with mild cognitive problems or psychological support for clients with depression can still require substantial resources. In the case of depression, the support needed cannot be accounted for in the RUG-III/HC since the depression scale DRS is not included in the algorithm of the RUG-III/HC, neither is an item about psychotherapies. The depression scale is included in the RUG-III/LTCF but not for clients with only physical functioning problems.

The study shows that the RUG-III/HC system offers possibilities for identifying clients based upon their case-mix index, and for allocating resources to keep them at home longer. The results also show the importance of the availability of rehabilitation services in the community setting, allowing frail older people to follow these therapies at home and stay longer in the community. If these therapies are not available at home or in short-term rehabilitation centers, these clients may be institutionalized too early. These results are in line with the results of a previous study on the same population (8). The study described the positive effect of interventions offering rehabilitation in order to avoid institutionalization of frail older people.

Another finding from that study, showing that clients receiving night care had the highest relative risk of being admitted into residential care, is also conclusive with the CMI distribution of this population. The average CMI of night care clients in the community was as high as the average CMI of people being institutionalized (1.57). The level of care needed by these clients showed to be too high to be delivered in the community setting.

As the RUG-system analyses the needs as well as the utilization of services, caregivers have to be aware whether clients are receiving the services they need. Underutilization of services due to lack of access of care (e.g. because of

unavailability of services or financial issues) are very relevant in this case. If a client is placed in a high ADL need group such as PE, but should also be receiving high level of rehabilitation, this client will be classified into a lower RUG group than clients who have the same level of ADL needs and already receive the rehabilitation services (as PE is lower than RC). It is the responsibility of policy makers to implement tools which can help caregivers to identify these clients and to organize and offer the services and therapies they need. Offering them the necessary therapies can help older people to stay longer at home and become less functionally dependent.

Moreover, if informal caregivers are the main carers, clients often will use a lower level of formal care or therapies, such as nursing care or occupational therapy. Therefore, these clients will also be in a lower RUG group while they do use resources (time) from informal care. For this reason, informal care time should also be included in the calculation of the RUGs. The RUG III system can account for some of the time informal caregivers spend, but not for all the time. A particular innovation in RUG-III/HC was that informal care time was used in its validation and an additional set of CMIs was calculated including informal care (24). In this case, especially emotional support and supervision offered by informal caregivers may be still underestimated.

Strengths and limitations

Strengths of this research are the large population size with follow-up assessments and the use of the interRAI HC instrument, allowing for the calculation of the RUG-III/HC algorithm. A limitation of this research is that the population of the study consisted of frail older people who received home care interventions and that this population is not representative for the whole community care setting, so the CMIs calculated in the study cannot be generalized for all older people in the community.

Conclusion

The study showed the differences between the characteristics of the case-mix of a population of community care clients and a sample of clients from this population who entered residential care. In both settings, there were clients with different

levels of resource utilization. In the community care, in particular, there were clients in groups of high level of services and therapies, and these therapies have to be available for people in the community. People entering residential care had a significant higher average CMI value but there were clients with low level of service utilization but who had still ADL, IADL, mild cognitive problems or showed feelings of depression, loneliness or isolation. Interventions designed to avoid early admission to residential care should target clients in need of these interventions making use of tools like the interRAI HC and its outcome variables, which are suitable for care planning and allocation of services and resources in order to optimize care.

Abbreviations

NIHDI: National Institute for Health and Disability Insurance

InterRAI LTCF: interRAI Long Term Care Facilities instrument

InterRAI HC: interRAI Home Care instrument

RUG-III: Resource Utilization Groups

CMI: Case-mix index

CM: Case management

ADL: Activities of Daily Living

ADLH: interRAI Activities of Daily Living Hierarchy scale

IADL: Instrumental Activities of Daily Living

IADLP: InterRAI Instrumental Activities of Daily Living Performance scale

CPS2: InterRAI Cognitive Performance scale 2

DRS: InterRAI Depression Rating scale.

Conflict of interest

None

Author Contributions

dAMJ, DA, FB: study concept and design, statistical methods. dAMJ, , VDT, VD, MJ, CS, DA, VAC, FB: critically interpretation of results, review of article. dAMJ: drafting the manuscript. All authors read and approved the final manuscript.

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Chapter 7

General Discussion

Introduction

Long-term care policies for community dwelling older persons usually focus on providing high quality care and services, so that clients can live in their homes for as long as possible [1, 2]. In this context, the Belgian federal government launched the third protocol agreement, also known as Protocol 3. This framework has the goal of supporting older persons to stay at home longer, by guaranteeing access to affordable formal services, along with improving coordination and integration of care [3]. Under this agreement, several bottom-up innovative home care interventions were financed since 2010. This doctoral thesis reported some results of this evaluation.

As the goal of these interventions was to keep frail older people at home longer with good quality of life and low burden of the informal caregivers, it is important to gain insight in the whole situation of these clients. A holistic view of their situation and of their informal caregivers provides information on the possibility for clients to remain at home for as long as possible. The interRAI HC instrument, being a comprehensive geriatric assessment (CGA), is suitable to assess this situation [4]. In this thesis, this assessment instrument was used in order to analyze the determinants of burden of informal caregivers, the risk of institutionalization of frail older people and their resource utilization at home.

In summary, this thesis aimed at evaluating the use of the interRAI HC instrument in the evaluation of care for fail older people at home. As this assessment offers many possibilities for this evaluation, the following research questions were formulated:

1- What is the evidence in the scientific literature for using the interRAI Home Care instrument to evaluate home care interventions?
2- What are the factors mostly associated with informal caregivers' burden in the population of the study?

