## Comprehending the Comprehensive Geriatric Assessment

### Feasibility, outcomes and experiences of frail older people

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Cover illustration: Two roads diverged in a wood by Emma D Westgård

#### **The Road Not Taken**

Two roads diverged in a yellow wood, And sorry I could not travel both And be one traveller, long I stood And looked down one as far as I could To where it bent in the undergrowth;

Then took the other, as just as fair, And having perhaps the better claim, Because it was grassy and wanted wear; Though as for that the passing there Had worn them really about the same,

And both that morning equally lay In leaves no step had trodden black. Oh, I kept the first for another day! Yet knowing how way leads on to way, I doubted if I should ever come back.

I shall be telling this with a sigh Somewhere ages and ages hence: Two roads diverged in a wood, and I— I took the one less travelled by, And that has made all the difference.

Robert Frost (1874–1963).

Poem published in Book Mountain Interval, Henry Hold and Company, New York, 1916

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#### ABSTRACT

Despite existing knowledge on how to approach frail people in health care, the care they receive is commonly not designed to meet their complex needs and support them in maintaining their activities of daily living. One way to support frail older people when needing health care could be to enable them to share their life-stories and communicate their wants and wishes. Learning about a person's social history can be a key element in comprehending older people in their care needs.

**The overall aim** of this thesis was to evaluate the Comprehensive Geriatric Assessment (CGA) for frail older people aged 75 or older and to explore their experiences of care following a CGA.

**Methods:** A pilot study with 30 frail older people ( $\geq$ 75 years) was performed to determine the feasibility of the CGA, the process and procedures, instruments and proof of principle. Participants were included to the CGA intervention group or the control group that received regular medical care. After the pilot was determined to be feasible, the full RCT was carried out with an additional 125 participants. The 155 participants were followed up at one and six months. During the RCT 10 participants from the CGA ward partook in additional qualitative interviews, which explored through narratives 1) what personal resources they had and how they experienced health care services using three dimensional-analysis, and 2) how they experienced receiving a CGA, using a conventional content analysis.

**Results:** Identifying and screening frail older people who might benefit from a CGA was successful, and those receiving the intervention were met by staff practicing increased attention to safety, ADLs, assistive devices, and discharge planning (Study I). The participants to a high extent agreed that the CGA care met their needs (Study II). The CGA participants experienced having a voice when receiving health care services by using their personal resources (Study III), and they felt respected as a person who could communicate, understand and participate in their care (Study IV).

**Conclusion:** CGA provides care that is better adapted to frail older people's needs, as they themselves felt that the care met their needs; however, no statistically significant effects for frail older people receiving care based on CGA were achieved. The lack of additional results supporting the CGA could be due to difficulties performing pragmatic intervention trials in clinical hospital settings leading to a risk of low statistical power. In addition, a CGA during a single hospital stay is probably not enough to have long-term effects, since frail older people are in need of integrated care provided by multidisciplinary teams. To best benefit frail older people when receiving health care, an organized continuum of care is needed. In order to secure the care is based on what people need, a person-centered approach is fundamental.

**Keywords**: Frailty, person-centeredness, historical background, life stories, capability, activities of daily living, well-being, occupation, fragmented care.

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## SAMMANFATTNING PÅ SVENSKA

Trots en ökad kunskap kring sköra äldre personer och deras behov av vård, är vården ofta inte organiserad för att tillgodose de sköra äldre personernas komplexa vårdbehov. När sköra äldre personer söker vård är det av vikt att de har möjlighet att uttrycka sina behov och önskemål, samt att deras livsberättelse tillvaratas. Kunskap om en persons liv och deras bakgrund kan vara en nyckel till att förstå äldre personer och deras behov av vård.

Det övergripande syftet med avhandlingen var att utvärdera ett strukturerat omhändertagande av äldre (på engelska Comprehensive Geriatric Assessment, CGA) för sköra personer 75 år och äldre, samt att utforska deras upplevelser av att få vård enligt CGA. Initialt genomfördes en pilotstudie för att testa genomförbarheten av CGA, där totalt 30 sköra äldre personer medverkade. Dessa fördelades slumpmässigt till en interventionsgrupp som fick vård enligt CGA, och en kontrollgrupp som fick ordinarie medicinsk vård. Pilotstudien visade att interventionen var genomförbar, vilket i sin tur ledde till att en större studie genomfördes. Där deltog ytterligare 125 sköra äldre personer, vilka slumpmässigt fördelades till de två grupperna. De totalt 155 deltagarna följdes upp efter en och sex månader. I samband med uppföljningarna genomfördes också kvalitativa intervjuer med tio av deltagarna som fått vård enligt CGA, med syftet att fånga deltagarnas personliga resurser och livsberättelse, samt deras upplevelser av att erhålla vård enligt CGA.

Resultaten visar att det var fördelaktigt ur flera synvinklar att bedöma och behandla sköra äldre personer enligt CGA. Deltagarna som fick vård enligt CGA riskbedömdes i större utsträckning jämfört med kontrollgruppen, deras hjälpmedelsbehov och förmåga att utföra aktiviteter i dagliga livet uppmärksammades också och det genomfördes i större utsträckning en utskrivningsplanering. Resultaten visade också att de som fått CGA-vården tyckte att vården mötte deras behov i större utsträckning än de som inte fått vård enligt CGA, att deras personliga resurser tillvaratogs, samt att de upplevde sig bli respekterade som personer som hade möjlighet att kommunicera, förstå och delta i sin vård.

Sammanfattningsvis visar avhandlingen att vård enligt CGA är bättre anpassad för sköra äldre personers behov, då de upplevde att vården mötte deras behov. Trots detta kunde inga andra statistiskt säkerställda effekter av CGA påvisas i studierna. Det kan bland annat bero på att det är svårt att genomföra interventionsstudier i klinisk sjukhusmiljö. Vidare kan vårdtiden vara avgörande då en enstaka kortare sjukhusvistelse kanske inte är tillräcklig för att ge en långsiktig och hållbar påverkan på sköra äldre personers hälsa. Sköra äldre personer behöver en integrerad vård som genomförs av multiprofessionella team. En sammanhållen vårdkedja är grundläggande för att få vård som är anpassad till de sköra äldre personernas behov. För att möta de sköra äldre personerna och deras komplexa behov är det också viktigt att vården är personcentrerad.

## LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Westgård T, Ottenvall Hammar I, Holmgren E, Ehrenberg A, Wisten A, Ekdahl W, Dahlin-Ivanoff S, Wilhelmson K. Comprehensive geriatric assessment pilot of a randomized control study in a Swedish acute hospital: a feasibility study. Pilot and Feasibility Studies 2018; 4:41.
- II. Westgård T, Dahlin-Ivanoff S, Andersson Hammar I, Wilhelmson K. Can Comprehensive Geriatric Assessment meet frail older people's needs? Results from the randomized controlled study CGA-Swed. (In manuscript)
- III. Westgård, T, Wilhelmson K, Dahlin-Ivanoff S, Lagerlöf Nilson U. Voices of Ill Frail Older People: Personal resources and experiences of health care services. (In manuscript)
- IV. Westgård T, Wilhelmson K. Dahlin-Ivanoff S, Ottenvall Hammar I. Feeling Respected as a Person: a Qualitative Analysis of Frail Older People's Experiences on an Acute Geriatric Ward Practicing a Comprehensive Geriatric Assessment. Geriatrics; 2019; 4:1.

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### **ABBREVIATIONS**

ADL	Activity of Daily Living			
CI	Confidence Interval			
CGA	Comprehensive Geriatric Assessment			
ED	Emergency Department			
I-ADL	Instrumental Activity of Daily Living			
MCD	Median Change of Deterioration			
MMSE	Mini Mental Status Examination			
OR	Odds Ratio			
ОТ	Occupational Therapy			
P-ADL	Personal Activity of Daily Living			
PCC	Person Centered Care			
РТ	Physical Therapy			
RCT	Randomized Control Trial			
SRH	Self-Rated Health			
WHO	World Health Organization			

## **DEFINITIONS IN SHORT**

Activities of daily living	People's daily self-care activities.		
Capability	The possibilities and type of life people are able to live, or their real opportunity to do and be what they have reason to value (Sen, 2001).		
Frailty	A geriatric set of symptoms characterized by an increased vulnerability because of decreasing biological reserves due to the aging process (Clegg et al., 2013).		
Frail older people	In this thesis defined as adults 75 years or older who have three or more geriatric set symptoms.		
Integrated care	Health care systems that are united to achieve good coordinated care for the patient.		
Occupation	Everything people do to occupy themselves (Townsend, 1997).		
Person-centered	A patient is viewed as a person with personal resources and limitations (Ekman e al., 2011).		
Personal resources	Assets that people have learned from life experience or that are innate.		

## **1 INTRODUCTION**

In this thesis, Comprehensive Geriatric Assessment (CGA) [1, 2] is seen as one way to improve health care for frail older people. Despite existing knowledge on how to approach frail people in health care, the care they receive is commonly not designed to meet their complex needs [3]. To enable older people when they become acutely ill and are at risk due to frailty, a comprehensive method for screening, assessing and providing treatment is needed. This thesis' ambitions is to comprehend the Comprehensive Geriatric Assessment from different angles. Through the use of both quantitative and qualitative methods, frail older people's outcomes were measured and their voices were listened to, to understand their experiences of receiving a CGA. The manner in which old age has been historically constructed impacts the lens in which older people today are viewed and treated in society [4]. Throughout history, a curiosity in the process of aging, health, well-being and how older people can benefit society is well documented [5]. Understanding health care organization and people's experience of health care using a historical approach can give added value to this thesis.

### 1.1 COMPREHENSIVE GERIATRIC ASSESSMENT

The Comprehensive Geriatric Assessment (CGA) is the accepted golden standard for the management of frail older people when acutely admitted to the hospital [2, 6-8]. CGA is a multidisciplinary diagnostic and treatment process that pinpoints medical, psychosocial, and functional limitations in a frail older person in order to develop a comprehensive plan to maximize a person's health and well-being [9, 10]. With a CGA, health care of the frail older person extends beyond the regular medical management of an illness or disease. It entails multidisciplinary and interdisciplinary screenings, assessments and evaluations including but not limited to physical, cognitive, affective, social, and environmental components that can influence a person's health. CGA is based on the principle that the comprehensiveness of a multidisciplinary team will best identify a variety of treatable health problems that could lead to better health and well-being outcomes for frail older people where possible [11, 12].

#### 1.1.1 CARE OUT OF NECESSITY

CGA was first developed in the 1930s in England by Dr. Marjorie Warren, as her response after being assigned to a nearly impossible task of caring for 700 chronically ill patients. The majority of these patients were bedridden and labeled as feeble and incurable. Despite this, Warren assembled a team and performed examinations on all of the patients, while documenting in detail their social histories. Following this comprehensive assessment, a third of the patients were transferred to nursing homes, nearly a quarter of the patients were transferred to psychiatric services, and the remaining 350 were under her care for chronic conditions [13].

