Tampere University

PAULIINA HALONEN

Chronic Diseases and Multimorbidity Among the Oldest Old

Prevalence, trends, and associations with self-rated health, functioning, long-term care admission, and mortality

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To Kaisa

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I have been very privileged to have an opportunity to undertake this thesis journey. It all began with an email from a friend, who knew I had a dream of working in research. In this email, Professor Marja Jylhä was looking to recruit a researcher to work in the Vitality 90+ Study. In a matter of weeks, I had resigned from my previous job and started a new one with no idea what lay ahead. This email was my first lucky break, followed by a meeting with my custos-to-be, probably the most steadfast and determined supervisor any doctoral candidate can have. Professor Marja Jylhä made me believe that I was capable of doing research, something for which I will be forever grateful. She has never accepted easy answers, never allowed me to take any shortcuts in research. That, in addition to her knowledge and wisdom, is why I have learned so much during these years under her supervision.

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Lempäälä, 11 December 2023
Pauliina Halonen

ABSTRACT

Chronic diseases are one of the most significant public health concerns in aging societies, with major implications both for the organization of social and health care and for individuals' quality of life, functioning, and care needs. Age is the single most important risk factor for many chronic diseases, and therefore the oldest old people who live to over 90 years are at an increased risk for developing chronic diseases based on their age alone. Multimorbidity, or the co-occurrence of two or more diseases, has become increasingly common in aging populations. Studies on morbidity among those living the longest lives can provide important insight into whether the increase in life expectancy is accompanied by better, worse, or unchanged health and into what is to be expected when increasing numbers of people live to very old age. There is still a scarcity of health research that addresses populations aged over 90; most former studies have concentrated on younger population segments. This study investigated the prevalence of chronic diseases and multimorbidity in a population aged over 90 and explored the associations of chronic diseases and multimorbidity with self-rated health and functioning, disability in mobility and activities of daily living (ADL), long-term care (LTC) admission, and mortality. In addition, the study assessed the reliability of self-reported survey information on chronic diseases by comparing it with national health register data.

The study used data from six repeated cross-sectional surveys conducted between 2001 and 2018 as part of the Vitality 90+ Study. The study population for each survey round consisted of all residents aged 90 and over in the city of Tampere. Response rates were close to 80% in each survey wave. Altogether the data comprised 5,441 respondents. Register data on LTC admission, mortality, hospital discharge information, and drug reimbursement were linked with the survey data. The study used several regression analysis methods in addition to agreement measures to address the research questions.

The level of multimorbidity was high in both women (82%) and men (77%). The most common chronic diseases were hypertension, heart disease, arthritis, and dementia. Multimorbidity was associated with poor self-rated health and poor self-rated functioning, ADL and mobility disability, and an increased risk for mortality. The number of diseases showed an increasing trend over time, with the biggest

increases seen in the prevalence of hypertension, arthritis, and diabetes. The only condition that showed a decreasing trend across the years was depression. The prevalence of dementia was high (ca 41%) but it showed a slightly declining trend. The most common chronic conditions comorbid with dementia were hypertension, heart disease, arthritis, and depression. The disease that showed the strongest association with ADL and mobility disability and with LTC admission was dementia. The population attributable fraction (PAF) for mortality was highest for dementia. Most of the associations found were more pronounced in women than in men. Agreement between the survey data and health register data was almost perfect for Parkinson's disease, substantial for diabetes and dementia, and moderate for heart disease and hypertension.

The study has two main conclusions: First, the morbidity profile of the oldest old people is characterized by a high level of dementia, depression, and multimorbidity as well as by an increasing number of chronic diseases over time. The findings reflect the advances that have been made in the diagnostics and treatment of chronic diseases even in very old age. Second, the results show that survey methods can be used in population-based health studies to acquire information on chronic diseases with acceptable reliability among the oldest old.

Dementia is a common condition among the oldest old. It is associated with lower functional ability and an increased need for LTC, and it is predictive of mortality. The growth of the oldest old population means that the number of people with chronic diseases is set to continue to increase. As age remains the most important risk factor for diseases, effective prevention among the oldest old is very difficult. New practices and models of care need to be developed to provide effective treatment for old people with multimorbidity. The main emphasis should be on improving the quality of life of people living with diseases. It is imperative to recognize the growing need for care posed by the increasing number of people with dementia and to make sure that adequate support and long-term care is available.

Keywords: chronic disease, multimorbidity, longevity, disability, self-rated health, long-term care, mortality, survey methodology

TIIVISTELMÄ

Elinajanodotteen pidentyessä ja tarttuvien tautien ehkäisyn ja hoidon parantuessa pitkäaikaissairaudet ovat yleistyneet, ja niistä on muodostunut keskeinen kansanterveydellinen haaste, jolla on seurauksia sekä yksilön että yhteiskunnan tasolla. Ikä on useimpien pitkäaikaissairauksien merkittävin riskitekijä. Vanhoista vanhimmat ovat siten merkittävässä riskissä sairastua pitkäaikaissairauksiin jo pelkästään korkean ikänsä vuoksi. Useamman pitkäaikaissairauden samanaikainen esiintyminen, monisairastavuus, on yleistynyt pitkäikäisyyden yleistyessä. Vanhoista vanhimpien sairastavuuden tutkiminen voi tuottaa tietoa siitä, mitä terveydentilalta voi odottaa myöhäisessä vanhuudessa, kun yhä useampi saavuttaa hyvin korkean iän. Tutkimustietoa vanhoista vanhimpien sairastavuudesta on toistaiseksi kertynyt vähemmän, kuin muun vanhusväestön sairastavuudesta. Yli 90-vuotiaat ovat moninainen väestöryhmä, ja yhä useampi elää hyvin vanhaksi sairauksista ja toimintakykyvajeista huolimatta.

Tämän tutkimuksen tarkoituksena oli selvittää pitkäaikaissairauksien ja monisairastavuuden esiintyvyyttä 90 vuotta täyttäneessä väestössä, sekä näiden yhteyttä toimintarajoitteisiin, itse arvioituun terveyteen, pitkäaikaishoitoon päätymiseen ja kuolleisuuteen. Lisäksi tutkimuksessa tarkasteltiin 90 vuotta täyttäneiden itse raportoiman sairaustiedon yhteneväisyyttä kansallisen rekisteriaineiston kanssa. Aineisto muodostui Tervaskannot 90+ tutkimushankkeen kyselytutkimuksista vuosien 2001 ja 2018 välillä, sekä näihin tietoihin yhdistetystä rekisteriaineistoista, jotka sisälsivät tietoja pitkäaikaishoidosta, kuolleisuudesta, erikoissairaanhoidossa annetuista diagnooseista sekä lääkeostoista. Kyselyjen vastausprosentti oli korkea joka kyselyvuonna. Aineisto sisälsi havaintoja yhteensä 5 441 vastaajalta. Aineiston analyysissä hyödynnettiin eri regressiomallien lisäksi yhtäpitävyyttä mittaavia tilastollisia menetelmiä.

Monisairastavuus oli hyvin yleistä sekä naisilla (82 %) että miehillä (77 %). Yleisimmät sairaudet sekä miehillä että naisilla olivat verenpainetauti, sydänsairaus, nivelrikko ja muistisairaus. Monisairastavuus oli yhteydessä huonoon itse arvioituun terveyteen ja huonoon itse arvioituun toimintakykyyn sekä toimintarajoitteisiin

päivittäistoiminnoissa ja liikkumisessa. Lisäksi se ennusti pitkäaikaishoitoon päätymistä sekä kuolleisuutta naisilla. Sairauksien esiintyvyys nousi vuosien aikana. Erityisesti verenpainetauti, nivelrikko ja diabetes yleistyivät. Muistisairaus oli yleinen (noin 41%), mutta harvinaistui hieman tarkasteluajanjakson aikana. Muistisairauden kanssa esiintyvät yleisimmät sairaudet olivat verenpainetauti, sydänsairaus, nivelrikko ja masennus. Masennuksen esiintyvyys väheni. Muistisairaus oli yhteydessä toimintarajoitteisiin päivittäistoiminnoissa sekä liikkumisessa, huonoon itse arvioituun terveyteen ja huonoon itse arvioituun toimintakykyyn sekä pitkäaikaishoitoon päätymiseen ja kuolleisuuteen. Yhtäpitävyys itse raportoitujen sairaustietojen ja rekisteriaineiston välillä oli lähes täydellinen Parkinsonin sairauden osalta, huomattava diabeteksen sekä muistisairauden osalta ja keskinkertainen sydänsairauden ja verenpainetaudin osalta.

Tämän tutkimuksen tulosten pohjalta voidaan tehdä kaksi pääasiallista johtopäätöstä. Yli 90-vuotiaiden sairastavuusprofiilia määrittää pitkälti muistisairauden, masennuksen ja monisairastavuuden yleisyys sekä se, että sairauksien lukumäärä näyttää tässä ikäryhmässä yhä kasvavan. Lisäksi tutkimuksen tulokset osoittivat, että itse raportoitua sairaustietoa voidaan käyttää väestöpohjaisessa terveystutkimuksessa tiedon lähteenä, kun kliiniset tutkimukset eivät ole mahdollisia. Tutkimuksen tulokset heijastavat sairauksien parantunutta diagnostiikkaa ja hoitoa vanhusväestöllä sekä muistisairauksien merkitystä toimintarajoitteiden, itse arvioidun terveyden, pitkäaikaishoidon tarpeen sekä kuolleisuuden kannalta. Hyvin vanhojen ihmisten määrä kasvaa tulevina vuosikymmeninä Suomessa merkittävästi ja tämän ikäryhmän tarpeisiin vastaaminen tulee luomaan haasteita palvelujärjestelmälle. Koska ikä todennäköisesti pysyy voimakkaimpana pitkäaikaissairauksien ennustajana, sairauksien ehkäiseminen vanhoista vanhimmilla on vaikeaa. Iäkkäiden monisairaiden ihmisten hoitaminen vaatii uudenlaisten hoitomallien ja käytäntöjen kehittämistä terveydenhuollossa. Painotuksen tulee olla sairauksien kanssa elävien ihmisten elämänlaadun ylläpitämisessä ja säilyttämisessä. Muistisairautta sairastavien ihmisten määrän lisääntyminen vaatii riittävän ja tarpeenmukaisen tuen ja pitkäaikaishoidon mahdollistamista.

Asiasanat: pitkäaikaissairaudet, monisairastavuus, pitkäikäisyys, toimintakyky, itse arvioitu terveys, pitkäaikaishoito, kuolleisuus, metodologia

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ABBREVIATIONS

ADL	Activities of daily living
ATC	Anatomical Therapeutic Chemical
CI	Confidence interval
COPD	Chronic obstructive pulmonary disease
CRHC	Care Register for Health Care
CRSW	Care Register for Social Welfare
CVD	Cardiovascular diseases
FPR	Finnish Prescription Register
GEE	Generalized estimating equation
HR	Hazard ratio
IADL	Instrumental activities of daily living
IRR	Incidence rate ratio
LE	Life expectancy
LTC	Long-term care
NPA	Negative percent agreement
OR	Odds ratio
PAF	Population attributable fraction
PPA	Positive percent agreement
SHR	Subhazard ratio
WHO	World Health Organization

LIST OF ORIGINAL PUBLICATIONS

Publication I Halonen, P., Enroth, L., Jylhä, M. & Tiainen, K. 2017. Pitkäaikaissairaudet ja monisairastavuus hyvin vanhoilla sekä niiden yhteys toimintakykyyn ja itse arvioituun terveyteen – Tervaskannot 90+ -tutkimus. Gerontologia, 31(4), 269–281. *(Chronic conditions and multimorbidity in the oldest old – associations with functioning and self-rated health. The Vitality 90+ Study.)*

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Publication III Halonen, P., Raitanen, J., Jämsen, E., Enroth, L. & Jylhä, M., 2019. Chronic conditions and multimorbidity in population aged 90 years and over: associations with mortality and long-term care admission. Age and Ageing, 48(4), 564–570.

Publication IV Halonen, P., Jämsen, E., Enroth, L. & Jylhä M. 2023. Agreement between self-reported information and health register data on chronic diseases in the oldest old. Clinical Epidemiology, 15:785–794.

1 INTRODUCTION

Most high-income countries today have largely completed the epidemiologic transition from famine and infectious diseases to chronic degenerative diseases. The main focus of public health monitoring and interventions has thus shifted to non-communicable chronic diseases, which are now an important aspect of health policy planning in high-longevity countries. One of the major trends driving the worldwide increase in the prevalence and public health significance of chronic diseases is population aging. (Prince et al., 2015.) In Finland, life expectancy (LE) has risen sharply during the 20th century, and more and more people are living to the oldest ages. In the age cohort born in 1930, 19.8% reached the age of 90 years (*Human Mortality Database*, 2023), and it has been suggested that over half of the people born in the 21st century in countries with high LE rates will live to be over 100 (Christensen et al., 2009). Along with the growing significance of chronic diseases, population aging has created other public health concerns, one of the most notable of which is the growth of multimorbidity, or having two or more concurrent chronic conditions. The most important risk factor for most chronic diseases and multimorbidity is aging, which at least for the time being cannot be prevented.

The oldest old constitute a rather heterogeneous group of people in terms of health, lifestyle habits, marital status, and socioeconomic background, despite the selective mortality that throughout the life course favors those with a healthier lifestyle and higher socioeconomic position (Jylhä, 2020). This age group is often sidelined from health research for various reasons. Health problems such as cognitive decline and functional limitations can prevent the oldest old from participating, and the recruitment of people living in care facilities can also be highly challenging (Jylhä, 2020). Furthermore, there are concerns as to whether people with cognitive decline can provide sufficiently reliable information about their health status.

Despite these limitations and challenges, it is evident that more research is needed on the health of the growing population of the oldest old. Care needs are largely concentrated at the end of life and in the oldest ages (Aaltonen et al., 2017b), and it

is not clear whether people live to the oldest ages in better or worse health than before.

This study examines chronic disease morbidity in the oldest old population in Tampere, Finland: the prevalence and trends of chronic diseases and multimorbidity, the implications of diseases on health-related outcomes, and the agreement of survey information with health register data based on the results of four peer-reviewed published studies. Additionally, this summary chapter presents new findings not described in the four articles on morbidity trends among people without dementia to obtain a more comprehensive understanding of the prevalence of diseases in the study population.

2 INCREASING LONGEVITY IN AGING SOCIETIES

2.1 Changing demographics and increases in life expectancy

Changes in fertility and mortality patterns with the modernization of societies or the 'demographic transition' has led to increases in LE throughout the world (Kirk, 1996). LE has risen sharply over the past century, both globally and in Finland (Klenk et al., 2016; Knudsen et al., 2019). In Finland and the other Nordic countries, LE at birth is above the global average. Nordic men have a higher LE than men in high-income countries on average, whereas Nordic women's LE is the same as the average for high-income countries. (Knudsen et al., 2019.) In 1971 LE at birth in Finland was 70.1 years: 65.9 years for men and 74.2 years for women. By 2022 those figures had risen to 81.2 years, 78.6 years, and 83.8 years respectively. LE at birth has decreased from 2019 to 2022, but it is still higher than at the beginning of the 2010s (Official Statistics of Finland (OSF), 2022b). Furthermore, despite the recent downturn, LE is projected to rise so that by 2060, LE for women will be 90.5 years and for men 87.4 years (Official Statistics of Finland (OSF), 2021a). Women's higher LE is a universal phenomenon, but the gender gap is slowly reducing as women's LE has stagnated in recent years (Crimmins, Shim, et al., 2019; Official Statistics of Finland (OSF), 2022b) and most increases in LE have been due to the lengthening male LE (Knudsen et al., 2019). The rapid rise of LE has been described as 'the greatest human accomplishment of the past century' (Crimmins, 2015).

The main drivers behind the increases in LE are the decline in child mortality with the improved management of infectious diseases, followed by higher cardiovascular disease (CVD) survival in older ages (Crimmins, 2015). This 'epidemiologic transition' (Omran 1971) has closely accompanied the demographic transition. Although this theory has faced some criticism for oversimplifying mortality trends occurring in a particular period in particular countries (Mackenbach, 2022), it does provide a useful overall understanding of the mortality trends seen worldwide. Originally Omran (1971) introduced three successive phases of the epidemiologic transition during which mortality patterns change in the population: 1) the age of pestilence and famine (LE between 20 and 40 years), 2) the age of receding pandemics (LE increasing from around 30 closer to 50 years), and 3) the

age of degenerative and man-made diseases (LE exceeding 50 years). Later, Olshansky & Ault (1986) proposed a fourth stage, the age of delayed degenerative diseases.