3- What is the effect of home care interventions on delaying or avoiding institutionalization of frail older persons?
4- What is the resource utilization of frail older people in the community?

As the interRAI assessments have several applications, our research took different approaches, but all of them related to the fact that the interventions in the study were designed to avoid or delay nursing home placement. The outcomes from the interRAI HC (scales) were used to stratify the population of the study in order to evaluate outcomes (informal caregiver's burden and institutionalization) according to the different sub-groups of impairment. In addition, the items of the interRAI HC and its outcomes (Client Aseessment Protocols – CAPs and scales) were used to construct the model for the predictors of informal caregiver's burden. The algorithm of the RUG-HC/III, consisting of several interRAI HC items and scales, was the basis of the classification of clients to identify their case-mix in the community and to compare it to clients entering residential care. These different applications of the interRAI HC instrument showed the benefits of using this assessment instrument in this research. The instrument can be considered a valid tool for research as well as for care planning and care evaluation. Our conclusions are in line with the results from the systematic review (chapter 3) but in our research the application of the instrument happened with a broader scope.

In this chapter, we provide an overview of the main findings of this study, as well as recommendations for future research, for policy and for practice.

Main findings

Systematic review of interventional studies using the interRAI HC instrument

This literature review showed how the interRAI HC instrument was previously used in research to evaluate home care interventions. Eighteen studies were identified in which the interRAI HC instrument was used as an evaluation tool and in six of these studies the intervention was the implementation of the instrument itself.

In 14 studies, the use of the interRAI HC instrument showed positive results. In 4 studies, the effectiveness of the instrument could not be proven. Most authors agreed that a comprehensive geriatric assessment such as the interRAI HC should be used in the evaluation of interventions due to its validity and usability. In addition, the standardization of the instrument improves collaboration between professionals and allows for benchmarking and for comparisons across settings and countries.

This systematic review showed other advantages of using the interRAI HC, such as the application of the assessment as a case management tool for the client. Some pitfalls were also mentioned by the studies: extensive training is necessary and professional caregivers need to have enough time to learn and to practice working with the instrument.

Many interventions described in the systematic review consisted of interventions of case management based on the application of the interRAI HC. These studies confirmed the effectiveness of the interRAI HC as a case-finding instrument and as a tool to identify the needs of older persons. The construction of care plans based on the interRAI HC outcomes was often mentioned in these studies. Moreover, case management interventions based on the interRAI HC reduced hospital admissions and the length of stay in hospitals, therefore reducing costs.

One of the articles pointed at the importance of a standardized assessment such as the interRAI HC to harmonize data collection across countries. The interRAI Suite of instruments was also seen as a great opportunity for supporting integrated eCare and for sharing high quality data between and within care organizations and care sectors. This is possible due to the standardization of common items across care settings, which can assure a minimum high quality level in the gathering of information and in the care planning.

Based on this literature review, we can conclude that the interRAI HC instrument could be recommended to be used in our research. The main message about the use

of the instrument is that it contains comprehensive information about the client's situation and it is a valid instrument to be applied in research in home care interventions. The validated output from the instrument (CAPs, scales, RUG III) can also be considered as useful tools for evaluation and comparisons.

Additional information about the use of the interRAI HC in research can be found in a more recent systematic review (2018). This review focused on a wider range of research types, thus not only on evaluation studies [5].

The identification of the determinants of informal caregiver's burden using the interRAI HC instrument

Chapter 4 explored the determinants of informal caregivers' burden. As informal caregiver's burden is a risk factor for institutionalization, it is important that interventions also tackle this problem when aiming at keeping frail older people at home.

Available research in this topic usually describes the population of frail older people as a whole and studies analyze informal caregiver's burden for an entire study population as if every client had similar profiles. Because frail older people have different characteristics and different degrees of impairment, the population of our study was stratified using the interRAI HC scales sIADLP, sADLH and sCPS2 [6, 7]. A total of three sub-populations were identified: a group with mild impairment, moderate impairment and severe impairment. The interRAI HC instrument was also used to operationalize the variables from two available frameworks which are well known in the study of burden: the Stress Process Model (8) and the Role Theory [9]. To our knowledge, this is the first article to combine both frameworks and to test several determinants from them. This was only possible because the interRAI HC instrument is comprehensive enough to provide items to be tested from both theories.

Furthermore, a validated scale was used to measure the perceived burden of informal caregivers: the Zarit Burden Interview 12-item (10). The need to use this

scale came from the fact that the interRAI HC instrument cannot measure burden, as it is not one of the goals of this instrument. A study performed by Ankri et al. in 2005 (11) examined the relationships between the three factors of the Zarit Burden scale 22-item and the situation of the dyad client-informal caregiver using items from the interRAI HC. The study confirmed the need for a thorough gerontological evaluation including the knowledge of the informal caregivers' situation, in order to assess burden as well as their specific needs and expectations. A new instrument specific for the informal caregiver is currently being developed by interRAI with the purpose of measuring aspects of caregiving as well as to evaluate the informal caregiver's perceived burden.

The advantages of the application of the interRAI HC instrument to analyze these determinants of burden were two-fold: we were able to test a large number of variables for association with informal caregiver's burden, and we were able to stratify the population based on the interRAI scales to account for functional and cognitive impairment. A stratification of the population based on these scales allowed for the refining of the results according to these impairment levels: mild, moderate and severe impairment.