Warren advocated for older people's medical rights and need for equal care, and she was unique in her approach when caring for them, seeing her patients not as diseases, but rather as people [14]. In doing so and as part of her vision for a CGA, she re-designed care facilities and made modifications to the hospital environment to better accommodate the physical needs of the older patients with the intent of improving their well-being. She re-organized staff, performed diagnostics and designed therapeutic treatment plans to best address her geriatric patient's needs. She understood and demanded that ill older people should have access to all medical specialist. Finally and perhaps most importantly she organized a multidisciplinary team to support the physicians and nurses already working on the "geriatric" wards. The competences of occupational therapists, physical therapists, speech therapists, podiatrists, social workers, and nursing assistants became fundamental in making up an integrated team. Warren envisioned a multidisciplinary team as necessary for rehabilitating and caring for older patients [13]. Her focus was not just medical, but encompassed a holistic appreciation of frail older people's social, functional, and psychological needs. With her team she observed what resources her patients lacked and established solutions for the easily identifiable and curable problems [12]. Following this comprehensive approach to care, approximately a third of the remaining 350 "incurable" patients were either discharged home or were relocated to residential homes for older people [13].

The CGA model has a fickle history. Despite being deemed as useful with frail older geriatric patients, it lacks a consistent track record of being implemented and practiced. The CGA all but disappeared and lay dormant for many years after Warren's pioneering discovery. The CGA resurfaced again in the 1970's in the United States as an approach to treat the growing number of geriatric United States veterans [15].

#### 1.1.2 NORDIC APPROACH TO CGA

In Sweden after changing the name of care service for older people from longterm medicine to geriatric medicine in 1992, a sort of renaissance toward geriatrics in Sweden and the other Nordic countries occurred. The countries joined forces to further develop gerontology and geriatric medicine with a Nordic perspective. The scholarly geriatricians from the Nordic countries configured the concept of a Nordic "Geriatric Work-Up" as a method to implement a Comprehensive Geriatric Assessment [16]. The aim was to create modern care for older patients that placed less emphasis on disease and medical treatments, and rather stressed social and functional status, which was determined to be equally important.

The Nordic approach further recognized that a multidisciplinary team was necessary and acknowledged that each team member would have their area of expertise, but that all must be dedicated to achieving common goals. Prior to being able to do a "Geriatric Work-Up", the assessment and scales determined to be useful were required to be translated into the different Nordic languages and be tested for validity and reliability [16]. Shortly after this groundwork and planning, to the best of the author's knowledge, the first Swedish Comprehensive Geriatric Assessment RCT study occurred in 1996 (nearly sixty years after its introduction) in Northern Sweden at a university hospital [17].

### 1.2 HISTORICAL FUNDAMENTALS IN THE DEVELOPMENT OF GERIATRIC MEDICINE

To comprehend how we have arrived where we are today, a step back in time while looking at the historical development of geriatrics and geriatric medicine is valuable in the context of this thesis. As early as the seventh-century B.C. it is documented that the Greeks despised the concept of aging, while prizing the attributes of a strong youth. Nevertheless, respect for older philosophers, statesmen and former warriors was common practice, and the wisdom of senior citizens was so highly valued that the city state was controlled by a council of twenty-eight men, aged 60 years or older [18].

Furthermore, history teaches us that for thousands of years the scientists and philosophers studying the aging body also made recommendations so that people could best achieve living a long life in a healthy body and mind. Hippocrates [19] in the mid-fifth century B.C. made methodic observations about older peoples functioning's in daily life, while observing their emotional state, their behavior, the surroundings in which they were living, and their physical status. He noted that chronic diseases occurring in later life typically did not go away and advised older people to keep active with their occupations and to continue in moderation with activities [5, 19].

In the fourth century B.C., Aristotle wrote extensively about the theory of old age and death in a book entitled *On Youth, Old Age, Life and Death, and Respiration* [20]. Aristotle was convinced that life was dependent on the maintenance of heat, which was regulated by the heart. In his theory when the flame is diminished one is old, and if the flame is left undisturbed the fuel will be depleted and the flame will be extinguished [5, 20]. However prior to the final stage of life and morbidity, a branch of Indian medicine called Sushruta Samhita [21] believed that humans had a limited life span and were susceptible to morbific tendencies. Yet, by practicing the science of rejuvenation it was believed that life could be prolonged, so people could better prepare for their afterlife. The science of rejuvenation relied on a diagnosis and prognosis, achieved through observations and predictions, where all aspects of the older person's conditions were considered to extend life.

Aspects of combining religion, medical studies and medical services are also evident throughout Sweden's long history. In 1477, Uppsala University was founded as the first academic institution, including the four faculties of philosophy, theology, law and medical studies. During this time the churches in Sweden managed the services for the poor, the sick, and the frail older people who could not care for themselves and who do not have family support [22]. This practice continued for hundreds of years as the Swedish church oversaw and controlled most hospitals and institutions providing medical care, social services and resources to the old and poor. The church's responsibility for support and care for its parish members, was approved by the crown and was consistent with the Reformation and the Lutheran ideals [22, 23].

Throughout Europe the church assumed a broad place and purpose in people's lives up until the 18<sup>th</sup> century. The church controlled most of the universities, and as a result influenced scholars' intellectual thinking. Critical thinking and philosophical analysis assumed Christian beliefs and dominated teaching in European universities until the 1700s [24]. However, during the enlightenment original thinking and scientific observations with evidence began to emerge. Like the rest of Europe, Sweden's institutions and society in the 1700s began distancing itself from the church due to scientific progress and became less reliant upon it [24]. In 1928, Sweden legally removed the church's influences from the medical sciences and passed the initial hospital law (1928:303). This gave the county councils the responsibility for public health care, including hospital care services, for all residents [25]. This law, now titled the Swedish Health and Medical Services Act, has since then been rewritten numerous times and most recently in 2017 (SFS 2017:30) [26] declaring that good health care is health care that is equal for all the people and must consider an individual's unique values [26].

#### 1.2.1 MODERN DAY GERIATRICS

During the last two centuries the world has seen gains in the sciences, medicine, health care, and industrialization, as well as greater access to resources, resulting in tremendously increasing people's standard of living [27]. An accumulation of these factors has resulted in many people living significantly longer. However geriatrics as a profession is young compared with other professions within medicine, and the first time the word geriatrics was spoken was in 1909. Dr. Ignatz Leo Nascher observed that there was no named specialty for the branch of medicine caring for older people [5, 28]. In 1945, Dr. Warren, the clinical geriatric pioneer and visionary, wrote in The Lancet about how she found it alarming that the medical profession has been so slow at waking up to their responsibilities towards the chronically sick and aging, and that society at large should not be complacent to do so little for this group [29]. She highlighted that the growing aging population was frequently met by a shortage of nurses in hospitals and home help in people's private homes, and warned that the problem was going to worsen. She called upon all who were studying aging people to acknowledge the obvious; that the specialized care and treatment of older people was of great economic significance and justified immediate attention [29].

Despite Warren's pioneering CGA approach, actions advancing the specialty of geriatrics have been slow. Geriatric medicine was labeled as the practice of physicians who failed at the more desirable specialties [30]. It was not until 1965 that the world's first professor of geriatric medicine was appointed in Glasgow, Scotland and Sweden's first geriatric professorship was established in 1967 in Uppsala [31]. The delay in Sweden was in part due to the physicians who could not decide amongst themselves what the new medical specialty should focus on. Therefore they delegated the matter to the politicians who decided that a geriatric professor should focus on the clinical work [32].

#### 1.2.2 SWEDISH GERIATRICS

A study exploring the organization of Swedish geriatric medicine in 2000 found that the organization was very heterogeneous regarding structure, staffing, care, and the use of terminology [33]. The lack of an overall structural plan for the role of geriatric medicine in Swedish health care, allowed the county councils to designate geriatric medicine as they saw fit, and these differences made it nearly impossible to compare different geriatric facilities around the nation. As a result major quality issues were identified and it could not be assured that older people had access to geriatric specialists [33].

To further confound matters, the Ädel reform of 1992 was the result of a commission appointed to find a better way of coping with the growing population of older people. The commission suggested decentralizing Swedish welfare for the care of older people due to an economic crisis [34, 35] and concluded that care of older people should be transferred from the counties to the municipalities. This reform was determined as necessary since parallel organizations were found to be inefficient and care coordination was unnecessarily complicated [35]. With this reform reassigned the responsibility for nursing homes and long-term care to the municipalities, who as a result were required to build their own facilities or pay for facilities providing these services. In part this reform was designed to prevent the "bed blockers" in hospital beds, who were declared ready for discharge, or the municipality would have pay for the use of hospital bed being unnecessarily occupied [36]. As a result, decline in the quality of care provided to older people occurred, since deskilled medical care was being practiced by the municipalities that lacked organizational experience in medical services [35].

Several years later the fate of geriatric medicine was once again a hot topic. In 2005, it was decided that it would remain as a unique specialty and would not become a subspecialty of internal medicine, which resulted in geriatric medicine remaining primarily as a hospital specialty [37]. At the end of 2010, seventy hospitals with 22,000 hospital beds were identified nationally, and approximately 2000 of these were available to geriatric medical units [37]. Geriatric hospital care services are not offered equally throughout Sweden [38]. Compared to the rest of the country, geriatric medicine services are best established at the six university hospitals, while the smaller hospitals typically have only a unit or a ward of organized geriatric service as part of their internal medicine clinics [37]. Currently, there are roughly forty independent geriatric medicine clinics. Otherwise geriatric medicine is a complimentary aspect of internal medicine clinics in Sweden, where acute care wards offer an initial investigation of older people requiring further planning of care, rehabilitation

and/or palliative care [37]. Some out-patient units offer geriatric medical clinics although they are usually designed as memory clinics, and patients can be referred from their primary care physicians to access these services. With regards to long-term care in nursing homes and for older people aging in place in their own homes, primary care and the family physicians are responsible for outpatient geriatric care [37, 39]. Currently, as almost all medical care and especially geriatric medical care in the country is financed publicly, private geriatric medicine clinics are only found in Stockholm [37, 39].

Sweden has a large aging population, and the Central Bureau for Statistics estimates that every fourth person in the Swedish population is expected to be 65 years or older by 2060 [40]. A growing demand for geriatricians exists in health care, however there is a shortage of available positions [37, 39]. Sweden has good intentions for increasing their capacity of geriatric specialists to meet the demands of the future, and 30-40 geriatric medicine specialists are entering the workforce every year. Unfortunately, at the same time an equivalent number of geriatric specialists are preparing to retire (at age 65), so the ratio of geriatricians to patients available to treat and manage the growing population is actually decreasing [37]. Despite evidence supporting CGA [1, 41-44], resources have not been prioritized to support this care approach for ill, frail older people. Lastly, because research on acute geriatric care units and outpatient care modeled on the CGA is severely limited in Sweden [45, 46], we have limited knowledge about using this approach with frail older people, in their continuum of care after discharge from the hospital ward too.

### 1.3 FRAILTY

Historically, older people with multiple illnesses, diseases, and disability were labeled as chronically sick and feeble [29, 47]. The term frailty was established in the medical literature in the late 1980s [48]. Frailty occurs in people whose reserves and ability to resist stressors presented to the body's physiological systems are restricted [49]. It is commonly defined as a geriatric set of symptoms characterized by an increased vulnerability because of the biological reserves decreasing due to the aging process [50]. Being frail is strongly linked to being dependent in activities of daily living and to morbidity, and makes a person more vulnerable and at higher risk of being hospitalized, disabled, and dying [51].

The frail older population is heterogeneous and will not always show the typical symptoms of a disease. They do not fit the criteria of traditional organbased disease classifications [8] assumed in science, medicine and health care. Furthermore treating the complex needs of frail older people is a challenge while delivering health care services [52], since services are not typically adapted to address geriatric frail people's needs when they require a hospital admission. They risk being marginalized when in need of acute medical care due to the lack of geriatric competence and resources [53].