Following dramatic changes in causes of death during the first three phases, Olshansky & Ault (1986) state that in the fourth stage there are only small changes in these major causes of death, but the age distribution of deaths shifts from younger to older age ranges. More recently, it has been noted that in high-income countries mortality in older ages remained very much stable until the 1980s, and then began to decrease more rapidly among people aged over 60 than those aged 15-59 years (Mathers et al., 2015). The increases in LE at age 60 from 1980 to the early 2010s were largely attributable to reductions in CVD and diabetes mortality in both women and men. Improvements in health care coverage and effectiveness as well as reductions in risk factors (high blood pressure and tobacco use) are considered the main reasons behind the decrease in disease-specific mortality. (Mathers et al., 2015.)

Today, older people live longer than before once they get old, and deaths are more concentrated at older ages (Crimmins, 2015). In Finland, the median age at death in 2020 was 85.5 years for women and 77.8 years for men (Official Statistics of Finland (OSF), 2020). These trends in LE along with the decreasing fertility rate in Finland (Roustaei et al., 2019) have led to a shift in the population age structure where the largest age groups are no longer those aged 30 but people aged over 65.

The rapid growth of the oldest old population was discussed as early as 1985 by Suzman & Riley (1985). Using the term 'oldest old' for people aged over 85 years, they noted the uniqueness of this population group in terms of their needs, resources, and sociodemographic features. The growth of the oldest old population has continued since and accelerated over the past 20 years. In Finland the number of people aged over 90 has increased from 22,637 in 2000 to 58,330 in 2021. By 2040, it is projected that the figure will climb to 140,757 (Official Statistics of Finland (OSF), 2021b, 2022a) (Figure 1). The share of women increases with age, and in the population aged over 90 they account for over 70% (Enroth et al., 2020; Jylhä, 2020). In Finland, the share of birth cohorts surviving to age 90 has increased slowly but steadily (Jørgensen et al., 2019) and in the 1930 birth cohort 19.8% lived to age 90 (*Human Mortality Database*, 2023). Globally, it has been suggested that over half of the people born in the 21st century in high-LE countries will live to be over 100 (Christensen et al., 2009). Scott (2021) has called these transitions in demographics a 'longevity transition', observing that the recent gains in LE at the older ages has shifted the interest from an 'aging society' to a 'longevity society', with implications for both individuals and policies.

The population for the present study consists of the oldest old, referring to people aged over 90 years, although the literature review mainly presents findings for people aged over 80 or over 85 years.

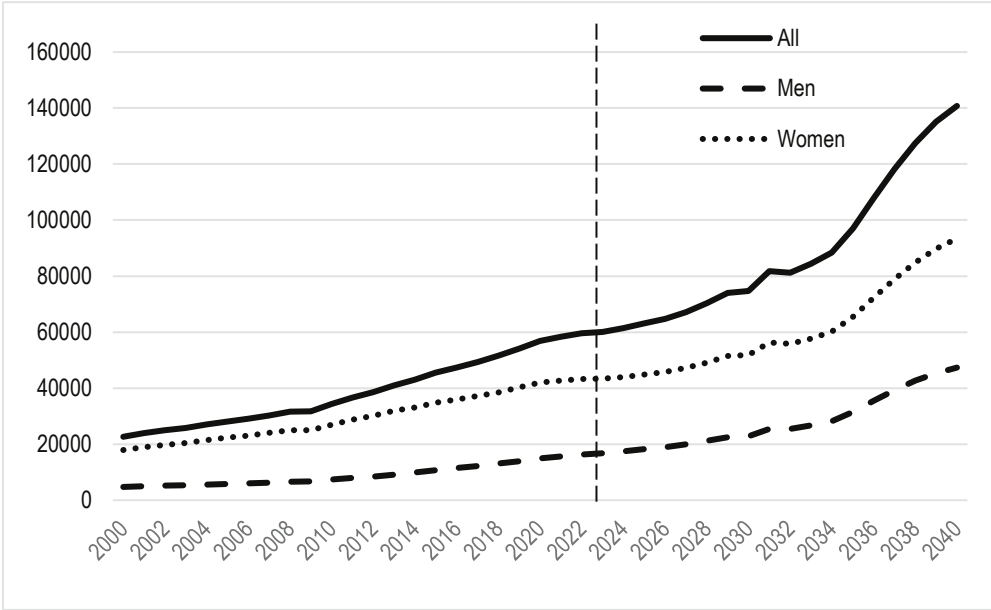


Figure 1. Number of people aged over 90 years in Finland from 2000 to 2021 and projection from 2022 to 2040 (Official Statistics of Finland (OSF), 2021b, 2022a)

The rise in LE has led to discussions over whether people's longer lives are accompanied by more healthy years, or whether the extra years gained are lived with disabilities and increasing morbidity. One approach to conceptualizing this issue is to use a summary measure of population health, such as healthy life expectancy, which provides an estimate of the number of years a person of a certain age is expected to live in good health taking into account age-specific mortality, morbidity, and functioning (Salomon et al., 2012). In 2019, healthy life expectancy at birth in Finland was 71 years: 70 years for men and 72 years for women. Healthy life expectancy at age 60 was 18.5 years: 17.3 for men and 19.5 for women (WHO, 2021).

The notion of compression of morbidity, originally proposed by Fries (1983), means that LE without disability, chronic conditions, or other poor health, increases more than total LE, resulting in more years lived in good health (Robine et al., 2020). The opposite scenario, 'failure of success' or expansion of morbidity, results from improved medical interventions to reduce the lethality of chronic diseases, which

together with a stable incidence and lack of measures to prevent or cure diseases leads to a longer LE lived with chronic diseases and disability (Gruenberg, 1977; Robine et al., 2020). In the dynamic equilibrium scenario, the severity of diseases decreases to the extent that their disabling effect is reduced. Even if diseases occurred at the same or at a higher rate than before, their reduced disabling effect means the amount of time spent in poor health does not increase (Manton, 1982).

Evidence of the compression of morbidity in terms of disability has been reported both for younger old people and those aged over 85 (Cai & Lubitz, 2007). Some studies have found decreasing ADL disability among the oldest old but mixed evidence on cognitive functioning (Jylhä, 2020). In the Vitality 90+ Study, evidence for the compression of disability was detected from 2001 to 2018 (Enroth et al., 2020). Studies among older populations have reported increase in the incidence and prevalence of several chronic diseases and multimorbidity over time (Christensen et al., 2009; Crimmins, Zhang, et al., 2019; Steffler et al., 2021). Enroth et al. (2020) found an expansion of CVD and dementia morbidity especially among the oldest old men. Furthermore, population aging means that the number of people with chronic diseases and multimorbidity is growing (Steffler et al., 2021). However, there is some evidence that the disabling effect of diseases has weakened to some extent, supporting the dynamic equilibrium scenario (Christensen et al., 2009; Hossin et al., 2019). In high-LE societies it has been proposed that the main focus of health policies should be turned to increasing healthy LE in order to reduce the societal and individual burden of longevity (Scott, 2021).

2.2 Biology of longevity and health

Biological aging is a time-related, progressive, and complex process of molecular and cellular decline, characterized by an increased susceptibility to disease and death. The rate of aging differs greatly between individuals. (Carmona & Michan, 2016.) Even though there still exists no universally accepted measure of biological aging rate, various measures are available for predicting lifespan and a few also for predicting health span (Jain et al., 2022; Jylhävä et al., 2017). With regard to the aging process and its impacts on the body, people who live to a very old age are survivors and may also differ in terms of biological manifestations from those who die earlier (Atzmon et al., 2004; Horvath et al., 2015). It has been suggested that the rate of biological aging is slower among very old survivors (e.g. Kananen et al., 2016). Aging is a major risk factor for chronic diseases and the risk becomes more pronounced in advanced

ages (Olshansky, 2016; Sanders et al., 2012). Several measures of biological aging rate have found to be associated with age-related chronic conditions (Ferrucci et al., 2020; Jylhävä et al., 2017).

Aging leads to deterioration in the compensatory mechanisms that work to maintain homeostasis. Resilience to stress from the internal and external environment is high during early life and midlife, but a decline in the compensatory mechanisms leads to accumulation of damage and ultimately to declining functioning and frailty (Ferrucci et al., 2020). The concept of frailty has been adopted to measure age-related deterioration in many physiological systems, which increases vulnerability to sudden health changes caused by minor stressors (Clegg et al., 2013). Several frailty measures have been developed but there is still no international standard measurement for frailty (Dent et al., 2016). Frailty and multimorbidity are closely related concepts that partly overlap. According to Fabbri et al. (2015) they are expressions of the same phenomenon, that is the age-related loss of resilience and increased vulnerability to external stressors. Multimorbidity can provide a measure of the clinical expression of vulnerability, and the accumulation of diseases at the individual level can serve as a proxy for the speed of aging (Fabbri et al., 2015). Fabbri et al. (2015) emphasize the importance of studying multimorbidity to advance our understanding of the aging process.

Biological aging and age-related diseases share some basic mechanisms, such as inflammation, oxidative stress, and cellular senescence (Franceschi et al., 2018). Fabbri et al. (2015) suggest that since it is most likely that these processes are driven by the same mechanisms, addressing these mechanisms could deter the development of diseases and multimorbidity and therefore deliver major gains in health status. An increased understanding of the molecular processes that underlie aging has contributed to advance of research in this area (Campisi et al., 2019).

3 THE BURDEN OF DISEASES IN VERY OLD AGE

3.1 Chronic diseases of the oldest old

The US Centers for Disease Control and Prevention defines chronic disease or chronic condition as a long-lasting condition that requires ongoing medical attention or limits daily activities, or both (CDC, 2022). Instead of 'chronic disease', the World Health Organization (WHO) uses the term 'noncommunicable disease' to differentiate these diseases from communicable infectious diseases. WHO describes noncommunicable diseases as conditions of long duration and a result of a combination of genetic, environmental, physiological, and behavioral factors (WHO, 2023b). With a focus on a public health perspective, the Finnish Institute of Health and Welfare recognizes chronic diseases and conditions as having major implications for mortality (Finnish Institute for Health and Welfare, 2022). These different conceptualizations of 'chronic disease' all refer to the long duration of the condition, the high public health burden, and shared risk factors, that is smoking, lack of physical exercise, unhealthy diet, obesity, and excessive consumption of alcohol. According to WHO, the main drivers for these diseases are urbanization, unhealthy lifestyles, and the aging of the populations globally (WHO 2023b). The major chronic diseases listed by CDC are heart disease and stroke, cancer, and diabetes, whereas the Finnish Institute of Health and Welfare identifies cardiovascular diseases, diabetes, asthma and allergies, chronic respiratory diseases, cancer, memory disorders, musculoskeletal diseases, and mental disorders as the most important conditions (CDC, 2022; Finnish Institute for Health and Welfare, 2022). It is not self-evident which diseases or conditions are considered 'chronic', and this may vary over time. Furthermore, 'disease' and 'condition' are used interchangeably to describe a diagnosis or a person's health state. (Bernell & Howard, 2016.) The present study uses both 'chronic disease' and chronic condition' to refer to a long-lasting illness or a health state that is not optimal concerning individuals' well-being or daily activities.

The prevalence of most chronic diseases increases with age. A Finnish review found that the prevalence of several chronic diseases was much higher among those aged over 85 years than among the younger old people. Specifically, dementia and CVDs were found to be more common among the oldest old. (Salminen et al., 2012.) The prevalence of CVD (including hypertension, stroke, heart failure, and coronary heart disease) is estimated to be around 80% among people aged over 80 (Lloyd-Jones et al., 2009). Other diseases that are highly prevalent among the oldest old include arthritis and dementia (Boeckxstaens et al., 2015; von Berenberg et al., 2017). It has been found that depressive symptoms are highly prevalent especially among the oldest people living in care facilities, even though major depressive disorder does not increase with age (Penninx & Comijs, 2012). The incidence of major chronic conditions, such as stroke, hypertension, heart failure, arthritis, cancer, and diabetes, also increases sharply after the age of 60 years (St Sauver et al., 2015), yet might level off among the oldest old (Akushevich et al., 2012). Studies suggest that the underdiagnosis of diseases in the oldest people is one possible reason behind the decline in disease incidence observed in the oldest old (Akushevich et al., 2012; Clough-Gorr & Silliman, 2012).

Conversely, the prevalence of some diseases, such as diabetes and cancer, does not increase notably with age but may in fact be less prevalent among the oldest old than the younger old (Bielak et al., 2012). Bielak et al. (2012) found that for several diseases, prevalence rates peaked among people in their 70s and were lower among people aged over 85 years. People who live beyond the average LE, i.e. long-living individuals, have earlier in life escaped major age-related conditions and represent the healthier end of their birth cohort (Ailshire et al., 2015). Ismail et al. (2016) found that the oldest old had delayed onset of chronic diseases compared to younger referents. Doblhammer & Barth (2018) found that people surviving to age 90 had a lower prevalence of dementia, ischemic heart diseases, cerebrovascular disease, cancer, depression, diabetes, and kidney disease than those who died between ages 85 and 90. Those who survived to age 100 had the lowest prevalence of most diseases, including dementia, throughout the oldest ages. In addition, the prevalence of most diseases increased with impending death. Evert et al. (2003) identified three categories of different morbidity profiles among the oldest old: survivors, delayers, and escapers. Among survivors, morbidity onset occurred before the age of 80 years, among delayers between ages 80 and 99 years, while escapers did not have diseases before the age of 100 years. Women were more likely to be survivors and men more likely to be escapers (Evert et al., 2003).

Both overall survival and morbidity-free survival to the oldest ages are characterized by female gender, higher educational level, lower blood pressure, lower cholesterol levels, absence of glucose intolerance, and nonsmoking status in midlife (Terry et al., 2005). However, it has also been argued that those living exceptionally long lives do not differ from the general population in their lifestyle habits earlier in life, i.e. they do not show lower levels of adverse habits (Rajpathak et al., 2011).

Despite the overall high prevalence of chronic diseases in this age group, there is much variation between individuals regarding their health status in very old age (Lowsky et al., 2014). Even though women on average live longer than men, men who live past 90 years are healthier than women at the same age (Vaupel, 2010) as women generally show higher rates of morbidity than men among the oldest old (Collerton et al., 2009; Salminen et al., 2012; Strauss et al., 2003). Gender differences have been found in the prevalence of hypertension and arthritis, which are more common in women, whereas men show a higher prevalence and incidence of cancer (Tanskanen et al., 2021) and CVDs (Collerton et al., 2009; Ismail et al., 2016). A factor consistently associated with a lower morbidity rate among the oldest old is high socioeconomic position (Enroth et al., 2013; Fors & Thorslund, 2015). It seems justified to argue, that the morbidity profile of those living the longest lives differs from the profile of younger old people.

Time trend studies of disease prevalence and incidence in the oldest old are limited, but some show an increasing prevalence of arthritis (Kwoh, 2012; Seeman et al., 2010), asthma (Seeman et al., 2010), diabetes (Barzilay, 2012; Crimmins, Zhang, et al., 2019), and cancer (Crimmins, Zhang, et al., 2019). A decrease in stroke incidence has been detected specifically for the oldest old men (Madsen et al., 2020). Additionally, recent evidence from Finland shows a stable cancer incidence among oldest old women and a slightly decreasing incidence in men, and a decreasing cancer mortality (Tanskanen et al., 2021).

One of the most significant conditions among the oldest old is dementia, since its incidence and prevalence are highly dependent on age. Dementia is therefore discussed separately below.

3.2 Dementia

Dementia is a syndrome characterized by a progressive deterioration in cognitive function. It can be caused by a disease or an injury. Dementia affects cognitive ability,

behavior, memory, and eventually the person's ability to maintain activities of daily living (ADL). (WHO, 2023a.) Neurodegenerative symptoms caused by dementia include difficulties with memory, language, problem-solving, and other thinking skills (Alzheimer's Association, 2021). Changes in mood and behavioral symptoms can also occur (WHO, 2023a). People with advanced dementia have a high rate of difficulties in physical functioning (Stenholm et al., 2015). Cognitive decline refers to a situation where memory-related tasks become more difficult but where the individual is still able to maintain their independence in daily activities (Juva, 2021). Dementia is strongly associated with mortality among the oldest old (Börjesson-Hanson et al., 2007; Doblhammer & Barth, 2018). In this study, 'dementia' is used as an umbrella term to describe the prevalence of memory disorders and cognitive decline.

The incidence of dementia increases with age in both women and men (St Sauver et al., 2015). Lucca et al. (2020) found an incidence of 6.7/100 person-years among people aged 80 to 84 years, rising to 14.0/100 person-years among those aged 90 to 94 years and higher still among the oldest study participants. Corrada et al. (2010) reported an annual dementia incidence rate of 18.2% in people aged 90 years and an exponential increase in the rate toward the oldest ages, reaching 40.7% in centenarians. The most common diseases that cause dementia are Alzheimer's disease (60-70% of cases), vascular dementia, Lewy body dementia, and frontotemporal dementia. Additionally, there are mixed forms. (Myllykangas, 2021; WHO, 2023a.) Among people aged over 85 years, vascular dementia, limbic-predominant age-related TDP-43 encephalopathy (LATE) dementia, and primary age-related tauopathy (PART) are proportionally more prevalent than in younger people, among whom Alzheimer's disease is the most important form of dementia (Myllykangas, 2021). The oldest old are more likely to have two or more causes of dementia than younger people (Alzheimer's Association, 2021).