By assessing clients with the interRAI HC and analyzing the results of the scales, clients could be identified in different stages of impairment, as well as the informal caregivers with different levels of burden. The results from the analysis were consistent with Pearlin's Stress Model, which explains that burden should be viewed as a process that progresses as impairment increases.

The results showed that the only common determinants for all three populations were informal caregiver being the adult child, which is an element from the Role Theory, and cohabitation. This means that adult children living with their frail older parent are the highest risk group for burden. This finding is consistent with previous research, since adult children often have to care for others (e.g. their own children) and also have an employment [12, 13]. Behavioral problems, depressive symptoms,

previous admissions to nursing homes and risk of falls were risk factors for burden in the population with severe impairment. Risk of falls and IADL impairment were significant for the population with mild impairment. For the sub-group with moderate impairment, depression and conflict with family members were the significant determinants.

The results of this chapter provide tools for professional caregivers and policy makers to identify frail older people in the community for whom informal caregivers might be at risk of burden. Caregivers would be able to identify clients whose informal caregivers are in need of extra support in order to improve their situation. As already known, burden is a major risk factor for nursing home placement [14, 15, 16] and informal caregivers of older people with a high level of impairment as well as depression, usually have high burden. Home care interventions should target these risk clients with effective interventions to avoid or to decrease their informal caregivers' burden and prevent clients from early institutionalization.

A potential operationalization of the results of this study can be performed by means of a risk algorythm for burden. The algorithm can be constructed with the interRAI HC items which were significant in this study, for the different levels of impairment. Professional caregivers would receive the results automatically after filling out the assessment. This type of algorithm is called an interRAI CAP (Client Assessment Protocol). Professional caregivers would then be informed when the informal caregiver has a potential risk of burden and they would have an indication of the level of this risk. The three steps to create an interRAI CAP in order to identify people at risk of a condition or to identify people with a certain problem are the following [17]:

1 - A review of relevant scientific literature in order to identify the key determinants of the outcome (in this case: informal caregiver's burden);

2- Use of existing interRAI datasets to construct models of prediction of the outcome;

3- Summary of expert opinion by interRAI members and other experts to generate specific guidelines for the CAP. Feedback is useful to ensure face, content, and construct validity of the CAP and to ensure that the CAP contents are relevant to clinicians and to social care providers.

InterRAI already has a CAP called Brittle Support, which is an indication of the availability of informal care. It is calculated by an algorithm with the following variables: client lives alone or not, total hours alone at home, variables about capacity for IADL functioning and presence of informal caregiver. The existing interRAI CAP does not evaluate the risk of burden of the informal caregiver.

Step 1 has been already performed and there are systematic reviews available for the predictors of burden [18]. Our prediction model (step 2) has the advantage of being adjusted for different types of sub-populations and of using a combination of two frameworks: the Stress Process model and the Role Theory. The next step will be to design an algorithm based upon the model predictions (odds ratios) which are adjusted for these sub-populations. This algorithm should then be tested in different countries to evaluate whether the outcomes of the CAP indeed identify clients for whom the informal caregivers perceive burden. For this step, it would be necessary that these tests also include the Zarit Burden Interview.

Step 3 would then follow by proposing the CAP model to a group of members of interRAI, responsible for the validation of the algorithms. They would discuss the validity of the algorithm as well as the relevance of its outcome levels (e.g. prevention, priority or high priority). The guidelines for the CAP would be written by experts in the field.

The effectiveness of home care interventions in delaying or avoiding institutionalization of frail older people

Chapter 5 analyzed the risk of institutionalization of frail older people receiving interventions in relation to a comparison group. In this chapter, the stratification of the population happened on the basis of the stratification in chapter 4, but with an adaptation, using the interRAI scales ADLH and CPS2. The analysis in this research question is based upon the refinement of the stratification strategy with the interRAI scales performed in the previous study. For this research question, the study population and the comparison group were both stratified according to two impairment levels: mild impairment and moderate to severe impairment. The two groups were chosen to ensure that there was enough level of differences between the clients' profiles in the sub-groups.

The aim of this chapter was to evaluate the effect of innovative home care interventions to keep frail older people at home. Identifying the most effective interventions is essential to make policy decisions. Our study not only aimed at analysing whether interventions had an effect on delaying institutionalization at a 6-month follow-up period, but also at identifying for which type of population these interventions were effective.

The results from this study identified the interventions which kept frail older people at home longer than in the comparison group. Case management, as a multi-component intervention, in combination with rehabilitation services, came out as an effective type of intervention for a population with mild impairment and for a population with moderate to severe impairment. The same results were found for projects providing only occupational therapy at home. Case management in combination with only occupational therapy was effective for the sub-population with mild impairment, as well as case management with occupational therapy and psychological support.

The results from this chapter can help policy makers to decide which interventions to foster and for which target populations they should be implemented, as well as to organize interventions tailored to their client population in order to avoid institutionalization.

Even though the goal of the interventions was to avoid institutionalization, sometimes nursing home placement is the only suitable outcome for an older person. This can be the case for older people with very high needs for whom it is not viable anymore to stay at home. In this case, institutionalization can be a 'desired' outcome. This was the case in our research for clients needing night care interventions. These clients receive regular care at home by professional caregivers or informal carers during daytime and still need assistance during the night. This assistance can be in the form of supervision, emotional support or physical help for ADLs. As night assistance can be very demanding from informal caregivers, organizations offering night care interventions took over this care. As expected, these cllients are admitted to a nursing home sooner than clients in the comparison group. These interventions were not effective at avoiding institutionalization but may have helped as a respite alternative for informal caregivers.