#### 1.3.1 DIFFERENT APPROACHES TO FRAILTY

Frail older people need to be routinely screened and assessed by geriatrically trained staff who use appropriate instruments to identify frailty [54]. However, a controversy surrounding frailty is that there are different views and approaches toward identifying it. One approach is the frailty phenotype, and the other is the Frailty Index. Fried et al. [55] published an operational definition of the frailty syndrome in 2001, using data from the Cardiovascular Health Study to achieve this definition. Out of this data, the phenotype of frailty was established [55]. Frailty was determined to be present when three or more of the five following criteria were fulfilled: unintentional weight loss, reduced grip strength, self-reported exhaustion, slow gait speed and reduced physical activity. Furthermore, a pre-frail state was defined when 1-2 of these criteria are identified. The frailty phenotype has been validated in terms of identifying people who are at risk for falls, hospitalization, disability, and death. However, the frailty phenotype has been criticized as being more suitable for research than for clinical purposes, since muscle strength and gait speed are not always possible to assess, due to the lack of dynamometers to test hand strength and/or due to the lack of space or time to assess gait speed [56]. The frailty phenotype is able to identify people at-risk, however it is not designed to suggest problem areas that may need intervention, and it does not take into account several common geriatric problems related to frailty such as cognition [56], vision, and balance [57-59].

The other approach is the Frailty Index (FI) proposed by Rockwood [60-62]. Since its development in 2001, the FI has been modified several times. The FI is determined by the number of accumulated pre-defined deficits observed in a person which includes their symptoms, diseases, and deficiencies. The higher the calculated FI, the more vulnerability and likelihood that a person is frail, which is associated with severity of illness and proximity to death [63]. The FI uses existing clinical data and can be applied to most health datasets as a comprehensive assessment of health. It has evidence of being a good tool for predicting adverse outcomes of mortality, disability, and cognition [64]. Rockwood et al. [60] also introduced the Clinical Frailty Scale (CFS) as an examination scale to summarize the level of frailty or fitness in an older person, after they had been examined by a geriatrician or experienced clinician. The CFS can be utilized as a judgment tool to screen for frailty and to distinguish degrees of frailty or fitness while roughly quantifying a person's general health status [60].

### 1.4 MODELS OF AGING

When considering an aging person's health, throughout the course of history many different aging models have been promoted. In recent decades, it has been suggested that older people should take responsibility and be accountable for their own aging. Different models demand walking on slightly different paths towards for example Successful Aging, Optimal Aging and Aging Well. The model of Successful Aging, suggests that a person who has little chance of having a disease or a disability resulting from a disease, will age successfully if they maintain high functional capacity related to physical and cognitive status and remain actively engaged throughout life [65, 66]. The model of Optimal Aging entails that a person has the capacity to function physically, functionally, cognitively, emotionally, socially, and spiritually to their satisfaction regardless of medical conditions, feeling satisfied and achieving wellness [67]. The Aging Well [68] model promotes personal behaviors and life-course environments that allow people to experience limited functional declines, specifically those caused by chronic conditions, so that people will remain independent and healthy as they age.

While these aging models have attempted to be comprehensive in nature, the World Health Organization (WHO) recognized that a gap exists globally in how the world's geriatric population is enabled to experience that they could remain active during the process of aging [66, 69]. The model of Active Aging [69] introduced in 2002, was intended to secure that older people would experience health, security and participation when aging. However, this model was found to lack comprehensiveness after 14 years, as ambiguity remained about how policy makers could support people to achieve Active Aging in a world that is so diverse, where resources are dissimilar and unequally distributed [70].

Therefore, in 2014 the WHO proposed Active and Healthy Aging (AHA) [71] as a new framework for optimizing the processes and opportunities to experience health and quality of life while aging. This conceptual framework comprised people's functioning, or capabilities and the body's systems. AHA included a person's well-being, activities, participation and diseases (including frailty) and encompassed the concept of resilience, or a person's ability to adapt to challenges that are physical, psychological or socially based [71]. However, while AHA was taking form and being molded in 2016 the WHO finally decided upon Healthy Aging, abandoning AHA and replacing the Active Aging framework from 2002 [72].

The model of Healthy Aging [72] includes and encompass Active Aging, and is formulated to distance itself from the discussion about the absence of disease in order to achieve aging in good health. Healthy Aging conceptualizes developing and stressing the need for action across multiple sectors to best enable older people to use their resources. Still a work in progress, the model of Healthy Aging is anticipated to be completed in 2020 with the intention of further amplifying the principles of Active Aging, adding the dimension that Healthy Aging is centered on the process of maintaining and developing functional abilities that enable people to experience well-being [72]. In taking this view, older people's functional abilities become the focus as they enable a person to be and do, what they have reason to value [73].

To best comprehend Healthy Aging [73] the components that encompass functional abilities must be understood. Firstly people have intrinsic capacities that make up their physical and mental capacity, and these are used in a person's daily activities. Secondly people have environmental characteristics that affect their functional abilities. Thus, considering functional abilities entails comprehending all the factors in a person's environments, including their health, social policies, attitudes, values and those people with whom they have relationships [72]. In this thesis, the understanding is that in order for a frail older person to experience Healthy Aging, it is essential that they are able to live in an environment that supports and preserves their intrinsic capacities and functional abilities [72, 73]

### 1.5 CAPABILITY TO SUPPORT FRAIL OLDER PEOPLE

Healthy Aging [72, 73] echoes the philosophy of Amartya Sen, who in 1979 developed a theoretical framework called the Capability Approach [74-76]. The original intent of developing this approach was to combine economics and philosophy as a means to explore and understand how a person's well-being might best be measured. Well-being and advantage were examined in the context of a person's ability to do valuable acts or reach valuable states of being [74]. It focuses on the possibilities and type of life people are able to live, which is their capability, or their real opportunity to do and be what they have reason to value. [77]. Sen's Capability Approach provides a basis for understanding frail older people's life situations.

People are their histories, and they must have the capability to say, act upon and narrate, if their capabilities are to become understood by others. Since people's capabilities are reliant on being recognized by others, it is necessary that another person replies and asks questions, supported through communicating and having a dialogue [78]. After identifying what people value, support should be offered for the selection of what they prioritize among the available resources [75]. Supporting frail older people when needing health care could be to enable them to share their life-stories and communicate their wants and wishes. Learning about a person's social history can be a key element in comprehending older people in their care needs, while the information shared demands recognition by another person [79]. These elements could enable frail older people to experience being capable when receiving health care services.

### 1.6 FORMING PARTNERSHIPS WITH FRAIL OLDER PEOPLE NEEDING CARE

In the mid 1950s Carl Rogers [80] developed the notion that his patients should be placing a person at the center of their own care. Further developed over the past seventy years, person-centeredness demands that patients are equal partners in a facilitating environment where they receive support and are enabled to participate by drawing on their strengths through shared decisionmaking, equality and mutual respect [80-82]. When using a person-centered approach, capabilities could become intelligible and recognized by others, thereby increasing the likelihood that a person might experience well-being. This is because a person-centered approach is one where people are viewed holistically, so they are understood, able to communicate and form a partnership with the health care staff responsible for providing them care [83].

In health care using a person-centered approach requires the understanding that patients are people, and that they should not be reduced to just being disease [83]. This approach was comprehended by Dr. Warren already in the 1930s when founding the CGA, as she practiced person-centeredness. By listening to her patients and learning about their histories, she better understood their needs and wants, which supported the team in designing a care plan that was comprehensive [84]. Person-centered care is a process, and it requires training and insightfulness to get to know the unique person. This can be achieved through the allocation of power and accountability while being approachable and flexible, so that the care is organized, integrated and directed towards a person's unique values [85, 86]. A person-centered approach acknowledges the unique expectations a person has, based on their understanding of the situation, and includes their social history and family resources while considering the person's weaknesses and strengths [83].

In health care, different disciplines have different traditions and different uses of terminology to essentially mean the same thing when forming partnerships in the care they give. For example the client-centered approach practiced by occupational therapists first introduced in the 1980s [87] was to enable clients to participate in the occupations they choose to do by including the social and cultural activities that were needed or expected to be done [87, 88]. Patientcentered care sought to focus medical attention on the individual patient's needs and concerns, rather than the physician's. The shift in the medical paradigm from addressing just the pathophysiology and illness-oriented care to other means of knowing and treating the patient emerged in the late 1960s [89]. The biopsychosocial model of patient-centered care was established so medical doctors would considers the patient in their social and living contexts. However, it was viewed as a deviation from the previous doctor-centered paternalistic approach to medical treatment, and the term patient-centered care was seen as a metaphor and was not working in practice when it was first introduced [89].

Forty years later the Institute of Medicine (IOM) [90] declared that patientcentered care was needed if high-quality medical care was to be delivered to all people, citing that healthcare harmed patients too frequently and that potential benefits of care were often lacking [90]. Health and medical care should be a system that guarantees a patient was fully included into every step of their consultation [91]. Most healthcare providers, policymakers and researchers agree that person-centered care represents a shift from a traditional, paternalistic, provider-driven and disease-focused approach towards one that fully integrates the patient's perceptions, needs and experiences, into every phase of a consultation, treatment and follow-up [92]. Through legislation Sweden has supported the shift from the historical medical approach in 2014 with the Patient Act (2014:821) [93]. It has been determined through policy that health and medical care in Swedish society should facilitating people's integrity, capability, freedom, participation and partnership by spelling out that patients are to be informed about their condition and available treatments, and that patients have the right to participate in all decisions about their care [93].

Occupational therapists use a client-centered approach when working together with frail older people by valuing their clients' subjective experiences, and by acknowledging their knowledge, hopes, and autonomy through participation [88]. Occupational therapy is unique from other disciplines in its approaches, as hope and understanding of what is possible and the potential to do and be is greatly emphasized [94]. However, the occupational therapist approach has been criticized for not contemplating contexts of the wider health care team [94], and calls for the profession to change their terminology by renaming client-centered to person-centered are ongoing [95]. This could facilitate better collaboration and coordinated health care in people's transitions between rehabilitation and the community [94]. This slight change in terminology could also have a dramatic effect in clarifying the equal and collaborative partnership occupational therapists have with the frail older people for whom they are providing occupation-focused services [95].

### 1.7 OCCUPATION TO ACHIEVE CAPABILITY

A person-centered approach when focusing on frail older people should contain their occupation. Occupation is everything that people do in their daily life to keep themselves occupied [96, 97]. Since occupation is an allencompassing field, it is often not understood or comprehended as significant. In the 1990s, Occupational Science was established as a new discipline encompassing the knowledge and study of man in activity, and the meaning of human occupation [98]. Occupational science emphasizes the power of occupation and explores how society, inclusion, and participation impact vulnerable people's lives [99], such as frail older people. To understand people (regardless if they are an individual, a group or a population), the undertaking of occupational science is about exploring what occupation means, by understanding the patterns and the relationship occupation has to health [100]. Occupational science considers engagement as it relates to social participation, health and well-being [98]. When older people are considered, their occupations should be understood as they relate to people's history of occupation and Activities of Daily Living as they are in the present [101], because there is a connection between occupation and health [102].