Population-based studies have reported dementia prevalence rates between 41.2% and 51.5% for people aged over 90 (Börjesson-Hanson et al., 2007; Corrada et al., 2008). In women the figure has been found to double every five years after the age of 90 (Corrada et al., 2008). A study using health claims data also found an increasing prevalence of dementia among people aged 90 to 100 years and a prevalence of 52.8% at the age of 95 years (Doblhammer & Barth, 2018). Compared with people aged over 65 years, who have an estimated dementia prevalence of 11% (Alzheimer's Association, 2021), the share of people living with dementia among the oldest old is high. Furthermore, it has been estimated that dementia is still underdiagnosed (Gauthier et al., 2021).

Recent studies in the US have reported decreasing prevalence and incidence rates of dementia (Farina et al., 2022), and in other high-income countries such as France and the UK age-specific incidence rates of dementia have been lower in more recent than in earlier cohorts (Livingston et al., 2020). In a meta-analysis by Gao et al. (2019), the incidence of dementia was found to decline in all age groups, but the decline was less evident among persons aged over 85 years. The rapid increase in the number of older people means that the number of those with dementia is increasing worldwide, especially in low- and middle-income countries (Livingston et al., 2020).

Dementia has gained increasing prominence as a public health issue in aging populations on account of its contribution to disability and death. In the Global Burden of Disease Study in 2019, Alzheimer's disease and other dementias were found to be the fourth most important contributor to disability adjusted life years, a global summary measure developed for assessing the burden of disease by combining life lost by premature death and life lived with disability (i.e. in a state of less than optimal health) (WHO, 2020) among people aged over 75 years (Vos et al., 2020). Worldwide, dementia is the 7th leading cause of death (Gauthier et al., 2021). In Finland, dementia was the third leading cause of death in 2020, accounting for nearly 20% of all deaths, and the second leading cause of death among people aged over 75 years (Official Statistics of Finland (OSF), 2021c). The number of people aged over 90 with dementia in Finland is expected to quadruple by 2060 (Viramo & Sulkava, 2015). Worldwide, 55 million people have a dementia diagnosis, and that number is estimated to rise to 150 million in year 2050 (Gauthier et al., 2021; Livingston et al., 2020).

Age is the most important risk factor for neurodegenerative diseases (see e.g. Hou et al., 2019). However, dementia is not an inevitable consequence of aging, even in oldest age (Qiu & Fratiglioni, 2018). The risk of dementia is also increased by certain gene mutations and genetic variations, which as yet are non-preventable (Loy et al., 2014). Livingston et al. (2020) have presented a life-course model of 12 modifiable risk factors for dementia, that could help to prevent or delay dementia, including several lifestyle-related risk factors, education, and conditions such as hypertension and depression. They estimate that 40% of all dementia cases are attributable to these risk factors and could theoretically be prevented by eliminating them (Livingston et al. 2020). However, most studies on risk factors have concentrated on earlier onset dementia, and it is not clear to what extent the same risk factors for incident dementia apply to the oldest old because of the remarkable contribution of age to the risk of dementia development (Vos et al., 2017).

3.3 Multimorbidity and comorbidity

In research contexts, the term 'multimorbidity' has been mostly used to describe situations where an individual has two or more concurrent conditions, with no emphasis given to any single condition (Nicholson et al., 2019; Tugwell & Knottnerus, 2019; Valderas et al., 2009; van den Akker et al., 1996). Multimorbidity was added as a Medical Subject Heading (MEsH) to the National Library of Medicines thesaurus in 2018 (Tugwell & Knottnerus, 2019), and the Finnish Current Care Guidelines for patients with multiple chronic conditions were released in 2021 (Monisairas potilas: Käypä hoito -suositus, 2021).

The term 'comorbidity' has been used in parallel with 'multimorbidity', but it is currently recognized as an independent term and a MEsH heading, referring to a situation where the emphasis in research or in clinical practice is on one specific index condition and the combined effects of additional co-occurring conditions (Nicholson et al., 2019; van den Akker et al., 1996). The definition of 'index' disease and comorbid disease depends on the context and can thus vary (Valderas et al., 2009).

There has been an increasing need to define and describe multimorbidity and comorbidity. With population aging it has become evident that most people develop several separate or related chronic conditions as they age (Barnett et al., 2012). Interactions between chronic diseases mean that the negative outcomes of multimorbidity are greater than could be expected based on the sum of the diseases individually (Vetrano et al., 2018). Health care systems and interventions are largely designed for people with one disease, who are typically younger, and for people with an occasional need for care. Thus, people with multimorbidity often face fragmented care and lack of care continuity. (Banerjee 2015; Vetrano et al., 2018.) Multimorbidity has been associated with a higher number of hospital admissions, referrals to specialist care, and higher health care expenditures (Marengoni et al., 2011). In a European-wide study, a higher number of chronic conditions was associated with a higher number of primary health care visits, longer hospital stays, an increased number of hospitalizations and the overall likelihood of being hospitalized (Palladino et al., 2016).

According to a review by Diederichs et al. (2011), the list of conditions included in multimorbidity studies can range from four up to as many as 102 conditions. In addition, the conditions included can differ in their nature and duration; most studies examine diseases rather than symptoms, but conditions such as anemia and loss of

vision and hearing may also be included. van den Akker et al. (1996) suggest that both chronic and acute conditions should be considered in multimorbidity assessments, but generally the emphasis is on long-term chronic conditions (Lefèvre et al., 2014). NICE guidelines for the clinical assessment and management of multimorbidity say that multimorbidity refers to having at least two long-term health conditions, including both physical and mental health conditions, ongoing conditions such as learning disability, symptom complexes such as frailty or chronic pain, sensory impairments, and substance or alcohol misuse (National Institute for Health and Care Excellence, 2016). From an epidemiology viewpoint, co-occurring diseases can have implications for the interpretation of causal associations, for example in assessing the role of diseases causing disability. Co-occurring diseases may also have interactions that modify the effects of treatment or prevention (Fried & Wallace, 1992).

The concept of multimorbidity has been criticized as being doctor- and researcher-centered, too vague and meaningless to be used in clinical settings or in policy planning, and as carrying overly negative connotation for the individual with multiple diseases (Ford & Ford, 2018). According to Valderas et al. (2009), different definitions of multimorbidity and comorbidity are appropriate for different purposes. Multimorbidity can be a relevant concept in primary care with its emphasis on the patient as a whole, whereas comorbidity can be more useful in specialized care, where the focus often is on a specific disease and any associated conditions. Public health and epidemiology make use of both multimorbidity and comorbidity. (Valderas et al., 2009.)

Multimorbidity and comorbidity measures

Lack of consensus on which multimorbidity measures to use in research has led to the development and adoption of various different approaches and indices. Charlson's Comorbidity Index includes 19 conditions that are weighted according to mortality. The index was originally validated among hospitalized patients with an intention to create a comorbidity index for use in longitudinal studies as a prognostic method for short-term mortality. (Charlson et al., 1987.) It has been validated for mortality prediction in several settings but was not designed to be used in community-dwelling older people (Newman, 2012). The Index of Coexisting Diseases (Greenfield et al., 1993) and the Cumulative Illness Rating Scale (Linn et al., 1968) both emphasize the severity of a condition. Index of Coexisting Diseases includes 14 conditions derived from medical records and laboratory data and was developed to predict complications and self-reported health after hip replacement. It classifies patients according to two dimensions: severity of each condition and

physical impairment. (Greenfield et al., 1993.) Cumulative Illness Rating Scale includes 13 conditions and assesses physical impairment related to the conditions. It has been used in inpatient settings, both in long-term care and, with modifications, in outpatient care. (Newman, 2012; Tilvis, 2009.)

Multimorbidity can be measured by a simple disease count, with coexisting conditions summed from a list of varying conditions. Count is one of the most commonly used multimorbidity measures in research (Lefèvre et al., 2014). Additionally, several indices of multimorbidity and comorbidity have been developed; one review identified 35 different multimorbidity indices in research (Stirland et al., 2020). As noted by Tilvis (2009), there are numerous possible combinations of diseases, and the choice of index will depend on the outcome of interest. Most indices measuring multimorbidity have been developed in specific populations of inpatient samples, concerning specific outcomes, and not representing the general population (Diederichs et al., 2011).

Given the complex health problems of the oldest old, the choice of the most appropriate multimorbidity measure is far from straightforward. In a follow-up study among people aged over 80, Charlson's Comorbidity Index, Cumulative Illness Rating Scale, and disease count predicted mortality and hospitalization but not functional decline. The authors concluded that none of the measures were significantly better than others (Boeckxstaens et al., 2015.) Because of its simplicity and usefulness in population-based research, disease count can be considered a suitable measure of multimorbidity in studies of older people, and it is used in the present study to describe multimorbidity in the oldest old individuals.

Multimorbidity pathways and clusters

Valderas et al. (2009) have presented three main pathways leading to the co-occurrence of diseases (Figure 2). First, diseases can co-occur in the same individual by chance, without any underlying causation or linkage between the diseases. Second, disease clusters can be observed due to selection bias in research, i.e. people seeking treatment are more likely to get diagnosed than the general population. The third pathway is causal and involves several causal mechanisms: 1) direct causation, 2) associated risk factors, 3) heterogeneity, and 4) independence. (Valderas et al., 2009.) Causation refers to a situation where one condition directly causes another condition, whether by exposing the individual to a subsequent condition or due to iatrogenic reasons. Associated risk factors mean that the risk factors for one disease are correlated with the risk factors for another disease. Heterogeneity refers to the accumulation of non-correlated risk factors in an individual, which may then cause several conditions. In the independence model, seemingly distinct diagnoses are

caused by a third, underlying condition. (Valderas et al., 2009.) Valderas et al. (2009) note that these models have not been extensively applied to studies of multimorbidity.

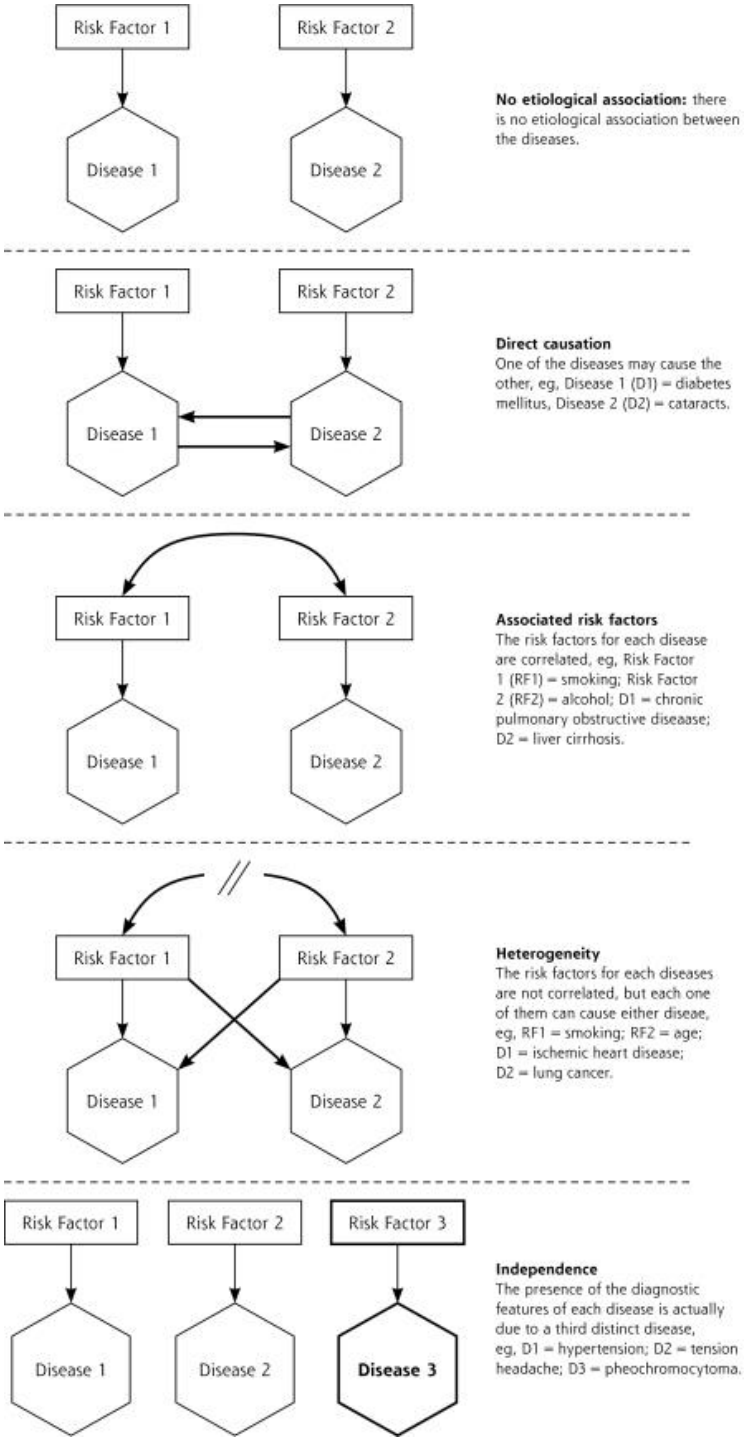


Figure 2. Etiological models of multimorbidity from Valderas et al. (2009)

Certain chronic diseases have indeed been found to cluster, suggesting that multimorbidity is not completely random. In addition, people with one disease are more at risk for developing multimorbidity, than those without a baseline condition (Kudesia et al., 2021). Disease clusters can show differing patterns in different populations, and among the oldest old people clusters are characterized by a high number of co-occurring diseases (Collerton et al., 2016; Formiga et al., 2013), cognitive and sensory impairment (Marengoni et al., 2020), and only very few people belonging to a 'healthy' cluster (Collerton et al., 2016). In the study by Collerton et al. (2016), hypertension, arthritis, and sensory impairment had a high prevalence in four out of the total five disease clusters identified, reflecting their high prevalence in the oldest old. Hypertension and arthritis have been found to be the most common incident dyad of diseases in oldest old women, and hypertension and cancer in oldest old men (St Sauver et al., 2015). According to Collerton et al. (2016), the most prevalent multimorbidity cluster included diseases related to circulatory system (e.g. hypertension, heart failure, renal impairment, diabetes), and the second most prevalent cluster included diseases and conditions such as sensory impairment, incontinence, falls, and cognitive impairment.

One of the most important conditions in multimorbidity clusters in old age is cognitive decline and dementia (Banerjee, 2015). Having multimorbidity with dementia has been associated with a greater risk for mortality, lower functional ability, and longer stay at institutional care than having multimorbidity without dementia (Snowden et al., 2017). Vargese et al. (2023) showed in the Vitality 90+ data that people with dementia and multimorbidity had a higher risk for ADL disability than those with multimorbidity but no dementia. The difference in disability between those with and without dementia increased from 2001 to 2018 (Vargese et al., 2023).

Multimorbidity is closely related to frailty and having at least two conditions increases the likelihood of being frail. However, not all people with frailty have multimorbidity (Fried et al., 2001). Multimorbidity is more common than frailty, and a meta-analysis showed that less than one-fifth of adults with multimorbidity are also frail. The association between multimorbidity and frailty is bidirectional, as they both are risk factors for each other. (Vetrano et al., 2019.)

Descriptive epidemiology of multimorbidity

It has been estimated that over half of the population aged over 65 years in high-income countries have multimorbidity (Barnett et al., 2012) and that the prevalence of multimorbidity is increasing in the adult and older population (Koné Pefoyo et al., 2015; Singer et al., 2019). In particular, it seems that the proportion of people

with more complex multimorbidity, i.e. with three, four or five concurrent diseases, is on the rise (Koné Pefoyo et al., 2015). Multimorbidity affects people of all ages, but its prevalence increases with advancing age and the mean number of diseases is higher in older ages (Barnett et al., 2012). As shown in Table 1, the prevalence of multimorbidity is high among people aged over 80: estimates are close to 80% and as high as 95.1% (Barnett et al., 2012; Collerton et al., 2016; Formiga et al., 2013; Hajek & König, 2023; Koné Pefoyo et al., 2015; Puth et al., 2017; Salive, 2013; Yao et al., 2020). However, a global prevalence study by Garin et al. (2016) found that multimorbidity prevalence varied in the oldest old and declined among people aged 80 or over in several countries. The study involved samples from Asia, Europe, and Africa and suggested that the variation seen between countries may be due to level of development, better medical management, and also certain country-specific risk factors for multimorbidity. The highest prevalence rates in the oldest old were found in Russia and Finland, and the lowest in South-Africa and Ghana. (Garin et al., 2016.)