The description of the case-mix of home care clients and a comparison with clients in residential setting

Chapter 6 described the case-mix of clients receiving home care interventions and compared it to the case-mix of clients being admitted into residential setting. As interventions in our study were designed to keep frail older people at home longer, clients receiving these interventions should have similar characteristics to clients in residential care. This comparison was useful to identify whether interventions aiming at delaying nursing home admission of older people were effectively reaching people with a certain risk of institutionalization. Frail older people receiving home care with a similar profile as frail older people already in residential care should be the ones targeted by these interventions. This is important information in order to create

policies for the eligibility of clients for these home care interventions and also to help plan staff and resources in the community.

The results from the case-mix indexes (CMI) for our home care population were comparable with the CMIs from clients entering residential care but the proportions varied. As in Shugarman (2000), we could also find very resource intense clients in our sample still living at home (medium and high rehabilitation groups RB and RC) as well as clients with high physical ADL care needs (PE). These older people still manage to stay at home while most other people with the same profile are living in a residential setting. These results are also comparable to the samples from a joint OECD and European Union report from 2013 [20].

In our study population, clients in the lowest group of resource utilization (PA) still had ADL and IADL needs, and some clients showed mild cognitive impairment (CPS=2). According to the results, clients not having high ADL, IADL or cognitive problems were still in need of aid because of loneliness or depressive symptoms. These clients were also at risk of institutionalization and needed the help from home care interventions.

The study showed that the RUG-III system offers possibilities to identify groups of clients by their resource utilization. Clients who have intense resource use are often found in residential setting but in the population of our study, these clients were still remaining at home, receiving rehabilitation therapies. These results pointed out the importance of the availability of these therapies at home or in short-term rehabilitation centers. The findings from this research are in line with the results from chapter 5 where projects providing these therapies were effective at avoiding institutionalization. The study on the resource utilization can help organizations identify the use of resources of clients and may help to determine eligibility to residential care. If clients are grouped in very low resource utilization groups, it means that they use a low level of resources and most likely do not need to be placed in a nursing home. By means of the interRAI HC assessment, professional caregivers can identify whether other problem situations are occurring such as loneliness,

isolation or depression and can provide services or make referrals to cover the clients' needs.

Innovative home care interventions can only be effective if they target the right clients. These clients are the ones who are at risk of institutionalization and they can be compared with clients being institutionalized. By using the interRAI HC instrument, the resource utilization of both populations could be calculated and compared.

As the RUG-system analyses the actual utilization of services, caregivers have to be aware whether clients are receiving the services they need. Underutilization of services should be avoided. It is the responsibility of caregivers to identify the clients' needs and organize and offer them the help they should be receiving.

Table 1 provides a short summary of the results of all studies in this PhD thesis. In the light of these results, we can make some recommendations for organizations, for policy makers and for future research.

Table 1: Summary of results

Study	Design	Main findings	Implications
The use of the interRAI HC instrument to evaluate interventions in the community	Systematic review	Most studies pointed out the interRAI HC as useful for care planning, care continuity, data sharing and benchmarking. Other advantages: - validity, - useful outcome measures, - makes it possible to identify clients' care needs - standardization - adequate for case management	The interRAI HC instrument can be recommended to be used in research to evaluate interventions. The validated output from the instrument (CAPs, scales, RUG III) can also be considered as useful tools for evaluation and comparisons.

		-suitable for benchmarking Some disadvantages; - extensive training needed to learn how to make the assessment - long time needed for first assessments	
The determinants of informal caregivers' burden	Cross-sectional	By applying the interRAI HC instrument, several variables were tested from the Stress Process model and the Role Theory. Two determinants were significantly associated with burden for all three sub-groups of impairment (mild, moderate and severe): cohabitation and the informal caregiver being the adult child.	Construction of a CAP to identify informal caregiver's at risk of burden at different levels: low risk and high risk, as well as already perceiving burden. This CAP will take into account the different levels of impairment (Stress Process model) and informal caregivers' role (Role Theory).

		Other determinants: For mild impairment: IADL performance and risk of falls. Moderate impairment: Conflictual relationship with family and depressive symptoms. Severe impairment; the presence of behavioral problems, previous admissions to nursing homes, risk of falls and depressive symptoms.	
The effectiveness of innovative interventions to delay or avoid institutionalization	Quasi experimental and longitudinal	For the subgroup with mild impairment, the most effective interventions were case management (CM) with psychological support and occupational therapy (OT), CM and OT, OT for people	The study showed which interventions have an effect on avoiding nursing home placement of frail older people with different levels of impairment. The goal is

		with visual impairment and CM in a residential setting with rehabilitation services. Interventions providing only OT also showed a certain level of effectiveness at avoiding institutionalization. For the subgroup of people with moderate to severe impairment: CM in a residential setting with rehabilitation services and OT interventions were effective. Night support at home with full supervision had a higher risk of institutionalization than the comparison group.	to finance these interventions in Belgium as they are less costly than residential care. Case management came out as one of the most effective interventions, and the combination with the use of a comprehensive assessment as the interRAI HC can show positive effects as seen in the first study (systematic review).