Since 1917, Occupational Therapy has been a discipline focused on gathering information about the patient's past and present occupation, combined with information about their skills, resources, interests and supports to design treatment plans [101]. Through an understanding of occupation, occupational therapy promotes health, well-being and functional activity to enable people with physical, cognitive and/or psychological conditions to participate in society [103] to the best of their capability. Occupational therapists make use of the human sciences, medical sciences, natural sciences, social sciences and technology to support research within occupational sciences. Engagement in occupation is an integral aspect of being human, like Capability and Healthy Aging; doing (i.e., occupation) and being (i.e., humanity) these relationships together form each person's identities, thus making them unique. Comprehending the complexities of meaning and purpose exclusive to the frail older person is of great importance since these people are already vulnerable.

If health care in a society is comprehensive and implemented to include frail older people, so that capability and participation are fostered, people will have the freedom to be and do as they choose, while keeping themselves engaged in the occupations that they value. However if these things are not safeguarded in a society, in an environment or by political acts, occupation can be deprived and/or occupation can become unjust due to the lack of opportunity for a frail older person to engage in occupation [99].

#### 1.7.1 ACTIVITIES OF DAILY LIVING

Understanding occupation can also be explored through activities of daily living. In 1948, at the Conference on the Problems of Aging, scholars and medical clinicians discussed the process of aging and the changes that occur over time which resulted in progressive loss of abilities and a progression towards an increase in death rate [104]. Following this conference a multidisciplinary team lead by Dr. Sidney Katz and Dr. Austin Chinn started a course on the uncharted waters to better understand the progressive losses seen in older people. They designed a study on older people who suffered hip fractures with the purpose of establishing methods for obtaining quantitative information about the progressive loss of abilities [104]. The results of the study established an Index of Independence of Activities of Daily Living (ADL), as a method to evaluate patient's functional independence or dependence in bathing, dressing, going to the toilet, transferring, continence and feeding [104]. The index characterized patterns of functional dependence in ADLs which were then graded on a scale so patients could be compared according to their level of independence in ADLs. Furthermore the progression of deterioration at follow-up assessments was found to be associated with increased rates of mortality [104].

Assessing and measuring ADLs as originally developed by a multidisciplinary team [104] seventy years ago remains relevant and useful today. When considering the health of older people, it is common practice to evaluate activity of daily living, as evidence supports that those presenting as frail are strongly linked as having dependency in ADLs [104]. An ADL assessment most commonly looks at the dependence and need for assistance from another person. Like many other models, frameworks and assessments used with older people, the ways to measure an ADL status are many. In order for data to be accurate and useful for the purpose of planning care and needs, health care providers and practitioners must too have access to valid, reliable, and easily administered instrument suitable for assessing ADLs [105]. To safeguard achieving these results, the ADL staircase was developed by Swedish researchers in the early 1990s as an extension of the original ADL instrument developed by Katz et al. [104]. Following a recent meta-analysis frailty was found to be a significant predictor of incident and worsening ADL and Instrumental Activities of Daily Living (I-ADL) disabilities [106]. Several studies that explored the ADL status of frail community-dwelling people supported and recommended feasible and effective interventions to prevent and preserve ADL amongst vulnerable and frail older people [57, 106]. One step in supporting frail older people would be to use a CGA to assess and

identify ADLs in people who are dependent and frail, by supporting them to maintain or improve their ADLs.

## 2 RATIONALE

Comprehending how health care services should be designed to meet the needs of frail older people when ill and in need of acute medical care services remains a challenge. A lack of consensus exists on several of the topics addressed in this thesis. Although consideration has been made to understand the historical frames that society has built upon over the years, much ambiguity remains surrounding the resources and assessment supporting geriatric medicine. Frailty is not always understood [107-110], Comprehensive Geriatric Assessment is not practiced, and a person-centered approach is not always used with frail older people who experience they were not invited to participate in their care planning or in making health care decisions [111, 112]. Thus health care services delivered may not be based on what the person experiences they need or value [113], which affects their capability and well-being. All of these elements are essential in providing the best possible care so a frail older person can remain capable and engage in meaningful occupation.

The rationale for this thesis is based on the supposition that frail older people can better achieve Healthy Aging if they receive a CGA delivered by a using interdisciplinary multidisciplinary team geriatric screenings. assessments and evaluations, to address physical, cognitive, affective, social and environmental hinders receiving care delivered by staff practicing personcentered care. CGA is based on the principle that by being comprehensive, the multidisciplinary team will identify treatable health problems that could lead to better health and well-being for frail older people, since the focus is on restoring healthy function and independence where possible [11, 12]. Remaining mindful of the historical perspectives regarding aging, geriatrics, and frailty while employing an occupational approach to describe how health care outcomes for older people have historically evolved and what role they play today is pertinent in comprehending how the Comprehensive Geriatric Assessment is useful. The evidence in this thesis is a synthesis and fusion of historical knowledge and definitions with today's tools, assessments, and evidence to support what we have achieved and where gaps and inconsistencies remain. In achieving this, a focus was on people's participation, capability, satisfaction, and use of personal resources to support Healthy Aging. The underlying principles are explored in attempting to comprehend the Comprehensive Geriatric Assessment with frail older people. Supported by qualitative and quantitative evidence, frail older people's experiences of the CGA and health care services were explored and the CGA's feasibility and outcomes it had on ADL independence, well-being and satisfaction for frail older people over time were investigated.

## 3 AIM

The overall aim of this thesis was to evaluate the Comprehensive Geriatric Assessment for frail older people aged 75 or older and to explore their experiences of care following a CGA.

The specific aims were:

- To examine the feasibility of the research procedures and to establish if the participants were assessed in accordance with the CGA.
- To investigate if Comprehensive Geriatric Assessment had an impact on frail older people's activities of daily living (ADL) status, self-rated health, and satisfaction with hospital care after an acute hospital admission.
- To explore how personal resources influence frail older people's experiences of health care services.
- To explore how frail older people experienced receiving CGA on an acute geriatric ward.

## 4 METHODS

In this thesis different methodological approaches were used. Two quantitative studies and two qualitative studies were carried out in order to best fulfil the aims of the thesis, see Table 1. The study setting was a university hospital in the western part of Sweden. All four studies were part of the project "Comprehensive Geriatric Assessment for Frail Older People in Swedish Acute Care Settings (CGA-Swed): A Randomized Controlled Study", a two-armed study which aimed to evaluate if Comprehensive Geriatric Assessment of frail older people in Swedish acute care could lead to maintained independence in everyday activities, health-related quality of life, and life satisfaction, as well as to improved satisfaction with care and reduced health care consumption [59]. Study I was the pilot of the RCT, and Study II explored the RCT's effects on ADLs, SRH, satisfaction with ADL, physical and mental health, and satisfaction with quality of hospital care up to six months later. Study III and Study IV included qualitative interviews with participants who had received CGA in order to explore their experiences of health care.

	Study sample	Study design	Data collection	Analysis
Study I	Frail older people requiring acute medical hospital care (77–96 years) (n=30)	Feasibility and pilot study RCT	Chart review, research assessment tools	Descriptive, independent t- tests
Study II	Frail older people requiring acute medical hospital care (76–98 years) (n=155)	RCT	Chart review, research assessment tools	Chi-square, Odds Ratio (OR)
Study III	Frail older people who had received a CGA (77–95 years) (n=10)	Narratives	Individual interviews	Three- dimensional analysis
Study IV	Frail older people who had received a CGA (77–95 years) (n=10)	Secondary analysis of qualitative data	Individual interviews	Conventional content analysis

Table 1. Overview of the study design approaches

### THE INTERVENTION IN THE CGA-SWED STUDY

#### Intervention group

The intervention was to be admitted to an acute geriatric ward practicing the Comprehensive Geriatric Assessment. These participants received diagnostic and treatment processes addressing their medical, psychological, social, and functional capabilities. The CGA ward had a multidisciplinary team organized and included a geriatrically trained medical doctor, nursing, occupational therapy, and physical therapy services. If necessary, the team would include a nutritionist and a social worker. A person-centered approach [83] was used to individualize the assessment's findings in order to create a tailored discharge care plan. See Figure 1.



Figure 1. Key components of the Comprehensive Geriatric Assessment (CGA). Original figure from publication [59] used with permission according to the Creative Commons Attribution 4.0 International License (http://creativecommons.org/licenses/by-nc-nd/4.0/).

#### Control group

Participants in the control group received normal acute medical care as deemed necessary by the medical ward. Treatments and services provided by multidisciplinary staff are not automatically included on the ward, rather referrals are required from physicians or nursing, if a consultation, assessment or treatment is required for example from an occupational therapist or physical therapist.

#### **Participants**

Participants were frail older people aged 75 and older seeking acute medical care at the emergency department. Inclusion criteria were: acute medical hospital admission via the emergency department,  $\geq$  75 years old, and screened as frail with the FRESH-screen. The exclusion criteria were: admitted via fast track for stroke, acute myocardial infarction, and hip fracture, or needing a higher level of care.

### 4.1 METHODS FOR STUDY I AND II

Eligible candidates for the RCT were identified in the emergency department by the care coordinator (a nurse assistant). The care coordinator was responsible for the recruitment and randomized procedures. Prior to inclusion into the study, potential participants were invited to join. They were informed about the study and were told that participation was voluntary. Information was both verbal and written. An opportunity to ask questions was offered. If they agreed to participate, a consent form was signed by the participant and then a computer-generated number randomization was assigned by the case coordinator. Allocation concealment with a sequentially numbered opaque sealed envelope (SNOSE) was used to randomize participants. Once transferred to the allocated wards, prior to the baseline interview the researcher performed a chart review and then completed the assessments and data collection with the participants on their respective wards. After discharge from the hospital ward, the participants were systematically followed up at one month, six months and twelve months in their home or residence. In this thesis, data from the 12-month follow-up is not included.

### **Participants**

In the full RCT study 178 frail older people were randomized to the control and intervention. After inclusion, fifteen participants were determined as noneligible and an additional eight participants were lost at baseline. All 30 participants from the pilot study (Study I) were carried over and in total 155 participants were included in the RCT (Study II), see Figure 2.

Data collection for the RCT was conducted from March 2016 to January 2020 by licensed health care professionals. Data was collected at baseline, one month, six months and twelve months.


Figure 2. CONSORT diagram for Study I and II.

### 4.1.1 OUTCOMES OF STUDY I AND II

#### Activities of daily living

The primary outcome measure for the RCT was ADLs. It was assessed using the ADL staircase [114], which is an assessment that measures the functional status of five personal ADL (P-ADL) items: bathing, dressing, going to the toilet, transferring, and feeding; and four instrumental (I-ADL) items: shopping, cooking, cleaning, and transportation. The nine items of the ADL staircase [115] are then summed up to measure the participant's independently managed activities. A score of zero is total independence in all activities and a score of nine is total dependence in all activities in the assessment.

#### Self-rated health

One of the secondary outcomes measured was self-rated health (SRH), which was a single question taken from the SF-36 [116]. This question asks a person "In general how would you say your health is?" There are five response options that are scaled as: excellent, very good, good, fair, and poor [116].

#### Satisfaction with ADL and health

An additional secondary outcome was measured by using three questions from the Fugl-Meyer LiSat-11 questionnaire [117]. The purpose of these questions was to explore how satisfied a person subjectively experienced their activities of daily living, physical health, and mental health. Participants were provided with seven options that scaled their level of satisfaction for each question individually. The satisfaction responses were: very unsatisfied, unsatisfied, somewhat unsatisfied, somewhat satisfied, satisfied, very satisfied, does not/cannot answer [117].