Women are generally more affected by multimorbidity at all ages (Barnett et al., 2012; Garin et al., 2016; Salive, 2013), and low socioeconomic status has been associated with higher multimorbidity prevalence (Barnett et al., 2012; Puth et al., 2017). However, there is some evidence that in the oldest old, socioeconomic differences in multimorbidity prevalence may diminish to some extent (Puth et al., 2017). In the Vitality 90+ Study, lower educational level was associated with higher multimorbidity prevalence (Enroth, 2017).

Table 1. Studies reporting multimorbidity (≥2 diseases) prevalence for the oldest old

Author(s), Year	**Data source and country**	**Age, n**	**No. of diseases included**	**Prevalence (95% CI)**	**Mean (SD) or median (IQR) number of diseases**
Barnett et al. (2012)	Clinical patient data from medical practice registers, Scotland	≥85 years 36,569	40	81.5 (81.1-81.9)	3.62 (2.3)
Formiga et al. (2013)	Interview data from community-dwelling people, Spain	≥85 years, 328	16	95.1%	n.a.
Salive (2013)	Administrative claims data of Medicare beneficiaries, United States	≥85 years, n.a	15	81.5%	n.a.
Koné Pefoyo et al. (2015)	Health administrative databases, Canada	≥90 years 54,302 in 2003,	16	74.6% in 2003, 83.2% in 2009	n.a.

		74,159 in 2009			
Collerton et al. (2016)	Health assessment and review of GP records from 53 general practices, England	85 years, 710	20	92.7%	4 (3-6)
Puth et al. (2017)	Telephone interview data, Germany	≥80	17	77.5% (73.2-81.3)	3.5 (3.2-3.7) 3
Yao et al.(2020)	Interview survey data, China	≥80, 1,305	14	56.5% (weighted prevalence)	n.a.
Hajek & König (2023)	Survey data, Germany	≥90, 261	19	85.1%	n.a.

n.a.: not available

The incidence of multimorbidity increases sharply with age, and age is the most pronounced risk factor for incident multimorbidity (Melis et al., 2014; St Sauver et al., 2015). Reported incidence rates vary greatly, ranging from 1.26 to 342/1000 person-years (Kudesia et al., 2021). Melis et al. (2014) found an incidence rate of 12.6/100 person-years among people aged over 75 without diseases at baseline, and an incidence rate of 32.9/100 person-years among people with one chronic disease at baseline, which means that having one condition increases the risk for having subsequent conditions. Among the oldest old, a US study found an incidence rate of 260/1000 person-years among men aged over 80, and 277.1/1000 person-years among women aged over 80 with zero or one chronic condition at baseline (St Sauver et al., 2015).

Besides age, risk factors of incident multimorbidity have not been fully explored. The overall incidence has been found to be slightly higher among women than men (St Sauver et al., 2015), but a Swedish study among older people did not find gender differences in the incidence rate (Melis et al., 2014). Lower education, a high number of earlier diseases (Marengoni et al., 2011), depressive symptoms, and poorer cognition have been associated with incident multimorbidity (Melis et al., 2014). Among life-style related risk factors, lack of physical activity has been found to increase the risk of incident multimorbidity. Combinations of adverse lifestyle factors, such as obesity and inactivity, were found to further increase the risk of incident multimorbidity. (Dhalwani et al., 2017.)

Variations in multimorbidity incidence and prevalence rates across studies are at least partly explained by variation in study populations since some studies are conducted among the general population and others involve patient samples with a specific baseline condition. In addition, the age distribution and ethnic background of study participants varies. Studies may also have different follow-up times and lack uniform criteria for defining multimorbidity. (Kudesia et al., 2021.)

4 HEALTH OUTCOMES RELATED TO MULTIMORBIDITY

4.1 Disability

Disability can be conceptualized as a gap between the demands of the environment and the person's physical or cognitive capacity, which makes it difficult or impossible for them to fulfill their social or role functions (Guralnik et al., 2012). Disability in old age is a highly significant outcome of interest, reflecting the individual's level of independence, care needs, and overall burden of diseases. As well as an important outcome, disability is predictive of adverse medical outcomes such as mortality, hospitalization, need for long-term care (LTC), and higher health care costs and expenditures, and it acts as a measure of quality of life. (Fried et al., 2004; Guralnik et al., 2012.)

According to Guralnik et al. (2012), the most widely used model in empirical research on the pathway from disease to disability is the framework originally presented by Nagi (1965) and later updated by Verbrugge & Jette (1994), who added the environmental aspect. The disablement process depicts the pathway from pathology to disability. In this process, pathology leads to impairments, which are dysfunctions and abnormalities in specific body systems, restricting normal physiological, social, or mental functioning. These in turn result in functional limitations, i.e. restrictions in basic physical and mental actions, such as impaired mobility, seeing, hearing or orientation in time and place. The impact of pathology on the level of disability is modified by both environmental factors (health care, rehabilitation, personal assistance, built environment) and individual characteristics, such as accommodation and psychosocial factors. Furthermore, new pathologies may occur when disabilities restrict functioning, or a secondary disablement process unfolds as a consequence of the first process. (Verbrugge & Jette, 1994.)

The WHO International Classification of Functioning, Disability and Health is a framework based on a biopsychosocial model of disability, the aim of which is to provide a coherent overview of health. In this model, disability is seen as an outcome of interactions between health conditions (i.e. diseases or injuries) and the context

in which the person lives (i.e. environmental factors and personal factors) (WHO, 2002).

Disability in old age can develop either progressively in association with underlying diseases or frailty, or catastrophically following an acute clinical event, such as stroke (Fried et al., 2004; Guralnik et al., 2012). Catastrophic disability occurs more often among younger old people, whereas among people aged over 85 years severe disability usually develops progressively (Guralnik et al., 2012).

It is not straightforward to distinguish the contributions of age and diseases on disability, which in old age can be described as an outcome of physiologic variation related to aging and diseases (Fried et al., 2004). Older people without any disease have also been found to report disability, and chronic diseases differ in their contributions to disability (Klijs et al., 2011). Furthermore, Klijs et al. (2011) concluded that the disabling effect of diseases increases with age. Disability plays a major role in the lives of people with multimorbidity. Rizzuto et al. (2017) found that older people (aged over 78 years) with multimorbidity lived with disability for the most of their remaining life.

Functional ability in old age is often measured by ADL or instrumental activities of daily living (IADL). The ADL index by Katz et al. (1963), was developed as an objective tool for monitoring the functional ability in aging populations and for assessing the effect of diseases on functional ability in older people. The index originally included six activities: bathing, dressing, going to toilet, transferring from bed and chair, continence, and feeding (Katz et al., 1970). The ADL index by Katz et al. (1970) assesses if a person can perform the activities listed without assistance, with assistance, or not at all. ADLs reflect a substantial degree of disability and identify well the most severely disabled individuals. The greater the number of items with which the person has difficulty, the more severe their disability. (Guralnik et al., 1996.)

The IADL scale proposed by Lawton & Brody (1969) includes activities related to daily tasks such as using a telephone, shopping, cooking, cleaning, doing laundry, using transportation, using medication, and handling finances. A hierarchical relationship between ADLs and IADLs is well established in that most people with ADL disability also have IADL disability (Guralnik et al., 2012). IADL items are related to independent living in the community and are more complex than ADL items (Guralnik et al., 1996).

The probability of ADL disability increases with age and people aged over 85 have a more than two times higher risk for ADL disability than those aged 75 to 79 years (Jagger et al., 2001). Jagger et al. 2001 found that the median age at ADL

disability onset (i.e. having difficulty, using aid, or cannot perform) was 78 years. Among the oldest old, Fong (2019) reported a median age of ADL disability onset (i.e. having difficulty with an activity) of between 91.5 to 95.6 years, depending on the activity. Those with major chronic diseases had an earlier onset of ADL disability than those without major chronic diseases (Fong, 2019).

Functional decline accelerates in very old age (Jagger et al., 2001; Raitanen et al., 2020). The estimated prevalence of ADL disability among the oldest old people differs by measure, but over half have ADL disability in at least one activity (Nybo et al., 2001). In the Vitality 90+ Study, 82.7% of men and 76.8% of women were independent in dressing and undressing and transferring from bed (Enroth et al., 2020). In the Healthy Finland Survey, 28% of men and 42% of women aged over 85 years had major difficulties in at least one daily activity and 17% of men and 19% of women had major difficulties in at least one basic activity (cooking meals, bathing, dressing) (Sääksjärvi et al., 2023). Women generally show higher rates of disability than men (Strauss et al., 2003; Terry et al., 2008; Thinggaard et al., 2016), and the incidence of long-term disability is higher among women (Strauss et al., 2003). It has been suggested that this is at least partly due to women surviving longer with milder disability earlier in life (Strauss et al., 2003).

Disability in different activities seems to decline in a hierarchic manner. Activities that require lower-extremity strength appear to deteriorate first (bathing, mobility, and toileting) followed by those requiring upper-extremity strength (dressing and feeding). (Ferrucci et al., 1998; Jagger et al., 2001.) Ferrucci et al. (1998) note that a disease may interfere in the progress of disability when one function is greatly affected by a disease (e.g. hand arthritis) while other functions remain intact. Thus, Ferrucci et al. (1998) present that the progressive disablement model in old age is particularly useful in describing the process in people with several conditions that affect their functioning.

4.2 Self-rated health

Self-rated health (or self-assessed health or self-perceived health) is a simple, subjective measure of general health status. It captures an individual's own assessment of health, reflecting their understanding of health within their cultural context and in relation to age-peers, as well as their knowledge of their past and present health status. (Jylhä, 2009.) Measured with a single-item question and widely

used in health studies, self-rated health is highly predictive of mortality among older people (DeSalvo et al., 2006; Jylhä, 2009). It is usually measured using a five-point scale ranging from 'excellent' to 'poor', or from 'very good' to 'very bad' (Jylhä, 2009).

The proportion of people reporting good health declines gradually with age. In a study by Lowsky et al. (2014), 48% of people aged 51-54 years reported good health, compared to 28% among people aged over 85 years. In a Finnish population-based study, 35% of men and 25% of women aged over 80 years rated their health as fairly good or good (Koskinen et al., 2018). However, when disabilities and chronic conditions are adjusted for, older people rate their health relatively better than younger old people (Jylhä, 2009). Nybo et al. (2001) found that despite a high prevalence of functional limitations, 56% of people aged over 90 years rated their health as excellent or good. In an Australian study, almost two-thirds of the oldest old reported at least good health (French et al., 2012). Women tend to report poorer health than men among both the younger old and the oldest old people (Nützel et al., 2014; Simonsson & Molarius, 2020). Other factors reported to have an association with poor self-rated health among the oldest old are depression, physical inactivity, impaired mobility, and pain (French et al., 2012; Simonsson & Molarius, 2020). In the Vitality 90+ Study, most diseases were not directly associated with self-rated health but indirectly via symptoms such as fatigue, depression, and impaired ADL and mobility (Lisko et al., 2020).

Among older people the association between multimorbidity and poor self-rated health seems to be cumulative rather than synergistic (Galenkamp et al., 2011), and it seems that a higher number of chronic diseases is associated with poor self-rated health even in the oldest old (French et al., 2012; Galenkamp et al., 2011). It has been found that having one disease decreases self-rated health relatively more than co-occurring diseases, but this association may be less evident among the oldest old individuals. This is most likely due to the overall poorer self-rated health of the oldest old without diseases compared with younger old people without diseases (Galenkamp et al., 2011). In the Vitality 90+ Study, self-rated health declined in a longer follow-up, and this decline was explained by an increasing number of chronic diseases and declining functioning (Galenkamp et al., 2013). The association between multimorbidity and self-rated health may be at least partly explained by the symptom burden of multimorbidity. Nützel et al. (2014) found that symptoms, specifically pain, disability, depression, and restrictions in independent living were associated with poor self-rated health in people with multimorbidity.

4.3 Long-term care

Long-term care consists of the constant support that people need with daily activities due to restrictions in their physical or cognitive functioning (Finne-Soveri, 2016). Under the Act on Client Charges in Healthcare and Social Welfare, a person is considered to reside in long-term care when they spend at least 90 days in a care facility (*Act on Client Charges in Healthcare and Social Welfare 734/1992*). The oldest old have care needs due to their relatively high prevalence of disabling chronic conditions and general age-related loss of function. The proportion of people living in LTC rises with age and the length of stay is longer for the oldest people (Aaltonen et al., 2017a; Gellert et al., 2018). Findings from the Vitality 90+ Study showed that in 2018, 32% of women and 24% of men lived in LTC, and the share of women living in LTC decreased from 2001 to 2018 (Enroth et al., 2020). Women show a higher risk for entering LTC than men (Kauppi et al., 2018; Martikainen et al., 2009) and spend on average more days in LTC than men (Martikainen et al., 2009).

Older people living in LTC have high levels of dementia and multimorbidity (Harrison et al., 2019). Among centenarians, a German study found a dementia prevalence of 85% for those living in LTC, compared with 27% for those without any care (von Berenberg et al., 2017). In a follow-up study among Finnish community-dwelling older people, dementia, mood disorders, neurological disorders, and severe multimorbidity (3+, 4+ or 5+ conditions) emerged as risk factors for entering LTC (Viljanen et al., 2021). A Finnish study of people aged over 65 years reported that dementia, Parkinson's disease, hip fracture, diabetes, stroke, and depression presented an increased risk for LTC (Nihtilä et al., 2008). Declining functional ability is often a result of chronic diseases such as dementia, and functional ability is one of the main drivers for the need of LTC (Luppa et al., 2010).

Before the health and social services reform in 2023, LTC for older people in Finland was financed by municipalities. Based on a universal, publicly funded system, LTC provision has changed significantly during the 2000s, shifting from institutional care provided in health centers and nursing homes to sheltered housing with or without 24/7 assistance. The private sector has assumed an increasingly prominent role with the growth of sheltered housing services provided by for-profit organizations. (Keskimäki et al., 2019.) As care policies have favoured living at home for as long as possible (Tynkkynen et al., 2022), the focus of LTC has increasingly shifted toward the end of life and older ages (Aaltonen et al., 2017a).

In the present study, LTC is defined as covering care that takes place on inpatient wards and in 24-hour sheltered housing, thus excluding home care, which is also part of the care system for older people in Finland (Keskimäki et al., 2019).

4.4 Mortality

Age is the most important element in predicting mortality (Koroukian et al., 2016). In humans, the mortality rate accelerates with age, and doubles every eight years after puberty (Finch et al., 1990). The oldest old have a high mortality rate: around 16% of those aged 90 die within a year (*Human Mortality Database*, 2023). The main causes of death in Finland in 2020 among people aged over 75 years were CVDs, dementia, and cancer (Official Statistics of Finland (OSF), 2021c).

Research on mortality predictors has given increasing focus to studying older people as deaths have become more and more concentrated in older ages. Koroukian et al. (2016) found that in older people the highest risk of death was among those aged 80.5 years or older, who have limitations in both ADLs and IADLs. Thinggaard et al. (2016) examined functional indicators as predictors of survival from age 90 to 100 years and reported that the most prominent predictors in both men and women were the chair rise test and better cognitive functioning, as measured by the Mini-Mental State Examination score (Thinggaard et al., 2016).

The role of functional ability in predicting mortality in old age has also been emphasized by others (Landi et al., 2010; Lee et al., 2008). Lee et al. (2008) found that at older ages, the ability of chronic diseases to predict mortality declined, and among the oldest old functional limitations were stronger predictors of mortality than diseases. Similar results have been presented by Landi et al. (2010), who in a four-year follow-up among community-dwelling oldest old individuals found that disability was a strong risk factor for death independent of the number of diseases. In the oldest old, ADL and mobility disability have been found to be stronger predictors of mortality in men than in women (Tiainen et al., 2013).

Diseases can have different survival effects, and it has been suggested that an increasing number of diseases does not necessarily have a major impact on survival (Marengoni et al., 2011). Among community-dwelling oldest old people, Ferrer et al. (2017) reported that dementia, cancer, and chronic obstructive pulmonary disease (COPD) were predictive of mortality during a follow-up of five years. Their analyses of combinations of diseases found that cancer was included in all combinations

predicting five-year mortality along with conditions such as anemia, hypertension, kidney disease, dyslipidemia, and visual impairment. A study focusing on multimorbidity patterns in community-dwelling people aged over 65 years up to the oldest ages, found that the mortality risk differs according to the pattern of multimorbidity within a similar frailty state (Nguyen et al., 2018). The highest mortality risk was observed among people with the 'neuropsychiatric' pattern, i.e. individuals with stroke, a psychiatric disease, and dementia, in all frailty states (Nguyen et al., 2018).