The comparison of the case-mix of home care clients and clients being admitted into residential care	Quasi experimental and longitudinal	The case-mix indexes (CMIs) of clients in home care and clients being admitted to residential care showed a large variability across the RUG categories (low, medium and high intense resource utilization groups). The overlap across settings mean that some low resource intense clients are also in nursing homes while some high resource intense clients manage to remain at home. These results are comparable to the RUG-III distribution from studies in other countries. Interventions designed to avoid early institutionalization should also target clients not having major ADL, IADL or cognitive problems but who have	An advice for interRAI would be to include the Depression scale (DRS) in the RUG-III/HC algorithm, as well as an item about psychotherapies. This is an important result from our study, showing that many clients being institutionalized at low levels of ADL, IADL or cognitive impairment, showed symptoms of depression, loneliness or isolation. As these results are in line with the results from the previous study showing the effectiveness of home care interventions, it is important to take into account the clients' CMI at the entry point of residential care. The RUG-III CMI can give a valid indication of a client's eligibility to residential care.

		problems of loneliness, isolation or depression. The results also show the importance of the availability of rehabilitation services in the community setting, allowing frail older people to follow these therapies at home and stay longer in the community. This result is in line with the previous study about the effectiveness of interventions.	

Implications for organizations

The interRAI HC is a comprehensive geriatric instrument which has been validated in several countries. The predictive value of its outcomes such as institutionalization (MAPLE scale), mortality (CHESS scale), risk situations (CAPs) and other adverse outcomes (pressure ulcers, depression, social isolation, etc.) is of essential value to care professionals in different settings [3, 20]. By means of these predictive outcomes, caregivers can construct care plans for their clients. It is thereforerecommended that organizations use these outcomes in their daily practice and that the instrument is filled out every six months or whenever necessary to evaluate the evolution of these outcomes.

In the home care setting, a shared electronic file can mean that caregivers can share information on the clients' situation and care plans. The use of an ICT tool to fill out the interRAI HC instrument and to share the information is crucial in order to enable all caregivers to view the results of the assessment and make a joint care plan. Since older people in the community can be admitted to a hospital or go for a short-stay in a nursing home, it is important that the data in the ICT system can follow the client. This allows for continuity of care. In Belgium, caregivers can fill out the instrument electronically and simultaneously so that each caregiver can have theirsaying on the way they view the client's situation. Multidisciplinary completion improves concertation and the construction of a care plan. The interRAI HC can also enable continuity of care and transfer of information across organizations and settings. Organizations should be willing to use this instrument to enable multidisciplinarity and information sharing. Moreover, investing in ICT is important, as well as providing time available for concertation.

In order to be effective, organizations should target the right population who really need their interventions. To identify the right target population, these organizations can use the interRAI Home Care instrument as a tool of assessment. The instrument

takes into account the whole situation of the older person so it can identify risk situations and problems, as well as the capacity of older persons to stay at home independently or with additional help. A comprehensive geriatric assessment is thus essential so that professional caregivers can make a thorough evaluation of their clients' potential.

In this PhD thesis, only older people considered by professional caregivers to be frail and at risk of institutionalization were included. This population can be very heterogene as clients can be at risk of institutionalization and not be very frail (Edmonton Frailty Scale cut off=6 (21)). This is the case for older people who feel very lonely at home, who have psychosocial problems or do not have any available informal caregiver as well, as for older people who have mild functional problems but are at risk of nursing home placement due to crisis situation. Organizations included clients in the interventions according to their needs. Some interventions only targeted very frail clients at high risk of nursing home placement (night care and day care interventions) and other interventions such as psychological support, occupational therapy and case management in combination with other interventions targeted clients with a wider range of frailty. The effectiveness of the interventions could only be explained if the design of the study allowed for this heterogeneity in the profile of the clients. The stratification of the study population showed to be an important strategy to account for these differences. Organisations offering interventions should use a comprehensive assessment to identify clients and target their interventions according to the different profiles of their clients.

In our study, the interRAI HC showed to be a suitable instrument for case management purposes. Home care organizations delivering case management can apply this instrument in their practice to improve continuity of care and care coordination, as well as to foster collaboration between organizations and caregivers. In the qualitative analysis of the study, a normative grid with 23 components was used, based on the Chronic Care Model (22) to evaluate the case management projects. One of the criteria for case management interventions was

to provide feedback to the frail older persons' general practitioners (GPs). This criterion turned out to be an important component in the multiple correspondence analysis (MCA) and it was identified as a proxy of structured inter-professional work (23). The organizations offering case management had to demonstrate whether they provided feedback to the general practitioners about the results of the interRAI HC (CAPs and scales) and about the results of their intervention. Organizations meeting this criteria showed higher awareness of the importance of the use of a multicomponent geriatric assessment tool (the interRAI Home Care) and the importance of sharing information in a structured and systematic way. As the incentives provided to GPs and geriatricians for their participation in the interventions was limited, GPs and geriatricians did not fill out the assessments themselves. They only provided information about their clients, in case the nurse (usually the case manager) contacted them for information. In cases of complex care, which requires a more intense type of case management, general practitioners were invited to multidisciplinary meetings about the clients and they were often present. During these meetings, in which participants focus on the care plan, the outcomes of the interRAI instrument (CAPs and scales) play an important role (4).

In this PhD thesis, case management showed to be effective in maintaining older people at home and delaying institutionalization. Organizations delivering case management should find strategies to support and motivate GPs and geriatricians to fill out the interRAI HC of their clients in a multidisciplinary way and to involve them in the intervention. As GPs and geriatricians often detect complex situations at home and recommend services to their clients, they are key professionals to make referrals to interventions such as case management. Feedback from the organization delivering the interventions to the GP or geriatrician is important in order to ensure the follow-up of the situation and to guarantee continuity of care. The interRAI HC can be a support tool for an integrative approach to the care for clients, especially due to its comprehensiveness, covering many of the components of the International Classification of Functioning, Disability and Health (ICF) (24). The 27 CAPs of the

interRAI HC, also fitting well with the components of the ICF, are important tools to help design a comprehensive and multidisciplinary care plan to the clients.