#### Satisfaction with hospital care

To measure the participants' perceptions of care quality, eight hospital care questions based on the Pyramid Questionnaire [118, 119] were asked at the 1-month follow-up. Participants were provided with a scale with the following responses to respond to each question: agree completely, agree partly, neither agree nor disagree, disagree, and disagree completely. The proportion of participants being satisfied (agree completely and agree partly) were compared between the intervention and control groups.

# 4.1.2 SAMPLE SIZE, POWER CALCULATION AND STATISTICAL ANALYSIS

The power calculation was based on the primary outcome (ADL, range 0–9), with an assumed loss of 22% to follow-ups based on previous research [58]. To detect a difference between the intervention and control groups with a two-sided test with a significance level of  $\alpha = 0.05$  and 80% power, a sample size of 156 was deemed sufficient to maintain power and was included in the study. The statistical analyses used in Study I were: descriptive statistics, mean, median, number (n), and percent (%). Non-parametric variables between groups using Student's t-test and group comparison were performed with Samples t-test. Analyses used in Study II were: descriptive statistics, mean, number (n), and percent (%). Chi-square and odds ratio (OR) were used to compare the groups. Two-sided significance tests were used throughout both studies' analyses and a value of  $p \leq 0.05$  and a 95% confidence interval (CI) were considered statistically significant.

The intention-to-treat principle (ITT) was used in the analysis of Study II when possible. To handle missing data, imputation based on the median change of deterioration (MCD) between baseline and follow-ups [57] was used. The reasons for this imputation method were that the frail older people were expected to deteriorate over time as a natural course of the aging process, and that deteriorated health often was the reason for not participating in the follow-ups. Worst-case change was imputed for those who died before follow-up. Sensitivity analyses were also performed to test MCD with complete cases to confirm that the results were aligned [120]. Due to contamination in the control group and non-adherence in the intervention group, a subgroup analysis was done on 66 participants in the control group and 55 participants in the intervention group.

## 4.2 METHODS FOR STUDY III AND IV

In Study III and IV, ten participants from the CGA ward were interviewed in their place of residence one month after discharge from hospital. Additional criteria for Study III and IV were scoring 25 or higher on the Mini Mental State (MMS) [121] or being declared as cognitively intact by the CGA physician.

All interviews were audio-recorded and transcribed verbatim by the present author. The researcher asked the participants about their life experiences using open-ended questions, which allowed for them to interpret the questions freely. Furthermore, general questions about hospital and health care experiences were explored and further developed according to the participants' responses. The participants were aged 77–95 and included seven women and three men. The demographics and characteristics of the participants are presented in Table 2.

### Narratives and Three-dimensional space (Study III)

In Study III, the stories collected were commonly narrated by the participants as causally linked events. Therefore in order to analyze the data a narrative analytic procedure called the three-dimensional space was employed to produce comprehensive and explanatory stories [122-124]. The threedimensional space is defined as the interaction, i.e. a personal and social experience; the *continuity*, i.e. the past, present and future dimension; and the situation, i.e. the place of the dimension [122-124]. Keeping in mind the unique historical stories of the participants, methodological concerns for the three-dimensional space [122] surrounding the health care experiences became the lens we used to view and organize the participants' stories and experiences. Using this method and procedure of inquiry enabled us to concentrate on the stories that the participants told about their health care experiences while allowing us to position the stories into categories related to their personal resources. These categories were then further analyzed until subcategories were identified. This dynamic process of connecting disconnected data elements in a coherent, interesting, and explanatory way was the goal of assembling this study's findings [125].

# Secondary analysis and Conventional Content Analysis (Study IV)

In Study IV, the stories and qualitative data from Study III were revisited in a secondary analysis to explore how frail older people experienced receiving CGA on an acute geriatric ward. Through the use of conventional content analysis [126, 127], our focus was to explore and understand the underlying meanings of how people experienced care on the CGA ward. This phenomenon has been sparsely explored and is underdeveloped in the current research regarding recipients' experiences of a CGA. In this analysis, the inquiry focused on how people experienced being hospitalized on a CGA ward, how they experienced they were treated, how they experienced receiving services, and if their expectations and goals were met while receiving care on the CGA ward.

Using a conventional content analysis, the process began with processing the data, which was written text in the form of transcripts. Using these transcripts, words were highlighted to capture key thoughts and concepts. Presumed thoughts and impressions of what the data was revealing were further organized until labels and codes began to emerge. Codes were then organized and sorted into categories to give the data meaning. The process helps researchers in gaining a richer understanding of the phenomenon being explored which is supported by the codes and categories being defined during the data analysis [127]. This inductive approach allowed the discovery of underlying meanings and content [127, 128], so that the large clusters of codes could then be organized and sorted into categories to give the data meaning [129]. Frequent meetings were held by the researchers to discuss emerging data, and to prepare the written report. Direct quotations from the participants were also used to strengthen the findings.

Participant	Age	Gender	Education	Previous occupation	SRH*	Living status
#1	88	Male	Trade school	Electrician	Good	Married, lives with spouse
#2	92	Female	High School	Grocery store: cashier/Painter	Fair	Widow, alone
#3	95	Female	Attended Elementary School	Shoe store: salesperson	Good	Widow, alone
#4	85	Female	High School	School secretary	Good	Widow, alone
#5	91	Female	Elementary School	Fishmonger, bus driver, street kitchen owner	Good	Widow, alone
#6	86	Female	Elementary School	Bakery: salesperson, bus driver	Fair	Married, lives with spouse
#7	77	Female	College	School principle, politician/member of parliament	Very good	Divorced, lives alone
#8	86	Male	Attended High School	Ambulance staff/Fire station dispatcher	Good	Married, lives with spouse
#9	82	Female	Elementary School	Women's clothing: salesperson	Good	Married, lives with spouse
#10	91	Male	Elementary School	Supermarket: executive	Poor	Widower, lives alone

Table 2. Demographics of Participants in Study III and IV

\* Self-rated health, asking "how would you rate your health: excellent, very good, good, fair, or poor".

# **5 ETHICAL CONSIDERATIONS**

This study is a registered clinical trial: ClinicalTrials.gov (NCT02773914). Ethical approval was confirmed by the regional ethics committee (EPN Gbg dn4 899-15). All participants signed informed consent forms and received both written and verbal information about the study prior to their inclusion. The participants were informed about confidentiality and that the data would remain anonymous so that participants could not be identified. Furthermore all participants were informed that they could withdraw from the study and could stop or decline from all data collection procedures at any time.

### Study I and II

There were several ethical issues that needed to be considered related to participation in the CGA intervention study. After being included in the study, the participants received assessments and evaluations according to the routines on the ward they were randomized to. This could result in the participants gaining increased awareness of their impairments and vulnerabilities, especially for the intervention group. Insofar as it was part of ordinary care, this did not imply any additional assessments. However, the data collection for the research study involved some extra assessments, especially for the control group. This could be considered both time-consuming and tiring for the participants. However, the comprehensiveness was expected to result in gains related to treatments and planning after discharge for the CGA recipients. Following the pilot study, we understood that due to the frail state of our participants, some chose to stop data collection due to illness or fatigue. Furthermore, some participants did not like the nature of the questioning or the assessments and were informed that they could choose to skip over different assessments if they were disinterested, or found something to be too invasive or challenging to participate in. Lastly, all participants were given the opportunity to complete the process at a later time, if they chose to do so. These later data collection follow-ups were also offered to be done via telephone if the participants did not want to have a home visit.

For the control group there were also ethical considerations. The control group did not receive a multidisciplinary intervention despite being screened as frail upon admission. Rather, they received normal medical care, which may not have addressed all their comprehensive and complex needs. However, if the researchers found any acute unaddressed needs during the data collections, they supported the participant in contacting health care services, if the participant consented. Furthermore, ethically we could not prevent control participants from receiving care on the CGA ward or any other ward that had an established multidisciplinary team if readmitted to the hospital for acute needs.

### Study III and IV

The interview questions used in Study III and IV were discussed, reviewed, and determined by the researchers to be sensitive and non-threatening for the participants. They were open in nature and allowed the participants to discuss, highlight, and focus on those experiences that they determined most relevant for the interview. Participants were allowed to decline to answer or could terminate the interviews if topics were sensitive. This did not happen, although several participants redirected responses to that which they perceived as more relevant, and expressed their satisfaction and gratitude for receiving a home visit and for being part of a research project, which they found to be worthy, in order to improve care for older people.

## 6 RESULTS

The participants in this thesis are presented in Table 3. They were similar in their demographics regarding sex, age, living status, and education. Participants in Study III and IV had high levels of self-rated health and cognition.

	Study I	Study II	Study III & IV
	n=30	n=155	n=10
Female	60%	58%	70%
Age (years)	86	86.9	87.3
Living alone	57%	64%	60%
Tertiary education*	10%	15.5%	10%
Self-rated health**	43%	30%	70%
Mini Mental State ≤24	43%	49%	0%

Table 3. Demographics of participants

\*Tertiary education: partial or completed university or college. \*\*SRH: excellent/very good/good

## 6.1 STUDY I

In the pilot study, the participants were recruited from the emergency department (ED) over the course of 32 weeks. Thirty people were approached and included, and all met the inclusion criteria and consented to participate. They were then randomized, sixteen into the intervention group and fourteen into the control group. All 30 participants completed the baseline data collection. Chart reviews were performed for all 30 participants comparing intervention and controls.

It was found that structured risk assessment to a higher extent was documented among the intervention group, which was statistically significant compared to the control group in addressing and documenting the risk for falls, nutrition, decubitus ulcers, and ADL status. The chart review showed that occupational therapy services were more often received, which was statistically significant for the intervention group compared with the control.

The inclusion process was frequently delayed due to the lack of available beds on the acute medical wards. Additional control wards were opened during the pilot study to increase inclusion rates. In the early stages of the pilot, it was identified that not all participants were screened with the FRESH-screen in the ED prior to inclusion in the study. Furthermore, it was confirmed by ED staff that the FRESH-screen was used more routinely by staff responsible for discharging patients from the ED, but not by those responsible for admitting patients to the medical wards. Understanding and accepting that the tool's use was not yet a routine among staff, this problem was rectified by adding the FRESH-screen to the baseline questionnaire used by the researchers to confirm that participants met the criteria for frailty and met the inclusion criteria for the study.

The baseline interviews took between 25 and 160 minutes, with a median time of 102 minutes. Data collection often required two, three, and on occasion four visits to the participants to complete the assessments. This was because the participants were too tired or too ill, and because hospital procedures took precedence over data collection.

During the pilot, eighteen 1-month follow-ups were performed. During these follow-ups, it was identified that flexibility in the data collection procedures was needed to keep people in the study. The order of assessment was reorganized, staggering the physical tests to allow for recovery, and we removed the following assessments during the 1-month and 6-month follow-ups: CIRS-G, Bergs balance scale, ICE-CAP O, and FES-I. However, these

assessments remained in the 12-month follow-ups. In addition, it was agreed upon that a shortened version of the questionnaire would be permitted to use over the telephone for those not permitting a home visit, and the primary outcome measure for the main study, the ADL staircase, was prioritized. In addition, several secondary outcome measures addressing physical health, fatigue, psychological state, self-rated health, and social environment were prioritized, as well as questions on whether there had been changes to home help/home health services. This method was applied on two occasions during the pilot study, once at the 1-month follow-up and once at the 6-month followup. The telephone interviews lasted 10 and 8 minutes, respectively.