Landi et al. (2010) proposed that the combined effect of multimorbidity and disability on mortality seems to be greater than the effect of disability or multimorbidity alone. Furthermore, due to its high prevalence among old people, multimorbidity has been estimated to account for approximately 70% of deaths in people aged over 78 years (Rizzuto et al., 2017). In a review on multimorbidity, Marengoni et al. (2011) hypothesized that disease severity, duration, and the interaction of chronic and acute diseases may be more important factors than the person's number of diseases.

5 SURVEY METHODS IN RESEARCH ON THE OLDEST OLD

Surveys are one of the most popular methods of data collection in health sciences research. Survey data can be collected from large population samples or specific subpopulations, and they provide valuable information for the design of public health actions. The use of survey questionnaires as a data collection method dates back to the early 1900s when epidemiologic research on health determinants began to gain traction. (Hageman et al., 2015.) Examples of population-based health studies that rely on survey information include the Health and Retirement Study (see Sonnega et al., 2014) and the Survey of Health, Aging, and Retirement in Europe (see Börsch-Supan et al., 2013).

Recruitment and data collection in studies on older people can often be complicated by a high prevalence of diseases, restrictions in both cognitive and physical functioning, and the relatively large share of people living in long-term care (Jylhä, 2020; Mody et al., 2008; Strotmeyer & Ward, 2012). Identifying the base population of the oldest old individuals can be challenging if population registers are not available (Jylhä, 2020). Health research among older people therefore often faces the problem of selection bias, and the results mostly represent the healthy part of the population (Jylhä, 2020; Strotmeyer & Ward, 2012). People living in long-term care might be unable to provide informed consent, to answer the questions, or participate in health examinations. Data collection can also be time consuming due to the special arrangements needed because of sensory impairment, fatigue, or cognitive problems (Jylhä, 2020). Excluding people living in care facilities would lead to underestimation of health outcomes, such as the prevalence of diseases and functional limitations, as shown by Kelfve et al. (2013).

The representativeness of the study population in research on the oldest old can be increased by using proxy respondents, who can provide information on behalf of those who are unable to answer for themselves (Jylhä, 2020; Gruber-Baldini et al., 2012). Kelfve et al. (2013) showed that excluding participants who use proxy respondents could lead to reduced prevalence rates for diseases and functional limitations. Participants using proxies have been found to be older, lower educated,

and in poorer physical and mental health than those who answer for themselves (Gruber-Baldini et al., 2012).

However, proxy responses are to some extent prone to bias. Discrepancies between proxy responses and self-responses can be due to the participant's or proxy respondent's characteristics, the nature of the domain concerned (subjective or objective), the relationship of the participant and the proxy, and differences in the assessment methods used (Lynn Snow et al., 2005). Furthermore, the accuracy of proxy reports may be influenced by caregiver stress and proxy respondents' depressiveness (Gruber-Baldini et al., 2012; Neumann et al., 2000). Proxies tend to overrate the participant's level of disabilities, specifically concerning cognitive status, social status, and ADL and IADL disability (Li et al., 2015). Conditions and symptoms that are not visible or are more subjective, such as depressive mood or bloating, show higher bias than observable, objective conditions (Gruber-Baldini et al., 2012). A study among octogenarians reported high agreement between proxy- and self-reported diseases for diabetes, atrial fibrillation, myocardial infarction, angina, and hypertension (Rydén et al., 2019).

Several studies among older people have used register data from different sources. Hale et al. (2019) emphasized the importance of using register data from general practices because of the variability observed in the agreement between self-reported and general practice recorded data, and the finding that frailty increased the discrepancies. A higher level of multimorbidity has been associated with lower agreement between self-reported and health register data in disabled older women and in octogenarians (Simpson et al., 2004; Teh et al., 2013). The discrepancy seems to increase with increasing age (Simpson et al., 2004). However, Simpson et al. (2004) found that in the case of diseases showing high overall agreement, the agreement remained stable despite increasing age.

In older people, several health conditions have been associated with poorer agreement between self-reported information on chronic diseases and register data. Diseases with major functional effects or requiring constant monitoring seem to be more accurately reported by self-reports, whereas diseases with fluctuating symptoms and remissions, not requiring monitoring, and with fewer effects on performing daily routines, show lower agreement (Simpson et al., 2004). CVDs were found to be largely underreported by centenarians themselves when compared with physician-reported and clinically confirmed diseases (Andersen-Ranberg et al., 2013). Self-reported information has been found to both over- and underreport disease prevalence (Koller et al., 2014; Muggah et al., 2013; Rydén et al., 2019).

The use of register data in health research has been motivated by challenges related to the use of survey methods, including poor response rates (Stedman et al., 2019), high costs, and time-consuming research processes (Casey et al., 2016). However, health registers are not inherently designed to provide data for research, and researchers have no say over what data is collected in the registers (Casey et al., 2016; Laugesen et al., 2021). Registers therefore also have their limitations and shortcomings for research purposes. Furthermore, registers may have problems with representativeness in that they rarely cover the whole population, and they are dependent on the availability of treatment and care seeking behavior. In Finland, however, national health registers are highly exhaustive and have been widely used in health research (Laugesen et al., 2021). Even so, Solomon et al. (2014) found that dementia occurrence was underestimated in the Hospital Discharge Register (now the Care Register for Health Care) and the Prescription Register when these sources were compared with a clinical examination. Laatikainen et al. (2020) found a high level of agreement between Finnish care register information and data from a population study concerning diabetes, coronary heart disease, asthma, and COPD but depression was underreported in the registers. Risk factors such as obesity and hypertension were poorly detectable in the registers (Laatikainen et al., 2020).

6 SUMMARY OF PREVIOUS LITERATURE

The oldest old constitute a unique population for health research in that they are faced with age-related deterioration in health, yet earlier in life they have likely been healthier than their birth cohort peers. As more people live to the oldest ages, variation in the health of the oldest old is bound to increase even further. Age is the single most important risk factor for several chronic diseases, and the incidence and prevalence of most diseases and multimorbidity increase with age. Aging and the development of diseases and multimorbidity share basic mechanisms in common, and to some extent they are bidirectional processes. They often result in disability and disability may also increase the risk of subsequent diseases. Both diseases and disability contribute to the high mortality seen in this age group. Their disease burden and disability mean that people living to the oldest ages often have care needs at least for some time before death, and the use of LTC is rather common among the oldest old.

Health in very old age deserves increased research attention. Even though the oldest old today account for only a small percentage of the population, they make up the fastest growing population segment in Finland and worldwide. The oldest individuals represent the result of increasing LE, the 'greatest human accomplishment' of recent times (Crimmins, 2015). Studying disease patterns and multimorbidity in the oldest ages can help gain a deeper understanding of aging. Previous studies have found that neurodegenerative diseases, for example, are more frequent in the oldest ages, whereas other diseases seem to reach peak prevalence in younger old age. These findings may change over time with advances in diagnosis and treatment as well as increasing longevity. Specifically in Finland, the oldest old have been less well represented in research, partly because of the challenges involved in studying a population group with high numbers of diseases, cognitive decline, and living in care facilities. Studies have been limited in terms of the number of participants, representativeness, and short follow-up times. Hence, there are still gaps in research on the health of the oldest old. Data for population-based health studies have been mainly collected using the survey method, but the emergence of health registers has broadened the tools available. Studying the oldest old is well

justified for purposes of better policy and service planning, as well as for providing guidance to clinical practice and future aging research.

7 RESEARCH AIM AND QUESTIONS

The aim of this study was to assess the level of multimorbidity and prevalence of chronic diseases among people aged over 90 years and to analyze how chronic diseases and multimorbidity are related to specific health outcomes. The research questions were:

1. What is the prevalence of chronic diseases, particularly dementia and related comorbidity, and how has this prevalence changed from 2001 to 2018? (*study I and study II*)
2. What is the association of chronic diseases and multimorbidity with disability, self-rated health, and self-rated functioning? (*study I*)
3. To what extent do chronic diseases and multimorbidity predict long-term care admission and mortality? (*study III*)
4. To what extent is there agreement between self-reported and health register data on chronic diseases? (*study IV*)

8 STUDY POPULATION AND METHODS

8.1 The Vitality 90+ Study

The Vitality 90+ Study was initiated in 1995 in response to the growing need to investigate the health of the increasing oldest old population (Enroth et al., 2023; Jylhä et al., 1997). Most of the data for the study have been gathered through mailed surveys, but qualitative interview data, physical performance tests, and blood samples have also been collected over the years. Since 1995 there have been altogether 10 survey waves, and from 2001 onwards the study population has comprised all community-dwelling and LTC residents of Tampere, Finland, aged 90 years or older. The main themes addressed in the survey are health and functioning, social relations, living arrangements, quality of life, and care needs (Enroth et al., 2023). The present study used survey data from 2001, 2003, 2007, 2010, 2014, and 2018.

The response rate has been high across all survey waves, ranging from 77% to 86%. Reflecting the overall increase in the population aged over 90 in Tampere and Finland, the number of survey participants has increased over the study period. The majority of study participants have completed the questionnaire themselves, but proxy responses have been collected for participants unable to complete the survey themselves. The proportion of proxy respondents has ranged between 12.7% and 23.5%. (Table 2)

Table 2. Vitality 90+ Study survey participants 2001-2018

Study year	**2001**	**2003**	**2007**	**2010**	**2014**	**2018**
Number of people aged 90 or over in Tampere	1,063	1,113	1,147	1,606	2,056	2,449
Respondents *n*	892	961	944	1,277	1,637	1,878
Response rate %	83.9	86.3	82.3	79.5	79.6	76.7

8.2 National registers

The Finnish Population Register

Data on mortality, i.e., the date of death, for the Vitality 90+ study participants, was obtained from the Finnish Population Register (now the Finnish Population Information System). The register contains personal information such as name, personal identity code, citizenship, and date of birth and death for all Finnish citizens and permanent or temporary residents (Digital and Population Data Services Agency, 2023).

Care Register for Health Care and Care Register for Social Welfare

The Care Register for Health Care (CRHC) and the Care Register for Social Welfare (CRSW) are national registers maintained by the Finnish Institute for Health and Welfare. CRHC includes information on inpatient care in hospitals and health centers and on day surgery and other specialized outpatient care. CRSW includes information on care periods in nursing homes and 24-hour sheltered housing services (Hyttinen et al., 2022).

The Finnish Prescription Register

The Finnish Prescription Register (FPR) is a national register maintained by the Social Insurance Institution of Finland. FPR covers all prescription drug purchases from community pharmacies, including the Anatomical Therapeutic Chemical (ATC) code for each purchase and a reimbursement code, if applicable.

All register linkages were done using personal identity codes and performed by Statistics Finland.

8.3 Analytic data and variables

Study I used data from the Vitality 90+ survey conducted in 2014 with 1,637 respondents. The survey included a question on chronic diseases and conditions which asked 'Has a doctor told you that you have…?' with 'yes' or 'no' response options. The diseases inquired in 2014 were 'hypertension, high blood pressure', 'heart disease (coronary artery disease, arrhythmia, myocardial infarction)', 'dementia, Alzheimer's disease, or problems with memory', 'stroke', 'diabetes', 'arthritis', 'hip fracture', 'depression, depressed mood', 'cancer', and 'Parkinson's disease'. The conditions listed in the survey served as the explanatory variables in the

analysis together with multimorbidity, categorized as having 0-1 conditions (reference category), two conditions, three conditions, four conditions, and five or more conditions.

Functional ability was assessed in the survey with five questions measuring ADL and mobility. The questions were 'Are you able to… 1) move indoors, 2) walk at least 400 meters, 3) use stairs, 4) dress and undress, and 5) get in and out of bed.' The response options were 'Yes, without difficulty', 'Yes, but it's difficult', 'Not without help' and 'Unable'. The outcome variables in the logistic regression models were 1) ADL disability (including response options 'Not without help' and 'Unable' to either the question on dressing and undressing or getting in and out of bed), and 2) mobility disability (including response options 'Not without help' and 'Unable' to questions on moving indoors, walking 400 meters, or using stairs).

Survey participants were asked to rate their health and functional ability on a five-point scale with questions: 'How is your health in general?' and 'How would you rate your functional ability? Is it…' with the response options 'Very good,' 'Fairly good', 'Average', 'Fair', and 'Poor'. The outcomes in the study were poor self-rated health (including 'Fair' and 'Poor'), and poor self-rated functioning (including 'Fair' and 'Poor'). Proxy responses were excluded from the analysis of self-rated health and self-rated functioning, which was limited to the 1,320 self-respondents.

Study II used Vitality 90+ survey data from six time points: 2001, 2003, 2007, 2010, 2014, and 2018. The data from all survey years were merged and comprised 5,440 different participants with 7,588 separate observations. Participants with missing values (n=105) on chronic conditions were excluded from the analysis, which was thus conducted among 5,386 participants with 7,483 individual observations. Two-thirds (69%) of the participants responded in one survey round only, 25% in two rounds, and 6% in three or more rounds, mostly due to the high mortality between survey waves. All available diseases (cancer was not included in 2010, lung disease was included only in 2018, and Parkinson's disease was not included in 2018) were examined cross-sectionally. Trend analysis over time was performed on conditions for which information was available from all six survey rounds. Dementia was considered to be present in all participants who had reported having dementia once, even if they did not report dementia in subsequent survey rounds. Altogether 136 participants did not report dementia in the subsequent survey round after reporting it in a previous round.

Study III used data from the Vitality 90+ surveys in 2001, 2003, 2007, and 2010 and linked data from the population register, CRSW, and CRHC until the end of year 2012. The data included 2,862 participants, of whom 1,650 responded in one

survey round only, 1,004 participated twice, 176 three times, and 32 participated in all four survey rounds. Mortality was assessed among all 2,862 respondents. The analysis concerning LTC admission included 1,954 participants living at home at baseline. The register information was used to determine admission to LTC. Survey participants were considered to have entered LTC in case a LTC decision was made by the municipal authorities or the participant spent at least 90 days in a care facility, a definition for LTC that originates from the Act on Client Charges in Healthcare and Social Welfare (*Act on Client Charges in Healthcare and Social Welfare 734/1992*) and that has been used widely in studies concerning LTC (Enroth, 2017; Kauppi et al., 2018; Martikainen et al., 2014). Date of death was obtained from the population register.

Conditions included in the analysis as predictors of mortality and LTC admission were hypertension, heart disease, dementia, stroke, diabetes, arthritis, Parkinson's disease, hip fracture, and depression. Multimorbidity was measured as having 0, 1, 2, 3, and 4 or more conditions, and disability was measured as a sum of the five variables described above. The responses were scored from 1 (able without difficulty) to 4 (unable). The total score ranged from 5 (able to perform all five activities without difficulty) to 20 (unable to perform all five activities) and was used as a covariate in the regression models. Other covariates were age, year of entering the study, and occupational status based on the participant's main occupation during working life, classified according to Statistics Finland's classification of occupations (Official Statistics of Finland (OSF), 1976). In addition, the participants were asked if they lived alone or with someone. For this study living arrangements were categorized as living alone vs. living with others and was used as a covariate in LTC analysis.

Study IV used Vitality 90+ survey data from 2014 and register data from CRHC and FPR. Data on ICD-10 (International Classification of Diseases 10th Revision) codes of the main and secondary diagnosis for all care episodes recorded in CRHC and prescription data with ATC codes and reimbursement codes from FPR were used in comparing the disease information obtained from the survey.

In 2014, 74 out of the 1,637 respondents did not give permission to link their responses with health registers and were therefore excluded from the data. FPR data were linked with 1,117 responses since permission to use this register information was obtained only for participants deceased before December 31, 2018. CRHC data were linked from the beginning of 1996 until the start of survey data collection on January 17, 2014. Data from FPR were linked beginning from January 1, 2010. Fifteen respondents had missing information on chronic conditions in the survey

and were excluded from the analysis. The final samples for the comparison of survey and CRHC data comprised 1,548 persons and for the comparison of survey and FPR data 1,107 persons. ICD-10 codes from CRHC and ATC and reimbursement codes from FPR were matched with the disease items in the survey as presented in Table 3. Table 4 presents the data and variables included in all four substudies.