This thesis pointed out that home care organizations have an important role in helping older people stay at home longer. Their role is to care for the older people, offering support when needed, also to informal caregivers. Applying the interRAI HC can help identify most vulnerable clients who need an intervention imminently as well as informal caregivers with a high risk of burden.

Moreover, organizations can apply the instrument to assess eligibility to nursing home placement. They can observe whether clients have very high ADL needs or cognitive problems and also check their social situation. If the needs are too high, such as night care at home, nursing home placement within a short period of time may be inevitable. In other cases, for people with lower needs, organizations should try to offer services to meet these needs allowing them to stay at home longer.

Implications for policy makers

It is essential for policy makers to have a solid base for their decisions. The results from this thesis can help them to plan and foster interventions to avoid institutionalization of frail older people. As the costs of residential care are often higher than the costs of community care [25,26], home care interventions should be fostered and should target the right people so that older persons can remain at home longer.

This thesis showed the benefits of a comprehensive geriatric assessment embeded in an electronic platform. Policy makers can enable continuity of care by promoting the interRAI Suite of instruments, which can be used in different settings, as well as foster the use of ICT to share clients' information. Financing ICT, training and time for filling out the assessment and concertation are important issues, already pointed out in this research. Organizations need to feel supported to implement and use the assessment. The benefits of the use of the assessment will keep organizations

motivated in the future but in the initial phase, support from the government and sectors is crucial.

The implementation of a case-mix system such as the RUG III in the home care setting and in the residential setting would enable policy makers to evaluate the case-mix of clients in both settings and compare them. It is important to know which resources clients mostly use at home and in the residential setting in order to plan workforce, therapies and services to clients. The RUG III case-mix can also vary according to regions in a country because of the availability of services and access to care and this is also important information for policy. A region where a few clients at home receive rehabilitation therapies and where most of the clients receiving therapies are already institutionalized could mean that these therapies are not available at home. Also regions where most clients with dementia are already institutionalized could point out the lack of day care centers or community services available for people with dementia. This is important information in order to plan services at home to meet the clients' needs.

This thesis also showed the importance of supporting informal caregivers as they are valuable partners in the care for older people. They should not be seen as a subsitution for formal care [28-30]. Ideally, when necessary, formal care should complement informal care so that informal caregivers can feel supported. Policy makers can foster interventions to empower informal carers in their daily care activities so that caring at home is still viable for them. Policy makers can also foster the provision of information to make informal caregivers aware of the risk of burden which increases as impairment increases.

Implications for research

The following aspects can be seen as the main contributions of this PhD to the field of scientific research on the evaluation of interventions in community care:

- By means of a systematic literature review, our study reported the application, as well as the advantages and disadvantages of using the interRAI Home Care instrument in the evaluation of interventions in the community. This is the first literature review to be performed about any of the interRAI HC instruments as a tool for evaluation. The review can help researchers to build interventional studies in the future, showing how to apply the instrument for the evaluation of different types of interventions, as well as how to avoid or overcome pitfalls which may undermine their research. In the review we concluded that some studies did not target the right population (people were not frail enough) or the intervention was usually evaluated for a whole population with diverse characteristics and levels of impairment. The stratification of the study population can be a valuable and robust strategy to perform impact evaluation for different types of clients, as interventions can have different effect depending on the level of impairment of the study population.

- To our knowledge, this is the first study in which the concept of objective burden, impairment profiles, characteristics of informal caregivers and frail older people are combined using several items from the interRAI HC for an in depth analysis of perceived burden. The study applied two frameworks – the Pearlin Stress model and the Role theory - to explain perceived burden by informal caregivers. The study showed that burden is not a static concept but progresses with impairment and that a whole population in the community should not be analyzed as being 'whole' but rather in sub-groups of impairment. For each sub-group of impairment, other risk factors applied and the burden was higher at higher impairment. Our study was

cross-sectional but, by using the sub-grouping of the population, burden showed to be progressive. Future models for prediction of burden should study further this dynamic process and take into account the progression of impairment. Older people and informal caregivers could be followed up using the interRAI HC instrument and the Zarit scale. Curves of impairment and perceived burden could be contructed to explore whether they both follow a pattern. The effect of home care interventions aiming at decreasing burden could then be evaluated.

- The classification of the population in sub-groups of impairment was an essential part of the evaluation of the home care interventions, in which we concluded that some interventions are more suitable for a certain type of population profile. By sub-grouping clients according to the validated interRAI scales, it was possible to identify the effect of the intervention for different types of clients' profiles, as the population in community care is broad and has different characteristics. By using the interRAI scales, the target population could be clearly identified. This information is useful for future studies to help finding the target population or strata of the population which are most suitable for the evaluation of different types of interventions.
- The application of the RUG-III/HC was an added-value for this research since it made possible to analyze the case-mix of clients living at home at the start of the intervention and of clients leaving permanently for residential care. The RUG-III is a valid algorythm to identify the resources used (in time and costs) and can be used for financing care. By applying this algorythm to our study population, it was possible to show that clients being admitted to residential care are at a greater level of service utilization and that it can be too costly to keep these clients in the community. Clients being institutionalized with lower resource utilization should ideally remain in the community, but these clients have often other problems like social isolation, loneliness or depression. Researchers could apply the RUG-III/HC

as an algorithm for eligibility to nursing home placement, but should also consider the client's social situation, as it is not included in the algorithm of the RUG-III/HC. Another important interRAI outcome variable lacking in the algorithm of the RUG for home care is the depression scale. As some of the interventions in our sample were targeting people with depressive symptoms, the RUG-III/HC could not take into account their situation. The RUG-III/LTCF for residential care has the depression scale in it, but not the RUG-III/HC. Our advice for interRAI would be to add this item to the RUG-III/HC algorithm at the base of the code, so that people with depressive symptoms in the lower categories of the RUGs can also be triggered.