## 6.2 STUDY II

The results in the RCT study showed no statistically significant differences between the intervention and control groups for the primary outcomes in the intention-to-treat analysis and subgroup analysis. However, for the intervention group in both intention-to-treat analysis and subgroup analysis, there was a trend toward a higher OR for improved ADLs at both follow-ups. In the subgroup analysis of the intervention group, there was a lower OR for most secondary outcomes, favoring the control group. One OR for satisfaction with ADLs from one month to six months was statistically significant (OR 0.45) in favor of the control group. All primary and secondary outcomes have been analyzed for complete cases, and they showed aligned trends.

Two of the eight hospital care questions that measured participants' perceptions of care quality one month after discharge were statistically significant for the intervention group. They reported to a higher degree receiving written information from the hospital (OR 2.19) and that care received in hospital met their needs (OR 2.83). In the subgroup analysis, there was a statistically significant result in favor of the intervention group that hospital care met their needs (OR 4.43).

## 6.3 STUDY III

The results of Study III identified the participants' personal resources that were established earlier in life and remained intact and useful when receiving health care services, despite being ill, frail, and old. These personal resources were identified as two categorical themes of: 1) *sense of service* and 2) *inherent abilities*.

The categorical theme *sense of service* focused on how the participants saw and experienced health care as a service. Within this category we identified three subcategories where the participants were identified as having the personal resources of being *service-minded*, *having confidence in organizing services* and *skills in conversing and negotiating*. *Being service-minded* was the personal resource pronounced by participants who in their work and life experiences were motivated to give good service, which required that they had respectable social and behavioral skills. To them, being service-minded meant that instructions were followed, questions could be answered, time was respected, and that one was flexible. The participants used their personal resources of being service-minded when discussing how they perceived the staff with regards to their service-minded approach when delivering health care services.

Having *confidence in organizing services* was described as a component of service by the participants. Having this personal resource required that a person felt competent and was motivated to bring together the necessary and available resources required to solve the problem with which they were faced. Participants described how this personal resource often demanded that the person knew how to access resources or find others who could. It also required a sort of efficiency and understanding of the task they were assigned to. With this confidence came the responsibly to see that the organization of services was carried out proficiently.

Being able *to converse and negotiate* while providing services and when interacting with others was the personal resource described among participants who were used to talking with customers, fellow members, and others because of their involvement in clubs, unions associations, and work experiences. Conversing with other people involved sharing knowledge and learning new information. The participants who had the personal resource of conversing and negotiating made use of these skills in their experiences and observations regarding what it was like to receive health care services. However, not all participants wanted to or were able to use these skills. This could be because the person chose not to demonstrate their abilities, or because the organization and situation restricted conversations that invited negotiation when receiving

health care services. This amplifies how despite having a personal resource, it may not always be feasible to use it.

The categorical theme *inherent abilities* described those inseparable qualities or characteristics that exist in someone. When the participants were receiving or waiting to receive healthcare, they frequently made use of their essential attributes. Two subcategories were identified within the category: *being resilient* and *being hopeful and optimistic. Being resilient* was the personal resource described by the participants in terms of how they throughout their lives were confronted with difficult situations where they had to find solutions and were able to bounce back despite having limited support and/or resources. In their storytelling, the participants described facing hardship and explained how they overcame by being creative, flexible, and adaptive. Being resilient throughout life is the personal resource participants described as helping them to survive a difficult situation, which allowed them to maintain a level of independence and well-being.

Being hopeful and optimistic surfaced as an inherent ability and as a personal resource amongst the participants who described having sureness about the future or that something that was going to occur would have a successful outcome. This favorable outlook was related to the participants' confidence in the health care system, and the optimism that they would receive the health care they needed so that they could maintain their health. Participants described being hopeful and optimistic because they had a genuine interest in the continued development of their own health and future. These narratives support that despite participants having the inherent abilities of optimism and being hopeful, if experiencing that they were forgotten or marginalized when receiving health care services or in making decisions about their care, it has a negative impact on otherwise optimistic and hopeful people's outlooks.

## 6.4 STUDY IV

In Study IV the participants described their experiences of receiving a Comprehensive Geriatric Assessment as a process where they felt "respected as a person" (core category), when participation in the decision (category) occurred while engaged in communication and able to understand, leading to four subcategories: actively participates, delegates, not able to participate, and marginalized, see Figure 3.



Figure 3. Experience of receiving a Comprehensive Geriatric Assessment portrayed as a hierarchical process. Original figure from Study IV used with permission according to the Creative Commons Attribution 4.0 International License (<u>http://creativecommons.org/licenses/by-nc-nd/4.0/</u>). Enhanced with color for thesis.

Actively participating necessitated a participant to be included, which required that they grasped an understanding of the situation where they together with the CGA ward staff engaged in communication, shared information, and reached a decision. *To delegate* was when a participant chose to authorize the staff on the ward to act on their behalf or to represent them in a situation, which required a decision to be made. This was seen as an active decision made by the participant who was informed and understood what they were consenting to. *Not able to participate* in decision-making involved that a participant was excluded or not invited by the staff to participate in the decision-making

process. This process could occur when the participant felt too ill or was determined by the staff as being too ill to participate in decision-making, which resulted in staff making decisions without consulting or informing the participant. *To be marginalized* meant that participation in decision-making could occur when the staff on the ward made decisions for the participant. This meant that they were not informed or given the privilege to understand what was being decided on their behalf despite their intact cognizance.

The core category "respected as a person" was further clarified by the categories engagement in communication and understanding. Engagement in *communication* refers to the process in which participants experienced they drew favorable attention or interest from staff while sharing and receiving information on the CGA ward. The level of engagement in communication was described as a fluctuating process. Variations in the level of engagement when communicating was associated with the person on the ward with whom a participant was exchanging information, and how interested and attentive that staff member acted during the exchange of communication. Unidirectional communication could also occurr when the shared information was not acknowledged or received, or when the staff gave them information but there was no opportunity to discuss. Understanding refers to the process where participants understood what was happening to them on the CGA ward. This could be experienced as a reciprocal relationship that was achieved between the participants and the staff. This process involved participants' use of their personal resources and previous knowledge to grasp a ward admission. Participants' understanding of their situtation and the way in which they processed their experienced circumstances could vary depending on how ill they were while on the ward. Participants experienced that when the information being delivered was comprehended, an optimal outcome between the staff and them was achieved resulting in a shared grasp and understanding. Understanding was perceived by participants who experienced that the staff were empathetic and/or competent and action-driven, which could result in offering suggestions and soultions to make the situation more safe or comfortable for the other person.

# 7 DISCUSSION

The findings from this thesis contribute to a better comprehension of the ways in which a CGA had mixed results in supporting frail older people's health. The results revealed that older people who might benefit from a CGA were successfully identified and screened as frail, and those receiving the intervention were met by staff practicing increased attention to safety, ADLs, assistive devices, and discharge planning (Study I). The participants to a high extent agreed that the CGA care met their needs (Study II). The CGA participants experienced having a voice when receiving health care services by using their personal resources (Study III), and they felt respected as a person who could communicate, understand, and participate in their care (Study IV). These findings support that frail older people can experience capability when the health care intervention they receive includes a person-centered approach, so they are enabled to participate in the occupations they value in their daily living (Study III & IV). The findings also add to comprehending the Comprehensive Geriatric Assessment.

### **Effects of Comprehensive Geriatric Assessment**

The pilot (Study I) was designed to secure that the Comprehensive Geriatric Assessment approach being used to assist frail older people in need of acute medical care was suitable and feasible. Essential to this process is the screening to secure that the people who have been selected for participation in the CGA RCT were in fact frail, and that they were assessed based on the CGA (Study I & II). Researchers have been challenged to first build upon the evidence underpinning the frailty interventions, prior to pushing the boundaries for comprehensive screenings and assessments [130]. This is significant since an unprecedentedly large number of older people will soon globally appear upon the doorsteps of our health care services, and an increase in the prevalence of frailty and vulnerability is to be expected among this wave of people [131]. One of the fundamental ways to identify people who are vulnerable is to perform frailty screenings and assessments when they are present in clinical settings [132].

Screening programs are considered popular since prevention is said to be better than the cure, and while an early diagnosis is thought to be effective for some people [133], ethically the consequent harm due to screening resulting in stigma and/or anxiety must be considered [133, 134]. In addition, studies on healthcare improvement [135] have identified that more medical tests and investigations are being ordered, however the provision of treatments has been lowered. A CGA should perform the necessary assessments, minimizing the hazards of stigmatization [107] to support, inform, and involve frail older people so they can best achieve capability to experience Healthy Aging. However, often the dialogue related to frailty findings has been found to emphasize the physiological aspects of frailty over the emotional and realistic sides [136]. The assessment results that are part of the CGA might be considered a double-sided sword. On the one hand, as the latent and hidden aspects to a person's health surface, the results could be considered good, since areas needing care and attention are identified. On the other hand, the assessment results might also be experienced as bad, since feelings of being stigmatized or feeling less satisfied with health can occur if the care needed is not available, or not organized to manage or treat that which was identified in the CGA. It is unethical to for example inform a patient of their treatable disease or impairment, but then withhold the necessary interventions due to lack of competence, resources, funding, or policy deciding whom to treat [137]. When it is done well, a CGA will deliver effective healthcare to vulnerable frail older people who otherwise might have received an ineffective, inefficient, and possibly unsafe response [138]. This is because a CGA is evidence-based and works to improve people's well-being and reduce hospital re-admissions, and when preserved in the service models and clinical pathways, it could minimize harm and ensure that the right healthcare is practiced at the right time [138].

This thesis supports in part that less could mean more when it comes to the satisfaction with ADL status in the subgroup analysis (Study II). This could indicate that normal medical care in a Swedish hospital, despite being less comprehensive and without a multidisciplinary team's use of assessments, could be considered satisfactory as participants in the control group were more satisfied with their ADL than the intervention group. This could be because receiving more comprehensive multidisciplinary evaluations, assessments, treatment, and planning might as a result have been polarizing in its effect after hospital care.

However, the participants in the intervention group had higher tendencies for improved ADL status and SRH compared with the control group. Thus, CGA versus normal medical care could be viewed as the two paths in a wood. The normal medical care path more frequently traveled fundamentally works and gets a person to their destination. Whereas the CGA path is less traveled by, it increases people's insight and understanding, since this path is more complex and encompasses provoking the senses that might otherwise not have been stimulated or comprehended. Thus, the CGA entails being made aware of things that might have otherwise been missed if only a conventional history and physical examination had been performed [10]. Nevertheless, the intervention group agreed to a higher extent that hospital care met their needs. This was significant since the results from the intervention group could indicate a higher quality of care on the CGA ward (Study II).

Lacking in this study were results supporting that the CGA intervention maintained or increased frail older people's ADL status and self-rated health. In the first CGA RCT study carried out in Sweden in 1996, the results then also failed to reveal results supporting ADL performance, mental health, and wellbeing [17]. A recent Cochrane report did not find that CGA had any significant difference in ADL between the intervention and control groups [2], which is in accordance with our findings. CGA UpToDate [8] found only one study reporting higher satisfaction with physical health rates among patients receiving CGA. A recent umbrella review highlights that evidence-based implementations of CGA are required in hospital services and that patientreported outcome measures such as health or quality of life would support the CGA to stay focused on the person-centered process related to the patient's priorities, but are usually not reported [7]. The main outcomes of CGA studies reported were usually death, disability, and institutionalization, and length of hospital stay and readmission were the typical operational goals of CGA [7]. In Study II, patient-reported outcomes were analyzed, however without statistically significant results.