Table 3. Survey items from the Vitality 90+ Study in 2014 matched with information from CRHC and FPR. Modified from Halonen et al. (2023)

Survey item	ICD-10	ATC code	Reimbursement code
Cancer	C00-C97	-	-
Diabetes	E10-E14	A10	diabetes, insulin treatment (103), diabetes, other than insulin treatment (215)
Dementia or Alzheimer's disease, problems with memory	F00-F03, G30	N06D	donepezil, galantamine, memantine, rivastigmine (307)
Depression, depressed mood	F31-F34, F38-F39	-	-
Parkinson's disease	G20	N04	Parkinson's disease (110)
Hypertension, high blood pressure	I10-I15	C02C, C03A, C03B, C03C, C03D, C03E, C07A, C07B, C07F, C08C, C08D, C09A, C09B, C09C, C09D	chronic hypertension (205)
Heart disease (coronary artery disease, arrhythmia, myocardial infarction)	I20-I25, I47-I50	C01A, C01D, C03A, C03C, C03D, C03E, C07A, C07B, C08C, C08D, C09A, C09B, C09C, C09D, C10A	heart failure (201), chronic coronary artery disease and related fat metabolism disorders (206), chronic arrhythmias (207)
Hip fracture	S72.0, S72.1, S72.2	-	-
Stroke	I60-I64, I69	-	-
Arthritis	M15-M19	-	-

ICD-10: International Classification of Diseases 10th Revision; ATC: Anatomical therapeutic chemical

Table 4. Data and variables in Studies I-IV

	Data	Multimorbidity	Outcome(s)	Covariates
Study I	Vitality 90+ survey in 2014 (n=1,637 all respondents, 1,320 self-respondents)	0 conditions, 1 condition, 2 conditions, 3 conditions, 4+ conditions	Poor self-rated health, poor self-rated functioning, ADL disability, mobility disability	Age, gender
Study II	Vitality 90+ survey in 2001, 2003, 2007, 2010, 2014, 2018 (n=7,483)	Number of conditions 0-7	Hypertension, heart diseases, arthritis, dementia, depression, diabetes, stroke and disease pairs and triads including hypertension, arthritis, heart disease, hip fracture, and depression	Age, gender, year of study
Study III	Vitality 90+ survey 2001, 2003, 2007, 2010, CRSW, CRHC, Population register (n=2,862 in mortality analysis, 1,954 in LTC analysis)	0 conditions, 1 condition, 2 conditions, 3 conditions, 4 conditions, 5+ conditions	Admission to long-term care, date of death	Disability score (5-20), living arrangements (alone vs. with others), occupational status, age, gender, year of entry
Study IV	Vitality 90+ survey in 2014, CRHC, FPR (n=1,548 from CRHC, 1,117 from FPR)	-	-	Proxy status

ADL: Activities of Daily Living; CRSW: Care Register for Social Welfare; CRHC: Care Register for Health Care; FPR: Finnish Prescription Register; LTC: long-term care

In all substudies, participants were classified as self-respondents if they provided the answers themselves, regardless of whether they had help. Proxy respondents provided the answers on behalf of the participant. Most of the proxy respondents were either relatives or acquaintances, others were care staff.

8.4 Statistical analysis

Study I

In study I, frequency calculations were first used to describe the distribution of the outcome variables (self-rated health, self-rated functioning, and ADL and mobility disability). Gender differences in the prevalence of each outcome were then tested using chi-square and Fisher's exact test. Logistic regression analysis (Hosmer et al., 2013) was used as a statistical method to examine the association between chronic conditions and the outcomes. The association of each condition and multimorbidity with the four outcomes was examined with univariate logistic regression models. Multiple logistic regression models adjusting for age were conducted separately for both genders. Additionally, the models for single conditions were adjusted for all other diseases. A p-value <.05 was considered significant, and odds ratios (OR) with 95% confidence intervals were presented for the results of the logistic regression analysis. The analysis was performed with IBM SPSS Statistics version 23.0 (IBM Corp., 2015).

Study II

In Study II, the cross-sectional analysis for each survey year included frequency calculations for each chronic condition among survey participants with and without dementia. Logistic regression analysis with dementia as the dependent variable was conducted for each year separately. The independent variables were individual conditions, number of chronic conditions, and the most common pairs and triads of conditions among participants with dementia. Triads of conditions were formed out of diseases that belonged to a pair of conditions with a prevalence higher than 10%.

Time trend analysis with generalized estimating equation (GEE) (Ballinger, 2004) was performed to examine the linear trend in the prevalence of the conditions over time. In GEE models, an independent 'working' correlation structure was used to account for repeated responses by the same individuals across several study years. A binomial distribution family with logit link function providing ORs was used to analyze the time trend in the prevalence of chronic conditions, and a negative

binomial distribution family with log link function providing incidence rate ratios (IRR) was used to analyze the trend in the number of chronic conditions across time. The models were adjusted for age and gender. The time trend analysis was performed separately for participants with dementia and without dementia. A p-value <.05 was considered statistically significant. Analysis was performed with Stata 15 (StataCorp, 2017a).

Study III

In Study III, risk of death was estimated with Cox proportional hazards regression (Cleves et al., 2004). Risk of LTC admission was estimated with competing risks regression (Fine & Gray, 1999), with death as the competing risk. Chronic conditions, disability, and living arrangements were treated as time-dependent covariates using data from all survey rounds available for each participant. Additionally, number of chronic conditions was treated as a time-varying covariate. However, if the participant reported less conditions in a later survey round, the former (i.e. the higher) number was left unchanged. The analysis was conducted separately for both genders. The follow-up began on the index date (start of data collection) of every survey year and ended no later than December 31, 2012. Hazard ratios (HR) and subhazard ratios (SHR) with 95% confidence intervals were presented.

The burden of chronic diseases was assessed using population attributable fraction (PAF) (Newson, 2013). PAF was computed based on the regression models adjusted for age, year of entry, and all chronic conditions.

A p-value <.05 was considered significant. Analysis was performed with Stata 15.1 (StataCorp, 2017b).

Study IV

In Study IV, the frequency of each condition was first calculated for all survey respondents with non-missing information on the conditions included in the survey (n=1,548). Frequencies were then calculated based on CRHC. For the subsample for whom information was available from both CRHC and FPR (n=1,107), frequencies were calculated for the five conditions (hypertension, heart disease, diabetes, dementia, and Parkinson's disease) from each source separately. Information from CRHC and FPR was then merged, and the participant was considered to have the condition if it was recorded in either register. Frequencies were then also calculated for this combination of register information.

The agreement between the survey and register data was assessed with Cohen's kappa statistics, a measure for evaluating bias in interobserver agreement for categorical data (Landis & Koch, 1977). The kappa measure takes into account the

probability that two raters agree in their classifications by chance, which might cause bias in simple percent agreement calculations (McHugh, 2012). Level of agreement was evaluated based on the scale by Landis & Koch (1977): <0.00 poor agreement, 0.00-0.20 slight agreement, 0.21-0.40 fair agreement, 0.41-0.60 moderate agreement, 0.61-0.80 substantial agreement, and 0.81-1.00 almost perfect agreement.

To further assess the concordance between survey and register data, positive percent agreement (PPA) and negative percent agreement (NPA) were calculated. PPA and NPA can be used to describe the level agreement when there is no gold standard is available for comparing measurements (McAdam, 2017). PPA is the proportion of positive agreement out of all positive responses in the reference method, in this case, the register(s). NPA is the proportion of negative agreement out of all negative responses in the reference method (Table 5). Analysis was performed with IBM SPSS Statistics 28.0 (IBM Corp., 2021).

Table 5. Calculation of PPA and NPA in Study IV

	Survey +	Survey -
Register +	A	B
Register -	C	D

PPA: Positive Percent Agreement; NPA: Negative Percent Agreement

PPA=100*A/(A+B)
NPA=100*D/(C+D)

8.5 Ethical protocol

The Vitality 90+ Study protocol was approved by the Regional Ethics Committee of Tampere University Hospital or the Ethics Committee of the City of Tampere depending on the study year, and the study had a research permit granted by the City of Tampere. The survey participants were informed of the study protocol and the aims of the study, and they were able to discontinue participation at any point. The participants were also able to contact the researchers during data collection. Informed consent was obtained from the study participants themselves or their representative. The participants were informed about the use of register sources

and were asked to give a permission to link the survey data with the information in these registers. Permission to use the register data was obtained from the register keepers. The participants' privacy was respected both in handling the data and in reporting the results. The anonymized data of the Vitality 90+ Study are stored at Finnish Social Science Data Archive (https://services.fsd.tuni.fi/catalogue/series/64?tab=description&lang=en).

9 RESULTS

9.1 Main characteristics of the study population

Most survey participants were women throughout the study period from 2001 to 2018, but the proportion of men increased over time. The mean age of the participants increased by 0.4 years from 2001 to 2018, when it was 92.7. The oldest participants were 105 to 107 years old, depending on the study year. The share of participants living in LTC decreased over time. In 2018 one-third of the participants lived in LTC. The proportion of proxy respondents decreased from 23.5% in 2001 to 12.7% in 2018. (Table 6)

Table 6. Characteristics of survey participants in the Vitality 90+ Study from 2001 to 2018

	2001	**2003**	**2007**	**2010**	**2014**	**2018**
	n=892	n=961	n=943	n=1,277	n=1,637	n=1,878
Age, mean	92.3	92.4	92.6	92.6	92.6	92.7
Gender						
Women %	80.7	80.2	79.5	81.2	76.9	73.9
Men %	19.3	19.8	20.5	18.8	23.1	26.1
In long-term care %	39.1	35.8	34.3	37.4	35.4	29.8
Proxy respondents %	23.5	22.3	17.4	17.6	18.3	12.7

9.2 Prevalence of diseases and multimorbidity

The prevalence of diseases reported in this section are derived from Study I based on the Vitality 90+ survey in 2014. The results for disease trends are derived from Study II and differ slightly from the rates in Study I due to minor differences in the treatment of missing data and the harmonization of data across study years in Study II.

The most common diseases among the survey participants were hypertension (62.0%), heart disease (54.8%), arthritis (45.0%), and dementia (42.7%), followed by

depression (17.9%), hip fracture (17.7%), cancer (16.9%), diabetes (15.8%), stroke (9.2%), and Parkinson's disease (1.5%). Four in five participants (81.0%) had multimorbidity, i.e. at least two chronic diseases (77.2% in men and 82.1% in women, *p* .047). Heart disease, cancer, and Parkinson's disease were more common in men, whereas hip fracture, arthritis, and hypertension were more common in women than men. (Table 7) (Study I)

Table 7. Frequency of diseases and multimorbidity among the Vitality 90+ survey participants in 2014

	Women	**Men**		**Total**
	n=1,117–1,249	**n=329–375**		**n=1,569–1,596**
	n (%)	**n (%)**	***p*[1]**	**n (%)**
Hypertension	805 (65.4)	185 (50.5)	<.001	990 (62.0)
Heart disease	663 (54.4)	205 (56.0)	<.001	868 (54.8)
Arthritis	579 (47.6)	131 (36.1)	<.001	710 (45.0)
Dementia	526 (43.0)	152 (41.8)	.672	678 (42.7)
Depression	227 (18.8)	54 (15.0)	.098	281 (17.9)
Hip fracture	233 (19.2)	45 (12.7)	.005	278 (17.7)
Cancer	180 (14.8)	85 (24.0)	<.001	265 (16.9)
Diabetes	190 (15.6)	60 (16.6)	.647	250 (15.8)
Stroke	108 (8.9)	37 (10.3)	.401	145 (9.2)
Parkinson's disease	14 (1.2)	10 (2.8)	.024	24 (1.5)
Multimorbidity				
0-1 diseases	200 (17.9)	75 (22.8)		275 (19.0)
2 diseases	283 (25.3)	92 (28.0)		375 (25.9)
3 diseases	306 (27.4)	78 (23.7)	.163	384 (26.6)
4 diseases	191 (17.1)	50 (15.2)		241 (16.7)
5+ diseases	137 (12.3)	34 (10.3)		171 (11.8)

[1]Chi-square test

9.3 Dementia and comorbidity

The crude prevalence of dementia first increased from 42.9% in 2001 to 47.1% in 2007 and then dropped back to 41.4% in 2018. The number of participants with dementia increased during the study period from 375 participants to 768. The most common comorbidities of dementia were hypertension, heart disease, arthritis, and depression throughout the study period from 2001 to 2018. (Table 8) Hypertension, arthritis, and heart disease were included in the most common disease combinations in participants with dementia. (Study II)

Among participants with dementia, the prevalence of hypertension, arthritis, and diabetes increased, whereas the prevalence of depression decreased. The mean number of other diseases increased from 2.0 in 2001 to 2.3 in 2018. (Table 8) Disease combinations including hypertension increased due to the sharp rise in the prevalence of hypertension. The largest increases were seen for the combination of hypertension and arthritis and the combination of hypertension and diabetes. The only disease pair showing a decreasing trend over time was the combination of heart disease and depression.

Among participants without dementia, the prevalence of hypertension, arthritis, and diabetes increased, whereas the prevalence of hip fracture and depression decreased. The mean number of diseases increased from 1.7 to 2.1 during the study period. (Table 8)

Although the proportion of participants with depression and hip fracture decreased, the absolute number of participants with these conditions increased during the study period. The number of participants with depression also increased among those with dementia, despite the proportional decrease. (Table 8)

Table 8. Prevalence and mean number of diseases from 2001 to 2018 among participants with and without dementia. Age- and gender-adjusted odds ratios (OR) and incidence rate ratios (*IRR) for the diseases across the years with 95% confidence intervals (CI). P-value for linear trend.

	2001 n=874	2003 n=937	2007 n=932	2010 n=1,263	2014 n=1,621	2018 n=1,856	OR	95% CI	*p*
Dementia	42.9	46.7	47.1	42.8	43.1	41.1	0.99	0.98–1.00	.007
Comorbidities									
Hypertension	32.0	36.1	38.5	42.1	55.0	60.3	1.08	1.07–1.09	<.001
Heart disease	55.5	56.6	49.2	51.8	52.9	52.2	0.99	0.98–1.00	.183
Arthritis	31.7	32.9	31.9	37.9	39.5	41.8	1.03	1.02–1.04	<.001
Stroke	10.1	9.6	6.4	6.8	11.8	8.2	1.00	0.98–1.02	.829
Diabetes	12.8	11.4	10.9	10.4	15.6	19.9	1.04	1.03–1.06	<.001
Hip fracture	20.0	21.7	13.9	18.7	19.5	18.9	1.00	0.98–1.01	.966
Depression	32.8	32.9	27.3	27.2	24.6	26.2	0.98	0.97–0.99	.003
Comorbidities, mean	2.0	2.0	1.8	2.0	2.2	2.3	1.01*	1.00–1.02	.001
Without dementia									
Hypertension	31.7	40.1	51.3	59.1	65.7	67.2	1.09	1.08–1.10	<.001
Heart disease	55.5	54.1	55.8	56.7	54.1	51.9	1.00	0.99–1.01	.644
Arthritis	38.9	35.5	46.5	47.0	47.0	46.4	1.03	1.02–1.04	<.001
Stroke	6.2	5.8	4.9	4.2	6.8	6.2	1.01	0.99–1.03	.441
Diabetes	9.4	9.0	11.2	12.9	15.3	17.8	1.05	1.03–1.07	<.001
Hip fracture	15.4	15.6	21.3	16.1	15.4	11.8	0.98	0.97–0.99	.003
Depression	17.0	16.4	16.6	12.9	11.8	9.8	0.96	0.95–0.98	<.001
No. of diseases, mean	1.7	1.8	2.1	2.1	2.2	2.1	1.01*	1.01–1.02	<.001

OR: Odds Ratio; IRR: Incidence Rate Ratio; CI: Confidence Interval

In the logistic regression models adjusted for age and gender, depression was consistently associated with dementia. Stroke, hip fracture, and Parkinson's disease were associated with dementia in several survey years, but the association was not persistent. Hypertension, arthritis, and cancer showed lower probability of occurrence with dementia in most survey years. Figure 3 shows the odds ratios in 2018. (Study II)

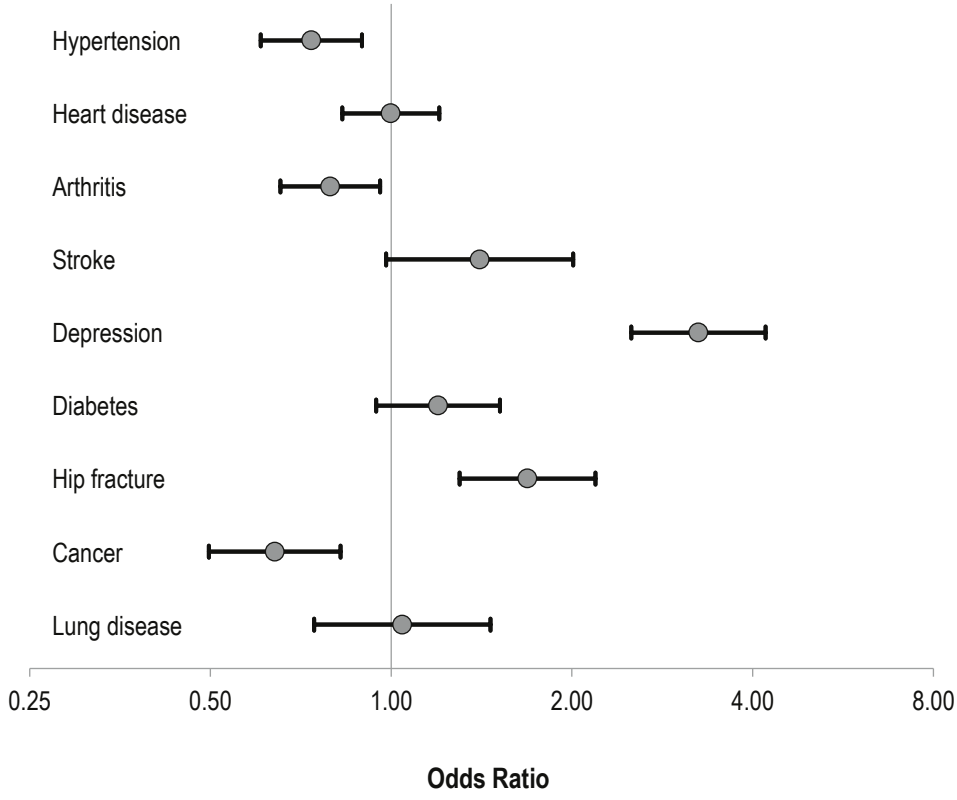


Figure 3. Association of diseases with dementia in the Vitality 90+ survey in 2018. Odds ratios with 95% confidence intervals from logistic regression models adjusted for age and gender.