Future research

Future research should evaluate the effect of case management interventions in home care for a longer period than 6 months because some interventions may have a more delayed effect than others. As caregivers delivering the interventions need time to mature and adapt to the context of the intervention, as well as clients and family members need time to adapt to changing situations in relation to care paths, a longer follow up period would be advisable for evaluation studies. As coordination of services can take some time to be launched, and the implementation of a care plan can be time consuming, interventions involving case management may not show effects in the short term, especially for clients with higher impairment. Future studies should analyze the medium-long term effect of these interventions, as well as study the dynamics case management can bring into the care system around the client. The purpose can be to explore whether professional caregivers indeed keep up or enlarge their collaboration as a result of case management. Moreover, the role of the informal caregiver should be further evaluated as to their involvement in the process of case management, and as to the impact of collaboration on avoiding or delaying nursing home admission.

In addition, future research should be conducted to examine the quality of care at home and its relation to clients' quality of life. Delaying nursing home placement is an important effect, but another essential issue is to evaluate how the intervention has an effect on the client's quality of life and on informal caregivers' burden.

Another interesting and important topic for research is the use of the interRAI HC instrument for care planning and as a measurement of quality of care. As care planning is crucial in case management, it would be important to learn how the interRAI HC instrument can improve coordination of care as well as the quality of the delivered care to the clients. This could be done by performing a mixed method study on the use of the CAPs (Client Assessment Protocols), which are triggers for risks or problem situations on several domains (physical functioning, clinical, social, etc.). The CAPs offer guidelines based on best practices to tackle these risks and problems. By studying how the CAPs are used in practice by caregivers, researchers can evaluate the effectiveness of the use of the CAPs for care planning and the benefits they may bring for the care outcomes. As the interRAI HC instrument provides risk adjusted Quality Indicators, the quality of care can be measured, which allows for the identification of levels of quality of care in several domains, as well as allowing for benchmarking across organizations. The hypothesis would be that, if caregivers apply the CAPs and their best practices guidelines in their care planning, quality of care would be higher.

This thesis has strengths and limitations, which should be mentioned.

Strengths

The fact that our study used a comprehensive assessment instrument with proven validity and reliability and that the outcomes from this instrument were applied in the stratification of the study population in this thesis, gave us a robust basis for the analysis of the determinants of burden and risk of institutionalization.

Moreover, the use of the interRAI HC enabled many possible determinants to be explored in the study of burden (e.g. behavioral problems, risk of falls, previous admissions to nursing homes, conflict with family members, among others), making it possible to combine two frameworks in this study: the Stress Process Model and the Role Theory.

Although our dataset for the study of burden had challenges limiting the ability to conduct longitudinal analysis, it should be recognized that the current dataset is the largest currently available containing data on the interRAI HC and data on the Zarit Burden scale.

In the study of the risk of institutionalization, a major strength was the availability of data from the national registry database CIN-IMA, which has comprehensive data on reimbursed health care services and medication consumption for the intervention group and the comparison group. Another strength of this research is the large sample size of the study population and of the comparison group from the CIN-IMA database.

Limitations

The fact that the study sample consisted of frail older people who had been selected by the projects themselves is a limitation of the research. As randomization was not possible, a bias may be present in the study. Due to the fact that not all frail older

people in Belgium received interventions, and not all older people in the general population are as frail as the people in the study, our sample is not representative for all older people in Belgium. However, in order to evaluate the effect of interventions, the criteria of frailty in the study population was essential in order to capture people with at least a certain level of risk of institutionalization.

Another limitation is the fact that not all variables collected in the study population were collected in the comparison group. This limitation was overcome by using as a comparison group a large registry database of care and drug consumption (CIN-IMA) and by matching the combinations of the common variables between both groups. In the last study about the RUG-III, this limitation was overcome by the creation of a control group.

The study of the burden of the informal caregiver had a cross-sectional design. Longitudinal data would allow testing the dynamics of the change in informal caregivers' burden according to changes in older person's and informal caregiver's situation. This type of study can still be performed in the future because we have now several measurements for each client and informal caregiver.

Conclusion

The interRAI HC instrument proved to be a valid instrument to be used in the evaluation of home care interventions. Furthermore, the use of the interRAI HC can improve continuity of care and concertation towards a care plan. The study pointed out the most effective interventions to keep frail older people longer at home and the determinants of burden of informal caregivers. By tackling the problem of burden and by offering clients the interventions most suitable for them, avoiding institutionalization can be accomplished.

List of Abbreviations

RUG-III HC – Resource Utilization Groups III Home Care

MAPLE scale – Methods for Assigning Priority Levels scale

CHESS scale – Changes in Health and End-stage disease, Symptoms and Signs scale

GPs – General practiotioners

CAPs – Client Assessment Protocols

MCA – Multiple correspondence analysis

CIN-IMA database – health consumption database of the Inter-Mutuality Agency

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Personal Contribution

The author of this PhD thesis drafted the introduction, the scientific articles and the discussion of this thesis. The author also carried out the analysis of 3 of the articles and collaborated together with Sophie Cès and Jean Macq for the analysis of the article about the effect of the interventions on institutionalization. All authors gave their final approval for each of the articles to be published.