The lack of additional results supporting the CGA could be due to difficulties performing pragmatic intervention trials in a clinical hospital setting with frail older people. Pragmatic trials usually include complex interventions that have multiple interacting components and often involve several health care professionals who are skilled and experienced to deliver the intervention [139]. These considerations are relevant and important since frailty is central in how services for frail older people should be developed and delivered.

Health is not always about absence of disease, a notion that society still overlooks despite the fact that already in 1946 the World Health Organization preamble defined health as complete physical, mental, and social well-being, not merely the absence of disease or infirmity [140]. Over 70 years later, the WHO has adopted Healthy Aging as a model for people as they age to maintain and develop functional abilities that enable experiencing well-being [72]. Consequently, an exploration of the other aspects of health in frail older people were explored in this thesis (Study III & IV).

# Filling a knowledge gap of experiences of receiving a Comprehensive Geriatric Assessment

Comprehending the results of an intervention is more complex than merely analyzing the statistical results of the RCT. In the quest of understanding what matters to frail older people when in need of health care services, individual interviews were performed. Patients' experiences of receiving health care when ill and frail exposed another side to the health care story. Frail older people require a well-coordinated response by multiple professionals addressing their health and social care needs [141]. They want to have their life-stories recognized [142] and through the use of the participants' narratives and histories, health care staff might better understand what people value so that their care could be personalized according to the patients' wants and wishes [143].

Participants discussed how they experienced participating (Study III & IV) so they could communicate and make decisions (Study IV) and use their personal resources (Study III) when receiving health care services. In this approach, when developing strategies to lessen the prevalence of co-existing conditions and to support those living with chronic physical illnesses exacerbated by health conditions that affect well-being, an attempt should be made to comprehend the link between the mind and the body [144]. Frail older people's view of health care services took form in their experiences of person-centered care, or lack thereof. When faced with illness, a partnership between the person and the health care staff should be fundamental in their care [83]. CGA is supposed to differ from a standard medical evaluation since it includes diverse domains that emphasize an older person's functional abilities, cognition, and quality of life achieved by integrating a person-centered multidisciplinary team [1, 145]. A CGA should restore healthy function and independence where possible [11, 12]. Through the development of a tailored treatment and followup plan, a coordinated management of care and evaluation of long-term care needs with enhanced communication and understanding should optimize living conditions for frail older people [41, 145, 146]. While the intentions of the CGA and health care services provided to frail older people may be good, in practice it could be that they did not always use a person-centered approach (Study III & IV). People experienced that health care services and staff did not systematically invite them into a partnership about their care. A previous study [108] has cautioned that a gap will continue to persist in health care if a clear understanding of the preferences that frail older people have is not acknowledged. This understanding is critical since it impacts meaningful outcomes and the benefits an intervention might have had. However, without this knowledge, frail older people are likely to be discriminated and disempowered due to their vulnerable state [108].

In Study IV, the participants described their different levels of understanding and communication on the CGA ward. Participants described staff on the ward practicing a person-centered approach that supported their participation in making care decisions and made them feel respected as a person. However, they also experienced feeling marginalized, excluded, and not understood. Health care staff must comprehend their patients' goals and capabilities, despite the fact that medical and health care policies might promote initiatives that overlook that patients are people [147]. When staff invite patients to participate, they are more likely to experience that they are self-reliant, comprehend the situation, and maintain a sense of control [148]. Conversely, when health care staff misinterpret or overlook a person, the patient's preferences will not be understood and this could be as harmful as misdiagnosing a disease [149].

In Study III frail older people described in their narratives that despite being ill, frail, and old, they have personal resources that were accumulated throughout life that remained useful in managing health care services. However, the experiences they described were both positive and negative, and were identified as being dependent on the staff and organization (Study III & IV). This was because their resources were not always at their disposal to be used when receiving health care. If people cannot draw upon all their resources when receiving health care services, including the health care staff, their social network and the physical environment, then they cannot achieve their full capability [150]. This is because people's ability to achieve desired goals is reliant on what they have access to [77]. When needing health care services, ill frail older people could be enabled to use their personal resources to be who they want to be, and be capable to achieve what they value. However, a frail older person with personal resources cannot do this on their own. All available resources need to be coordinated and integrated to support their capability. Capability is not merely about what a person achieves in their health care, it is about being part of the process in choosing the health care services that they value [75].

The findings of Study III and IV support that a partnership between the person and the healthcare provider was not always experienced. According to Kristensson Uggla [151], a person is always in an inferior position in their relationship to health care professionals when in a patient role. Known as a threefold patient disadvantage, hindrances occur due to institutional, existential, and cognitive factors, which can result in people feeling that they are in a state of uncertainty and that their situation is not productive. The *institutional* disadvantage occurs because a person is being placed at the bottom of the health care organization, which is strongly organized as a hierarchy. The *existential* disadvantage is associated with the experience of being a patient, yet who remains a thinking person with feelings and actions unique to each person. Lastly, the *cognitive* disadvantage is associated with the knowledge gap to fully understand their situation as a patient [151].

The results of Study III and IV furthermore revealed that there were instances when frail older people may have been experiencing person-supportive care [147] or personalized medicine [152, 153] instead of a person-centered care. In the instance of person-supportive care, people described being too ill or mentally unable to participate in their health care decisions, but received care to support them nonetheless. Personalized medicine entails a biomedical approach that focuses primarily on controlling and optimizing pharmaceutical interactions in patients [152], as people described they received medicine for their illness or infection. While both of these approaches may be supportive of the frail older person's needs, they do not involve a person's narrative, collaboration and partnership [152]. It is vital that the CGA staff invite patients into a partnership; otherwise, there is a risk that people will remain disadvantaged patients with a lack of knowledge and participation (Study IV). This could negatively impact satisfaction with well-being, and the use of personal resources might be diminished to support capability dependent upon a person's network and physical environment when receiving health care services (Study III). A capable person is a person who has the ability and desire to speak, communicating what they want to share, and able to act upon and take responsibility for that which they deem important [154]. In order to promote health and well-being and to support people's functional abilities, health care staff should strengthen their patients to be capable people so that each person's unique situation encompasses the wants and wishes of that person [93].

Moreover, the information and knowledge that the CGA staff discover when working in partnership with their patients must be formulated and shared systematically with the person's health care network, so that they too can comprehend and practice what has collaboratively been determined after the CGA. Frail older persons should be frequently followed up and reassessed so that changes to their care plans will reflect what they need, since states of frailty can fluctuate, which can impact a person's daily functioning [110]. If left unaddressed, the vulnerabilities of frail older people often result in decreased social engagement and quality of life, as well as increased dependency, demands for health care services, and mortality [131].

# The role of occupational therapy and the activities of daily living

Occupational therapists' focus is on restoring health through the enablement of occupation [155]. Human occupation should occur in settings where the person usually lives to best enable their occupational participation. While an occupational therapist plays a crucial role in a multidisciplinary team's approach to interdisciplinary care on a CGA ward [101], their task begins on the ward, but is not completed there. This is because their occupation-focused intervention should occur in the environment in which people live [155]. Thus, when working with older people the purpose and focus of occupational therapy should be to consider which occupations are most meaningful and important to people, with the ultimate mission of improving their participation so that they can engage in the occupations they deem valuable and meaningful [101]. The fundamentals of occupational science that we identified through the use of narratives were the occupational engagements and personal resources people used when needing and receiving health care services (Study III). Rudman [156] offers research that supports linking structural and narrative approaches as a way to examine dialogues concerning occupation, since the narratives are how people inform and construct who they are and what they do.

The participants in our studies endured and attempted to stay engaged in their daily activities despite needing health care services, since these were the things that made them feel human. However, despite having personal resources, the health care environment and networks were experienced as either supporting or hindering people's ability to achieve engagement in occupation. This is of great significance for frail older people, a frequently marginalized group when needing health care services, as it further might limit their power to act upon their preferences [99]. This is because we identified some environments described in people's health care experience as hindering their capability, also known as causing occupational deprivation [99]. Occupational deprivation from an occupational science perspective has historical, socio-economic, and political ties that ultimately result in depriving and denying people the right to occupational choice [100]. Without ill intent and unknowingly, health care experiences can cause occupational deprivation if the health culture being practiced by staff loses sight of using a person-centered approach securing respect for people's unique preferences, needs, and values [90].

#### From fragmented care to continuum of care

Even though we for centuries have been concerned with the question of how to approach older people when ill and aging, there still is no consensus today, and the question of how to clinically recognize and manage frailty remains [131]. Furthermore, even if a consensus existed, it would most likely have been achieved without including the perspective of the frail older people for which the services have been created [108]. Comprehensive Geriatric Assessment during one hospital stay is probably not enough to have long-term effects, since frail older people are in need of integrated care provided by multidisciplinary teams after discharge [157]. An earlier study identified that challenges in research remain when evaluating the use of CGA in the community and at the crossing point between hospital and community care [138]. Thus, rushing to implement CGA is not recommended if it is to be a one-off intervention event with limited follow-up, since CGA interventions should be sustainable [158].

Times have changed and so has the structure of health care. In part due to the Ädel reform [35], people are less frequently institutionalized to long-term care; rather, people are expected to age in place with support and resources from the municipalities [159]. This could be one reason why the CGA recipients after their discharge did not maintain or improve ADL status, since the discharge plan formulated by the CGA team may not have been accepted, understood, or followed by the primary or home health care team. An earlier study identified that this information should be comprehended and used as a complement to primary care consultative services, and by no means should a CGA plan be regarded as taking over the role of the primary caregiver's responsibilities [10]. Supported by Reuben et al. [157], a CGA team performing one-time frailty assessments can neither improve functional status nor affect mortality for patients, but rather the study underscored that frail older people who have been hospitalized would best benefit from a CGA that is continuously managed after discharge.

This carry-over of information should be built into the models and systems so that it is systematically reinforced after a hospital admission, as it would minimize the boundaries of care while supporting that CGA is a continuous process [130]. However, we do not believe this was always occurring in our RCT. Had it been the case, the necessary treatments, interventions, and institutional support would have been experienced as a continuous process, and health and well-being should have been enabled [135]. However, our results did not support our primary outcome related to activities of daily living, nor our secondary outcomes related to self-rated health or satisfaction with health.

In this thesis, it can in part be concluded that one of the reasons why the RCT (Study II) did not achieve the expected results was that care after discharge was fragmented, which may not have taken into consideration the recommendation and care plan set forth by the CGA team. This is supported

by the experiences of the participants reported in the qualitative interviews (Study III & IV). An earlier study proved that frail older people can maintain and improve ADLs despite frailty, which however was achieved through an organized continuum of care for frail older people [57]. Today, following a CGA and for frail people in general, geriatric admissions to hospital are much shorter, and time to rehabilitate and provide functional training is severely lacking. This is because hospital services are facing pressures to care for all the frail older people needing care, and some hospitals have even constructed early discharge practices with the justification that long-term problems can be addressed later [160]. As a result, frail older patient outcomes are not necessarily being improved, but rather they lead to an inefficient cycle of readmission, functional decline, institutionalization, and death [161].