9.4 Association of diseases and multimorbidity with disability, self-rated health, and self-rated functioning

Several diseases showed a significant association with poor self-rated health, poor self-rated functioning, and ADL and mobility disability after adjusting the regression models for age. Dementia showed an association with all four outcomes in both women and men. Depression showed an association with all outcomes in women and with ADL disability and poor self-rated health in men. Hip fracture showed an association with all outcomes and heart disease with all other outcomes except for ADL disability in women. Stroke showed an association with ADL disability in both genders. Arthritis showed an association with poor self-rated health in men. Cancer was inversely associated with poor self-rated functioning and mobility disability in women and ADL disability in men, and diabetes was inversely associated with ADL disability in men. (Table 9) (Study I)

Table 9. Association of chronic diseases with poor self-rated health, poor self-rated functioning, ADL disability, and mobility disability. Logistic regression models with odds ratios (OR) and 95% confidence intervals (CI) adjusted for age and all diseases.

	Poor self-rated health		Poor self-rated functioning		ADL disability		Mobility disability	
Women	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Hypertension	1.16	0.82–1.65	1.03	0.74–1.42	0.85	0.61–1.18	0.77	0.58–1.04
Heart disease	2.02	1.44–2.82	1.69	1.24–2.31	0.96	0.70–1.32	1.55	1.17–2.05
Arthritis	1.12	0.81–1.55	1.30	0.95–1.77	0.86	0.62–1.19	1.31	0.99–1.73
Dementia	1.79	1.27–2.52	2.07	1.49–2.87	10.67	7.59–15.07	3.76	2.80–5.05
Depression	2.84	1.90–4.21	3.50	2.35–5.23	1.82	1.25–2.65	2.23	1.50–3.32
Hip fracture	1.57	1.06–2.34	1.93	1.32–2.84	1.50	1.02–2.21	2.08	1.42–3.05
Cancer	0.8	0.50–1.27	0.52	0.32–0.83	0.88	0.56–1.39	0.55	0.37–0.81
Diabetes	1.04	0.67–1.63	0.84	0.54–1.31	1.18	0.76–1.82	1.34	0.91–1.97
Stroke	1.38	0.80–2.37	1.23	0.72–2.10	1.70	1.03–2.81	1.47	0.88–2.47
Men								
Hypertension	1.44	0.78–2.66	1.06	0.60–1.88	1.07	0.51–2.23	0.82	0.50–1.38
Heart disease	1.29	0.69–2.39	1.35	0.76–2.40	0.55	0.27–1.12	0.87	0.52–1.44
Arthritis	1.84	1.01–3.35	1.39	0.78–2.47	0.60	0.27–1.30	1.31	0.77–2.21
Dementia	2.82	1.51–5.27	2.69	1.50–4.82	16.15	6.78–38.47	4.85	2.90–8.12
Depression	2.33	1.04–5.24	1.59	0.72–3.52	3.53	1.51–8.24	1.44	0.71–2.89
Hip fracture	0.82	0.33–2.04	0.71	0.31–1.65	0.87	0.28–2.68	1.42	0.67–2.99
Cancer	1.37	0.71–2.64	1.68	0.91–3.09	0.27	0.10–0.70	1.30	0.73–2.33
Diabetes	1.01	0.46–2.23	0.79	0.37–1.68	0.29	0.09–0.96	1.09	0.55–2.17
Stroke	0.59	0.20–1.75	1.05	0.42–2.63	2.96	1.07–8.18	1.47	0.64–3.37

ADL: Activities of Daily Living; OR: Odds Ratio; CI: Confidence Intervals

The presence of at least three diseases was associated with all outcomes in women and with poor self-rated health and poor self-rated functioning in men. The presence of at least four diseases was associated with mobility disability and at least five diseases with ADL disability in men. (Figure 4) (Study I)

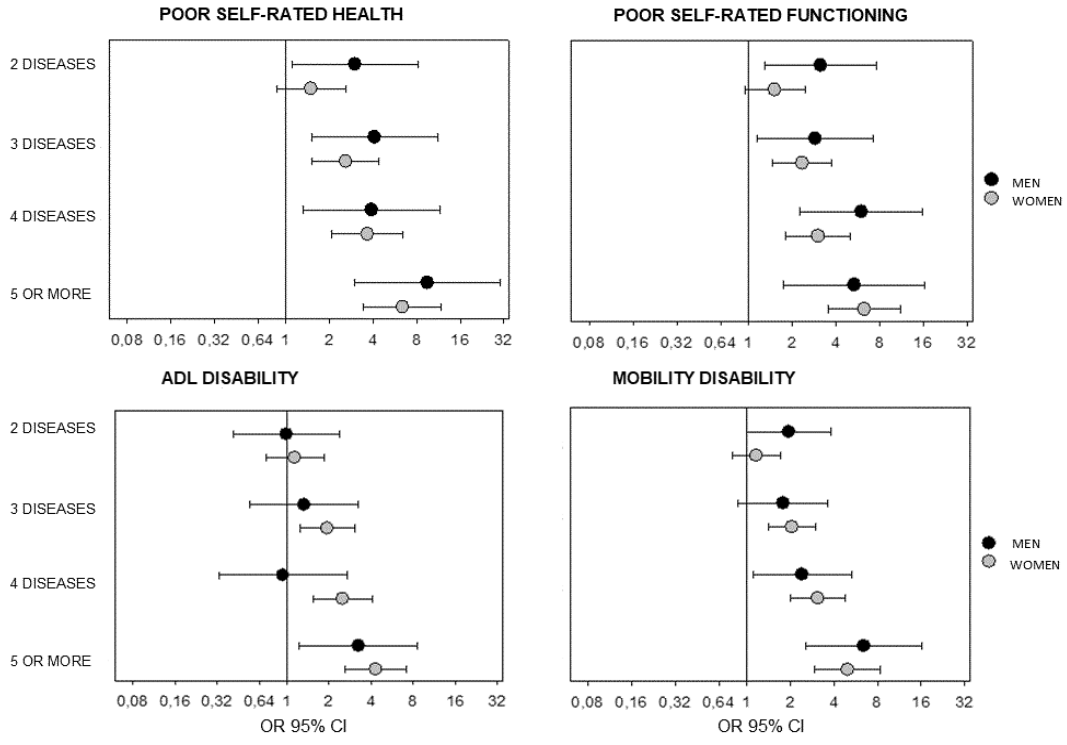


Figure 4. Association of multimorbidity with poor self-rated health, poor self-rated functioning, ADL disability, and mobility disability. Reference category: having 0-1 diseases. OR: Odds Ratio; CI: Confidence Interval

9.5 Association of diseases and multimorbidity with long-term care and mortality

The sample for the LTC admission analysis comprised 1,954 participants who lived in a private home at baseline. Of these participants, 46.1% of women and 33.8% of men moved to LTC during the follow-up. The average follow-up time to LTC admission was 2.1 years (range 4 days to 11 years). Among women, the risk of LTC admission was increased by Parkinson's disease, dementia, hip fracture, and depression in the adjusted models (Table 10). Having three (SHR 1.64, 95% CI 1.12–2.40) and four or more diseases (SHR 1.99, 95% CI 1.34–2.95) increased the risk of LTC admission in the adjusted model (Figure 6). In men, no individual disease or multimorbidity were found to predict LTC admission. The only predictor that showed an increasing risk was disability (SHR 1.10, 95% CI 1.04–1.17). (Table 10 & Figure 5) (Study III)

Dementia had the highest PAF for LTC admission in both genders (8.0% in women and 9.0% in men). Despite being the strongest predictor of LTC admission in the regression model, Parkinson's disease accounted for only 0.6% of LTC admissions in women. Hip fracture accounted for 5.0% and depression for 4.0% of LTC admissions. (Study III)

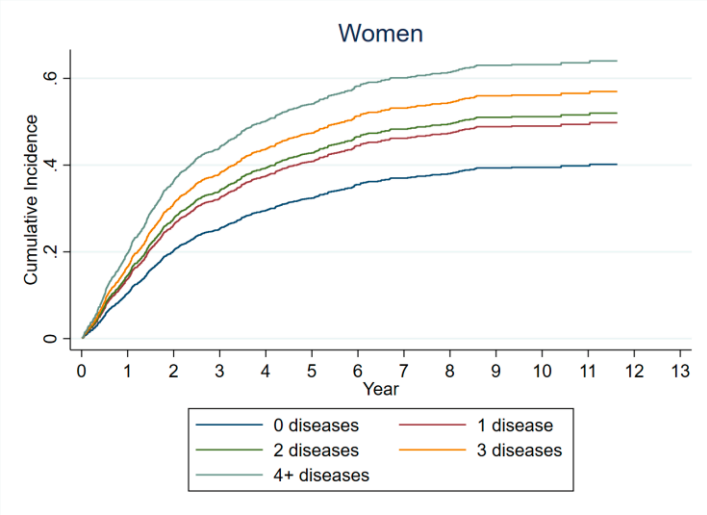
Table 10. Association of chronic diseases and disability with LTC admission. Competing risk regression models with death as a competing risk for women and men with subhazard ratios (SHR) and 95% confidence intervals (CI)

	Women				Men			
	Model 1		Model 2		Model 1		Model 2	
	SHR	95% CI	SHR	95% CI	SHR	95% CI	SHR	95% CI
Hypertension	0.98	0.84–1.15	0.98	0.83–1.17	0.97	0.64–1.45	1.07	0.68–1.68
Heart disease	0.90	0.77–1.06	0.86	0.73–1.02	1.33	0.93–1.91	1.31	0.90–1.92
Arthritis	1.16	0.99–1.35	1.08	0.91–1.27	1.40	0.96–2.06	1.34	0.90–2.00
Dementia	1.58	1.33–1.87	1.50	1.25–1.79	1.44	1.01–2.06	1.23	0.80–1.89
Depression	1.56	1.27–1.91	1.27	1.01–1.59	1.21	0.76–1.92	1.05	0.65–1.70
Hip fracture	1.52	1.24–1.86	1.42	1.14–1.75	1.21	0.71–2.06	1.27	0.72–2.24
Diabetes	1.01	0.78–1.32	1.01	0.77–1.34	0.82	0.43–1.55	0.74	0.36–1.50
Stroke	1.11	0.74–1.67	0.97	0.63–1.50	0.93	0.36–2.36	0.68	0.24–1.93
Parkinson's disease	3.05	1.92–4.82	2.36	1.40–3.97	0.41	0.48–3.49	0.51	0.05–4.88
Disability score	1.08	1.06–1.11	1.07	1.04–1.10	1.14	1.08–1.20	1.11	1.05–1.18

LTC: Long-term care; SHR: subhazard ratio; CI: confidence intervals

Model 1 includes the variables separately, adjusted for age and year of entry.

Model 2 includes disability score and chronic diseases, adjusted for age, year of entry, occupational status, and living arrangements.



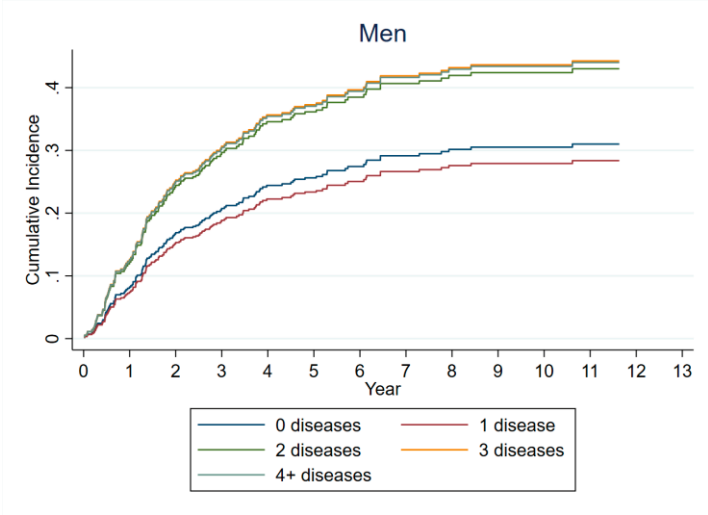


Figure 5. Cumulative incidence of LTC admission for women (left) and men (right) according to number of diseases from competing risk regression models with death as a competing risk. Models adjusted for disability, age, year of entry, occupational status, and living arrangements.

The sample in the mortality analysis comprised 2,862 participants. During the follow-up period of 11.6 years, 75.2% of women and 77.3% of men died (Study III). Mean time to death was 2.5 years, ranging from 9 days to 11.6 years. In both genders the risk of death in the Cox regression models including all diseases, disability score, age, year of entry, and occupational status were increased by heart disease, dementia, diabetes, and higher disability score. In addition, depression increased the risk of death in women. In women, stroke also increased the risk of death in the model that only included stroke, age, and year of entry, but this association became nonsignificant in the fully adjusted model. Stroke or depression did not increase the risk of death in the fully adjusted model in men, but they were significant predictors in the models including only disease, age, and year of entry. Arthritis was associated with a lower risk of death in both genders in the fully adjusted model. (Table 11)

In women, one disease (HR 1.38, 95% CI 1.01–1.90), three diseases (HR 1.53, 95% CI 1.12–2.08), and four or more diseases (HR 1.59, 95% CI 1.16–2.16) increased the risk of death. In the model including the number of diseases adjusted for year of entry and age, an increasing number of diseases predicted mortality in men. However, the HRs attenuated and became nonsignificant when disability was added to the model. (Figure 6)

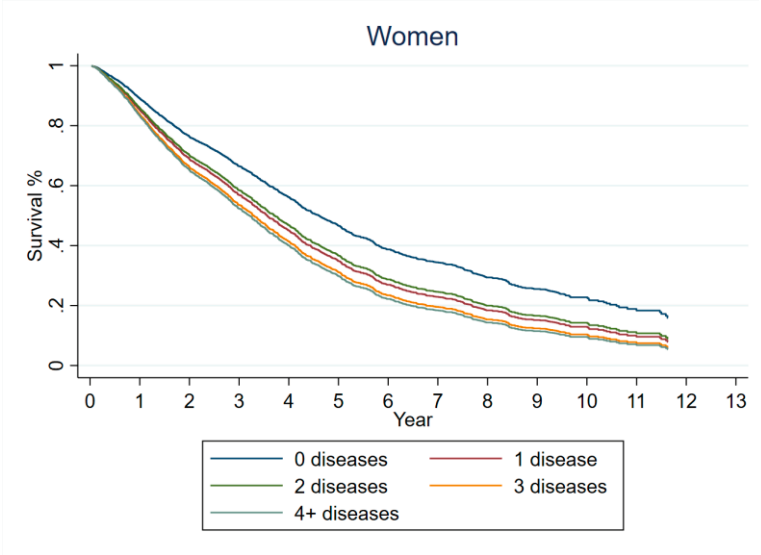
Table 11. Association of diseases and disability with mortality. Cox regression models for women and men with hazard ratios (HR) and 95% confidence intervals (CI)

	Women				Men			
	HR[1]	95% CI[1]	HR[2]	95% CI[2]	HR[1]	95% CI[1]	HR[2]	95% CI[2]
Hypertension	0.91	0.82–1.01	0.93	0.84–1.04	1.06	0.85–1.32	1.03	0.82–1.30
Heart disease	1.34	1.21–1.48	1.35	1.22–1.50	1.46	1.20–1.77	1.25	1.02–1.54
Athritis	0.84	0.76–0.93	0.80	0.72–0.90	0.78	0.62–0.97	0.68	0.53–0.85
Dementia	1.68	1.52–1.86	1.20	1.07–1.33	1.75	1.44–2.12	1.30	1.05–1.61
Depression	1.41	1.26–1.58	1.15	1.02–1.29	1.30	1.02–1.65	0.96	0.74–1.25
Hip fracture	1.12	0.99–1.26	0.91	0.80–1.03	1.24	0.94–1.63	0.94	0.70–1.27
Diabetes	1.39	1.20–1.61	1.27	1.09–1.48	1.64	1.23–2.20	1.67	1.24–2.25
Stroke	1.66	1.40–1.98	1.18	0.98–1.41	1.59	1.08–2.33	0.90	0.60–1.36
Parkinson's disease	1.26	0.91–1.76	1.02	0.73–1.43	1.11	0.52–2.36	0.37	0.17–0.82
Disability score	1.12	1.10–1.13	1.10	1.09–1.12	1.15	1.13–1.17	1.15	1.12–1.18

HR: hazard ratio; CI: confidence intervals

[1]Models including the variables separately, adjusted for age and year of entry.