Conflict of Interest

The author of this PhD thesis declares to have no conflict of interest in funding,

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List of Abbreviations, Curriculum Vitae, List of Publications and Appendices

List of Abbreviations

ADL: Activities of Daily Living

ADLH: Hierarchical Activities of Daily Living scale

CAPs: Client Assessment Protocols

CGA : Comprehensive Geriatric Assessment

CHESS scale: Changes in Health and End-stage disease, Symptoms and Signs scale

CIN-IMA database: health consumption database of the Inter-Mutuality Agency

CMI: Case-mix index

CPS2: InterRAI Cognitive Performance scale 2

DRS: interRAI Depression Rating Scale

GPs : General practiotioners

interRAI HC: interRAI Home Care instrument

InterRAI LTCF: interRAI Long Term Care Facilities instrument

IADL: Instrumental Activities of Daily Living

IADLP: Instrumental Activities of Daily Living Performance scale

MAPLE scale : Methods for Assigning Priority Levels scale

MCA : Multiple correspondence analysis

MDS : Minimum Data Set

MMSE: Mini-Mental State Examination

NIHDI: National Institute for Health and Disability Insurance

OECD: Organisation for Economic Co-operation and Development

RUG-III/HC: Resource Utilization Groups III Home Care

RUG-III/LTCF : Resource Utilization Groups III Long Term Care Facilities

WHO: World Health Organization

WHO-QOL-8: World Health Organization Quality of Life instrument 8

ZBI 12: Zarit Burden Interview - 12 items

CURRICULUM VITAE

Johanna de Almeida Mello was born in Belo Horizonte, a city in the Southeast of Brazil, on June 12 1973. In Brazil, she completed her first 3 years of studies in Civil Engineering, but then she moved to Belgium in 1997. She then decided to study Applied Economics at the KULeuven and obtained her Master's degree in 2001. In 2002, Johanna started working as a researcher at the Faculty of Applied Economics of the KU Leuven and in 2006 she started her career at LUCAS, Centre for Care Research and Consultancy. Johanna firstly conducted research on small scale living units for persons with dementia and since 2007 she has been involved in research about the interRAI Suite of instruments. Her PhD on the use of the interRAI Home Care instrument in the evaluation of care for frail older people, was supervised by prof. dr. Anja Declercq and prof. dr. Chantal Van Audenhove.

List of publications and presentations (from Lirias)

- IT (Articles in internationally reviewed academic journals)

de Almeida Mello J., Macq J., Van Durme T., Cès S., Spruytte N., Van Audenhove C., Declercq A. (2017). The determinants of informal caregivers' burden in the care of frail older persons: a dynamic and role-related perspective. *Aging & Mental Health, 21* (8), 838-843.

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Appendix 1 – Zarit Burden Interview 12[1]

Do you feel…?	"Never" (0)	"Rarely" (1)	"Sometimes" (2)	"Quite frequently" (3)	"Nearly always" (4)
That because of the time you spend with your relative, that you don't have enough time for yourself?					
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
Angry when you are around your relative?					
That your relative currently affects your relationship with family members or friends in a negative way?					
Strained when you are around your relative?					
That your health has suffered because of your involvement with your relative?					

[1] Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M: The Zarit Burden Interview: a new short version and screening version. Gerontologist. 2001, 41 (Supplem 5): 652-657. October.

That you don't have as much privacy as you would like because of your relative?					
That your social life has suffered because you are caring for your relative?					
That you have lost control of your life since your relative's illness?					
Uncertain about what to do about your relative?					
You should be doing more for your relative?					
You could do a better job in caring for your relative?					

Appendix 2 –WHOQOL [2]– Validated short version

1. Do you have enough energy for your everyday life?			1. completely 2. mostly 3. moderately 4. a little 5. not at all		
2. Do you have you enough money to meet your needs?			1. completely 2. mostly 3. moderately 4. a little 5. not at all		
How satisfied are you with…	Very satisfied	Satisfied	Neither satisfied nor dissatisfied:	Dissatisfied	Very dissatisfied
3. ... your health ?	1	2	3	4	5
4. ... yourself?	1	2	3	4	5
5. ... your ability to perform your daily living activities?	1	2	3	4	5
6. ... with your personal relationships?	1	2	3	4	5
7. ... the conditions of your living place?	1	2	3	4	5
8. In general, how satisfied are you with your life?	1	2	3	4	5

[2] WHOQOL Group: Development of the World Health Organization WHOQOL-BREF quality of life assessment. Psychol Med. 1998, 28: 551-558

8a. How often do you feel not in control of the important things happening in your life ?	1. Never 2. Seldom 3. Quite often 4. Very often 5. Always
8b. How often do you feel powerless about the things happening in your life?	1. Never 2. Seldom 3. Quite often 4. Very often 5. Always
9. How would you evaluate the overall quality of your life?	1. Very good 2. Good 3. Moyenne 4. Neither poor, nor good 5. Very poor *8. I DON'T KNOW*
10. How do you feel lately? Are you...	1. Very happy? 2. Happy? 3. Neither happy, nor unhappy? 4. Unhappy? 5. Very unhappy? *8. I DON'T KNOW*