The compounded evidence of this thesis supports the complex needs of frail older people and should determine our future responses. Acute hospital care must have competent people with the necessary skills to work with frail older people [130]. Comprehending the Comprehensive Geriatric Assessment requires that those doing the screenings and assessment follow the guidelines. Ethically after screening and making assessments, health care should ensure that an acceptable treatment is available for people identified as having a disease or impairment. This demands that facilities for treatment and rehabilitation are available, and that the nature of the condition is sufficiently understood so that a continuous process to support the findings is managed by providing counseling and treatment compatible with the required intervention [137] throughout the continuum of care [57].

# Old and new challenges for health care with frail older people

Much of what was explored and identified in this thesis has at some historical moment been addressed by health care staff, philosophers, politicians, policy makers, and researchers. While numerous of the questions addressed in this thesis have historically already been explored, they remain of significance and still resonate today, since they are not yet solved. Thus, the obstacles we face in today's society regarding health care for frail older people are not new; rather, they are in fact the same challenges that have existed throughout time. When revisiting history, we see that this thesis has identified what the Ancient Greeks long ago understood when approaching geriatrics [18]. By using a similar lens, the findings in Study III and IV confirm that older people have personal resources that should be valued and used when planning and making decisions. Similarly, after his observations and reflections of ill and aging

people [19], Hippocrates made recommendations thousands of years before the first CGA was conceived. He described how older people should be approached holistically, recommending what the geriatricians and occupational therapists of today do after observing people's functioning in daily activities and the occupations that they choose to engage, encouraging them to remain active in moderation in an old and aging body [19].

In addition, Aristotle's theory regarding the aging body still resonates today, as to how frailty can be framed (Study I & II) apropos the lack of reserves in the older person and their inabilities to recover fully after an illness due to depleted physiological capacities [5, 20]. If left untreated, a frail state will eventually lead to morbidity. Moreover, elements of ancient Indian medicine practices [21] are relevant and useful in supporting the approaches taken today when performing a comprehensive assessment of geriatric people (Study I & II). Both historically and in modern day, the observations one makes about the older person's conditions should be comprehensive and include all aspects of their circumstances so that care plans can be implemented to prevent, treat, and/or reverse illnesses with the purpose of prolonging life and well-being.

Since the status quo is not always experienced as satisfactory amongst ill, frail older people when receiving health care services (Study II, III & IV), continued critical thinking is needed today, as a quest for new evidence to promote health care services demands a further paradigm shift [162]. However, while no one solution or answer was discovered in this thesis as to how health care services for frail older people should be designed, it could be concluded that all this data, evidence, and knowledge remains fragmented and needs to be joined for the best result in moving forward.

## 7.1 METHODOLOGICAL CONCERNS

The specific aims of each study in this thesis steered and helped to determine the methodological choices for each study. The combination of quantitative and qualitative methods supported the author in exploring frail older people's outcomes as well as their reported outcomes and experiences, which is often lacking in CGA research with frail older people [7]. Furthermore, mixed methods in the studies comprising this thesis were in part driven by the quest for pragmatism rather than purely odds, statistics, and principle. Mixed methods are commonly motivated when quantitative methods alone are perceived as deficient when addressing the complexity of health care in research [163]. This factor was pre-determined in the case of this thesis in comprehending the Comprehensive Geriatric Assessment with frail older people. Despite this, the studies in this thesis have limitations as well as strengths.

### Staying true to the intervention

In quantitative research, a randomized controlled trial is considered to be a golden standard and highly confident when designing studies [164]. Prior to completing a full-scale RCT study, a pilot study was performed to determine the feasibility of the study design and to confirm a proof of principle that the study was practicing the intervention according to the protocol (Study I). Several methodological issues were addressed regarding recruitment rate, screening for frailty, and reorganization of the assessments' order due to fatigue amongst the participants. Furthermore, the Comprehensive Geriatric Assessment is grounded on assessments. Since accurate assessments are the initial step to ascertain appropriate management and thereby avoid over- and under-prescribing care [138], all the instruments used in this study were validated and reliable (Study I & II).

When the intervention ward was working according to the CGA, good results were achieved because ward personnel were trained to work according to the CGA. The multidisciplinary team operated interdisciplinarily and included OT services, ADL assessments, safety precautions, care planning, and discharge planning (Study I). However, the results of the full RCT (Study II) were not as good as anticipated after the pilot, which is due to the hospital's health care organization. Most likely related to the cutbacks [165], a shortage of hospital beds [166] caused the wards to unexpectedly open up more beds due to unreasonably long waiting times in the emergency department. The CGA ward and hospital in general were understaffed [167], and the addition of new beds resulted in health care staff quitting their jobs because of the sudden

reorganization and restructuring. As a consequence, new/temporary staff was hired to keep the ward running. This staff was not properly trained or informed of the ongoing CGA practices, and gave care based on their general competences. Furthermore, the staff that may have been trained could have had lapses in their enthusiasm and steadfastness, which resulted in periods of time at the start of the study where the intervention was not being carried out as planned. An earlier study supports that the more complicated and different the protocol is from normal routine, the more likely people are to wander back to familiar and usual practices, regardless of their motivation to comply [168]. This human factor was observed, and staff did not always work according to the CGA.

Furthermore, a contamination occurred in the RCT (Study II) since several control participants received the CGA intervention due to readmission or transfer to a ward practicing a comprehensive geriatrics team approach. These participants were removed from the subgroup analysis. In addition, we had to remove all nursing home residents since they were not prioritized for assessment by occupational therapists in the hospital, which we became aware of during the full-scale RCT. To be consistent, it was prudent to also remove all nursing home residents in the control group, so the two groups would be justly comparable at follow-ups (Study II).

There are several threats that can occur in an RCT, which can disturb the validity of the trial [168]. We identified two: 1) non-adherence to working in accordance with CGA, and 2) cross-contamination of the control group. These issues are believed to have led to low statistical power and poor results of the intervention in the RCT. Problems of contamination can frequently be overcome by increasing the sample size [169]. However, in this RCT study we did not calculate for the human factors of doing research, which included crosscontamination and non-adherence to study protocol. This resulted in 34 participants being removed in the subgroup analysis. While an intention-totreat analysis (ITT) is always preferable in an RCT and demands that all cases are analyzed with the intent of avoiding bias in a study [170], it only estimates the effect of recommending a treatment to study participants, not the effect of actually receiving the treatment [171]. Consequently, we reasoned that a subgroup analysis was equally important since protocol was not followed, and a true understanding of the CGA intervention could be better comprehended through this analysis. Authors should be forthcoming in presenting both the intention-to-treat and subgroup analyses [172], and we were mindful that the intention-to-treat data was flawed due to contamination and that the subgroup analysis lacked statistical power. Lastly, due to the old age and frailty of the participants in our study, a relatively high drop-out and/or death rate was

inevitable. The pattern of "missingness" is not random, since the likelihood that a response is missing is directly related to the data that were collected or requested [120]. Simply analyzing complete cases in our study was not relevant and could lead to bias about treatment effects. Therefore, a data imputation approach was used to manage the missing data. Missing values were replaced with a value based on the median change of deterioration (MCD) between baseline and follow-up of all who participated at the follow-up [173]. This imputation method was deemed appropriate due to the study sample of frail older people being expected to deteriorate over time as a natural course of the aging process, and because the reason for not fulfilling the follow-ups was often deteriorated health. Worst-case change was used for those who had died before follow-up.

### Listening to the voices

In qualitative research, trustworthiness is of the utmost importance [174]. In the quest for truth of the findings, credibility [175] is essential. To establish credibility in Study III and IV, we collected data using open-ended questions through interviews in people's place of residence. All interviews were conducted with people who had received care on the geriatric ward practicing Comprehensive Geriatric Assessment. This way, their experiences would be credible as they were founded on the same phenomenon. Qualitative research becomes more credible when categorical findings show quotations from the transcribed text in the report to support the results identified [174]. Understanding this, quotations from the participants' interviews were used to show how the similarities and differences within the categories were determined. To address dependability, we followed the method selected for the research analysis when analyzing the transcribed text. This helped to secure dependability when working as a team to ascertain that both the raw data and the categorized data were analyzed and interpreted to generate dependable results. Frequent meetings, discussions, and mulling over the data and findings until a consensus was achieved further supported this. The transferability of our results in Study III and IV is relevant for other researchers studying different vulnerable or marginalized populations in their experiences of health care services. Our results on the exploration of the use of a person-centered approach and whether participants were enabled to use their personal resources when receiving health care services may very well be transferable to studies of other groups.

A limitation in the qualitative studies may be that they only explored the experiences of frail older people who had received care on the geriatric ward practicing Comprehensive Geriatric Assessment and who were assessed as

cognitively intact. To strengthen these studies' results, a more diverse group of participants with lower cognitive status and a group who received regular acute medical care on the control ward should be considered in the future. This diversity might broaden and strengthen our understanding of how ill, frail older people experience health care services. Lastly, to broaden and diversify our findings and results, the experiences of health care staff practicing and delivering CGA services to frail older people would also have been beneficial.

## 8 CONCLUSION

This thesis concludes that CGA provides care that is better adapted to frail older people's needs, as they themselves felt that the care met their needs; however, no statistically significant effects for frail older people receiving care based on CGA were achieved. The lack of additional results supporting the positive effects of CGA could be due to difficulties performing pragmatic intervention trials in clinical hospital settings leading to a risk of low statistical power. In addition, a CGA during a single hospital stay is probably not enough to have long-term effects, since frail older people are in need of integrated care provided by multidisciplinary teams. Best benefitting frail older people when receiving health care demands an organized continuum of care so that they can achieve a good functional status, well-being, and quality of life both during and after care. In order to secure that the care is based on what people need, a person-centered approach is fundamental, so people will be partners and able to use their personal resources.

Mankind's quest for an understanding of the processes and consequences of care for frail older people continues beyond what this thesis addressed and identified. The search for an effective method to facilitate successful outcomes that enable living healthier lives despite frailty remains unresolved. The Comprehensive Geriatric Assessment can be comprehended as supporting Healthy Aging. However, without steadfast resources and organization during all phases of care, the jury is still out on whether it can be said with certainty that a CGA is the solution for frail older people. The results of this thesis are suggestive of what path needs to be further cleared and widened to become a mainstream road for future geriatric health care.

# 9 FUTURE PERSPECTIVES

Several of the lessons learned from this thesis that should be considered in future research perspectives are related to the element of insuring compliance with the CGA's recommendations. The thesis provides some ideas about what mattered to the participants, who agreed that the care received on the CGA ward met their needs. However, other aspects after discharge and when following up after the CGA did not support that they were satisfied with their health or functional status, nor had they maintained or improved their ADL status with higher odds than the control group.

For future research, it would be of interest to design a continuum of care study to secure that the CGA recommendations are implemented, monitored, reassessed, and updated in all care levels by all health care givers. This demands that care is integrated between the hospitals, primary care, and home health care to meet the changing needs and adapt to changes in functioning in frail older people. The research questions formulated would specifically focus on the impact a CGA intervention has with an integrated care versus ordinary follow-up care after a CGA by the primary health care organization. Additionally, related to this future research, an understanding of how CGA discharge and follow-up plans are received and understood would be explored along with the question of to what extent the plans are implemented to guide the primary caregivers in continuing care after the CGA.

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