[2]Models including disability score and all diseases, adjusted for age, year of entry, and occupational status.



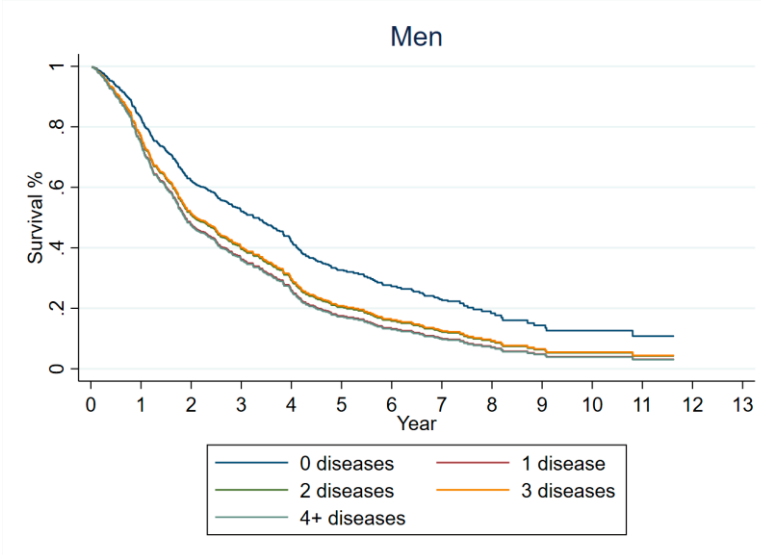


Figure 6. Cumulative survival for women (left) and men (right) according to number of diseases from Cox regression models adjusted for disability, age, year of entry, and occupational status

Mortality PAF for heart disease was 16% in women and 14% in men, for dementia 19% and 20%, and for diabetes, 3% and 5%, respectively. PAF for depression was 5% and 3% for stroke in women. Hip fracture accounted for 3% of deaths in men.

9.6 Agreement between self- and proxy-reported information and health register data

The agreement between survey and CRHC among all respondents with data from both the survey and CRHC available (n=1,548), was highest for hip fracture, diabetes, and Parkinson's disease, which all showed substantial agreement (Study IV). Moderate agreement was found for stroke, cancer, dementia, and heart disease, and fair agreement for hypertension, depression, and arthritis. The frequency of hypertension, dementia, and depression was clearly higher in the survey than in CRHC. Nearly all survey participants with a register entry of hypertension and dementia had also reported the condition in the survey, leading to a high PPA and low NPA for these diseases. Depression had a low prevalence in CRHC (5.7%), while the figure in the survey was 17.1%, leading to low PPA due to the mismatch in positive ratings.

Among the respondents for whom information was available from both registers (n=1,107), the level of agreement was higher when survey information was compared with combined data from both registers. Agreement was almost perfect for Parkinson's disease, substantial for diabetes and dementia, and moderate for hypertension and heart disease. Comparison of survey and FPR data showed a high PPA ranging from 89.8% to 100%, indicating that nearly every participant for whom the disease was recorded in FPR also reported it in the survey. NPAs were lower since many diseases reported in the survey were not recorded in FPR. (Table 12)

Table 12. Agreement of survey with CRHC and FPR.

	CRHC	PPA	NPA	FPR	PPA	NPA	CRHC + FPR	PPA	NPA
	κ[1]	%	%	κ[2]	%	%	κ[3]	%	%
Arthritis	.21	63.5	62.6						
Depression	.23	59.1	85.5						
Hypertension	.33	80.0	54.5	.37	89.8	58.8	.51	79.4	71.6
Heart disease	.52	78.9	72.7	.48	89.8	52.3	.51	77.5	74.4
Cancer	.57	54.4	96.1						
Dementia	.57	93.3	75.5	.59	96.9	61.5	.66	94.7	76.2
Stroke	.59	51.3	98.2						
Parkinson's disease	.61	91.7	99.2	.69	100	99.4	.81	92.9	99.5
Diabetes	.63	83.9	92.6	.68	97.6	91.8	.75	83.7	95.5
Hip fracture	.65	81.3	92.4						

CRHC: Care Register for Health Care; FPR: Finnish Prescription Register; PPA: positive percent agreement; NPA: negative percent agreement

[1]Kappa between survey and CRHC (*n*=1,548)

[2]Kappa between survey and FPR (*n*=1,107)

[3]Kappa between survey and combined register information (*n*=1,107)

Proxy respondents

The analysis conducted separately for proxy respondents showed the same kappa value pattern: agreement was substantial for Parkinson's disease, diabetes, and hip fracture and increased when the comparison was done using information combined from both registers. However, the agreement for dementia ranged from slight in the comparison between survey and FPR to moderate in the comparison between survey data and both registers and was lower among proxy than self-respondents. Proxy respondents reported dementia far more often in the survey than was recorded in either of the registers. (Study IV)

10 DISCUSSION

10.1 Summary of the main results

The present study examined the prevalence and trends of chronic diseases and multimorbidity among people aged 90 and over, a population group rapidly growing in size globally and in Finland. Another focus was to examine the associations of chronic diseases and multimorbidity with different health outcomes, i.e. self-rated health and self-rated functioning, disability, long-term care (LTC) admission, and mortality.

The most common diseases in people aged 90 and over were cardiovascular diseases (i.e. hypertension and heart disease), followed by arthritis and dementia. Multimorbidity was common as the vast majority of participants reported at least two diseases. The number of diseases increased during the study period from 2001 to 2018 among both study participants who had dementia and those who did not. The largest increases were seen for hypertension, arthritis, and diabetes. A declining prevalence was detected for dementia and depression. Depression was consistently more likely to occur in participants with dementia than those without dementia, whereas hypertension and arthritis were less likely to occur among participants with dementia than among those without dementia.

Among the diseases studied, dementia and depression showed the most prominent associations with poor self-rated health, poor self-rated functioning, and disability. Multimorbidity was associated with poor self-rated health and poor self-rated functioning, while its association with disability was not as evident. The two most important predictors of mortality were dementia and heart disease, and dementia was the most important predictor of LTC admission. Multimorbidity was a predictor of mortality and LTC admission in women but not in men. Lower functional ability was a predictor of mortality and LTC admission in both genders.

The comparison of survey information with national health register data revealed that self- and proxy-reported information on chronic diseases was highly consistent with register data concerning Parkinson's disease, hip fracture, diabetes, and dementia, whereas the agreement was lower for arthritis, hypertension,

depression, and heart disease. Overall, the level of agreement was adequate to justify the use of surveys in health research even among the oldest old.

10.2 Prevalence and trends of chronic diseases and multimorbidity

In line with previous research (von Berenberg et al., 2017; Boeckxstaens et al., 2015; Lloyd-Jones et al., 2009; Salminen et al., 2012), the most common diseases in this study population were hypertension and heart disease, followed by arthritis. The most noteworthy characteristic of disease prevalence was the high prevalence of dementia and depression. Despite the slight decline in the prevalence of both diseases, they are far more prevalent in the oldest old compared with younger old people.

The prevalence of hypertension increased during the study period from 2001 to 2018 and the prevalence of heart disease remained stable. The prevalence of arthritis and diabetes increased, as has been reported in some earlier studies on disease trends in older populations (Barzilay, 2012; Crimmins, Zhang, et al., 2019; Kwoh et al., 2012). The prevalence of stroke was stable and that of hip fracture decreased only among participants without dementia, although the incidence of both have been found to be decreasing (Korhonen et al., 2013; Madsen et al., 2020). The prevalence of depression was relatively high but showed a decreasing trend over the years.

Depression is highly related to several physical diseases and impairments (Penninx & Comijs, 2012), and therefore its high prevalence in the oldest old is not unexpected. As regards to the high prevalence of depression observed in the present study, it needs to be noted that the question on depression in the Vitality 90+ Study included also 'depressed mood'. An earlier Swedish study found a higher prevalence of depression among those aged over 90 compared with 85-year-olds. In the age group over 90 the prevalence of depression was 30%, and it was also reported that depression was underdiagnosed and undertreated. (Bergdahl et al., 2005.) It has been suggested that major depression is not highly present in the oldest people, whereas depressive symptoms are more prevalent compared with younger people (Penninx & Comijs, 2012). Studies have shown mixed evidence on depression prevalence trends. Moreno-Agostino et al. (2021) and Weinberger et al. (2018) showed an increase in depression prevalence, whereas a Finnish register-based study reported a

decrease in depression among people who had died at the age of 70 and who had dementia (Vargese et al., 2021).

Men had a higher prevalence of heart disease, Parkinson's disease, and cancer than women, whereas women had hip fracture, arthritis, and hypertension more often than men. These findings are in line with previous studies that show a higher prevalence of arthritis and hypertension in the oldest old women than men (Collerton et al., 2009; Kingston et al., 2014; Klijs et al., 2011), whereas men have cancer and heart disease more often than women (Collerton et al., 2009; Kingston et al., 2014).

Prevalence and trend of multimorbidity

In line with earlier research, multimorbidity was very common as the majority of participants had at least two diseases (Collerton et al., 2016; Formiga et al., 2013). There was a slight shift towards more 'complex multimorbidity' (Koné Pefoyo et al., 2015), as an increasing number of diseases was detected across the study years.

There is no standard definition for multimorbidity, which means the concept is operationalized in different ways in different studies (see for example Lefèvre et al., 2014; Soley-Bori et al., 2021). The number and types of conditions included in studies vary, and measurements are done in different settings and using different methods (Marengoni et al., 2011). Direct comparisons across studies are therefore difficult and to some extent futile. However, the level of multimorbidity observed in the present study is close to earlier estimates presented for people aged over 90 (Hajek & König, 2023; Koné Pefoyo et al., 2015). The high prevalence of multimorbidity seen in the present study was expected, but because the Vitality 90+ Study included only 10 diseases, the results most likely underestimate the true prevalence rate, as the level of multimorbidity tends to increase with an increasing number of diseases (van den Akker et al., 2001).

The present finding of an increasing disease burden is also consistent with earlier results showing an increasing prevalence of chronic diseases and multimorbidity over time (Chatterji et al., 2015; Christensen et al., 2009; Crimmins, 2015; Koné Pefoyo et al., 2015; Steffler et al., 2021; van Oostrom et al., 2016). Some studies have also found an increase in the length of time lived with diseases (Crimmins, 2015; Enroth et al., 2020). The increases in the prevalence of diseases and multimorbidity can be explained by several underlying mechanisms. As people live longer lives, they also have more time to be exposed to several risk factors that eventually lead to diseases (Olshansky, 2016). People develop more disabling but not necessarily fatal diseases and live with these diseases for a longer time before death, which thus increases their prevalence (Crimmins, 2015). Two examples are provided by arthritis and diabetes,

which show an increasing trend globally in adult populations (Crimmins, 2015; Long et al., 2022; Zhou et al., 2016). As some risk factors for diseases have decreased in many parts of the world (e.g. smoking), others such as obesity are continuing to increase (Blüher, 2019; Crimmins, 2015), putting more people at risk for obesity-related diseases, such as diabetes.

Increasing longevity thus explains at least in part the increasing prevalence of multimorbidity, but other factors may also come into play, as suggested by van Oostrom et al. (2016). Advances in health care have allowed for improved treatment of diseases even in very old age (see e.g. Oksuzyan et al. 2013). For instance, it has been shown that the treatment of hypertension even in very old age has health benefits and is therefore recommended (Beckett et al., 2008; Kjeldsen et al., 2016). Another possible explanation is that oldest old individuals have better access to health care services than earlier. Patients themselves and their relatives may have more expectations and demands for care, which is reflected in the number of diagnoses acquired. Adjusting the treatment threshold can also have a major impact on disease prevalence as exemplified by hypertension (Kaplan & Ong, 2007).

With respect to survey information, it is possible that reported prevalence rates are affected by changes in reporting behavior (Galenkamp et al., 2014). As Christensen et al. (2009) suggest, an increasing prevalence trend may reflect older people's medical knowledge. However, since this increase has been seen both in self-reported information and in register-based studies (see for example Beerten et al., 2022; Vargese et al., 2021), it is unlikely to be fully explained by reporting behavior or knowledge alone.

The increasing proportion of the oldest old people with chronic diseases and multimorbidity coupled with the overall increase in population size mean that the absolute numbers of people with the diseases rise substantially. Over the study period the number of people with dementia and depression increased even though the prevalence of these diseases declined. The growth of the oldest old population in need of care and support for multiple chronic diseases presents a major challenge for health care provision. The complexity of multimorbidity, specifically in terms of understanding the interconnections between symptoms and the challenges involved in the treatment of multiple conditions, becomes ever more pronounced in the oldest ages (Vetrano et al., 2018). It is acknowledged that people with multimorbidity need integrated, person-centered care (Banerjee 2015; Vetrano et al. 2018). Both the Finnish Current Care Guidelines and NICE guideline for the clinical assessment and management of multimorbidity say that optimizing care for people with multimorbidity requires patient-centered care models, continuity of care, and shared

decision-making (NICE, 2016; Monisairas potilas:Käypä hoito-suositus, 2021). As noted by Vetrano et al. (2018), guidelines for the treatment of multimorbidity are no longer focused on addressing disease-specific issues such as lowering blood pressure or increasing survival, but rather on maintaining the quality of life of people living with multiple diseases.

A study on the experiences of care of the oldest old people with multimorbidity and their carers found that they did not feel the care provided was adequate. Lack of care coordination, time, and understanding in primary care, poor management of multiple diseases, social isolation, financial problems, and the absence of support for independent living were major concerns for people with multimorbidity. The carers' main challenges were the burden of navigating the care system and lack of understanding of different treatments and medications. (Spiers et al., 2023.) The treatment of people with multimorbidity needs a strong primary care. It would ensure a person-centered approach to care and continuity of care, which are key to improving health outcomes in people with multimorbidity. (Calderón-Larrañaga et al., 2019.) So far interventions aimed at improving the outcomes of people with multimorbidity have been scarce, and many of them have been targeted at specific comorbidities of an index disease. The evidence is mixed on the impact of the interventions. (Smith et al., 2016.) A randomized controlled trial study FINGER has shown some evidence of reduced accumulation of diseases in older people having one disease at the baseline with a multidomain intervention including physical exercise, nutritional intervention, cognitive training, and management of metabolic and cardiovascular risk factors (Marengoni et al., 2018).

It has been suggested that improvement in lifelong bodily condition and health, i.e. a lower childhood infection burden, has contributed also to reduced old-age mortality and meant that current cohorts of old people can live longer lives (Crimmins, 2015). Now that the mortality in early life is already very low and there is only small potential for improvement, Crimmins (2015) and Olshansky (2016) state that a further reduction in old-age mortality will likely require interventions that can delay aging and postpone the onset of age-related diseases. The effect of an increasing number of people with dementia and increases in obesity and type 2 diabetes can further hinder the gains in LE. (Mathers et al., 2015.)

There is evidence that limitations in physical functioning have increased in middle-aged people (Martin & Schoeni, 2014). Recently Zheng & Echave (2021) studied several cohort differences in physiological status and found an increasing prevalence of physiological dysregulation, anxiety, depression, and some unhealthy behaviors specifically in younger cohorts (born in 1960s or later). In Finland,

Härkänen et al. (2019) have projected that the number of people with severe mobility limitations will most likely double from 2011 to 2044, if risk factors and limitations in mobility continue to develop similarly as during the period from 2000 to 2011.

It has been suggested that in order to lengthen healthy LE, it is necessary to reduce the incidence of comorbidities with increasing age (Scott, 2021). This in turn will require reducing inequality, especially by supporting those with less resources and poorer health and promoting preventive methods in healthy aging. Looking beyond the health care sector, it is suggested that adopting a wider life-course perspective to healthy aging and investing in research on the biology of aging would help to contribute to these goals in the longevity society. (Scott, 2021.)

Dementia and its comorbidities

The present findings on the prevalence of dementia were in line with earlier results (Börjesson-Hanson et al., 2007; Corrada et al., 2008; Wu et al., 2016). Women usually show higher rates of dementia than men (Börjesson-Hanson et al., 2007; Corrada et al., 2008; Huque et al., 2023), but in the present study this difference was not statistically significant. Women have been shown to be at increased risk for developing dementia particularly after the age of 80 (Sindi et al., 2021). The exact reasons for this gender difference in dementia risk are not fully understood, but it has been suggested that women's lower educational level in the past and their potentially greater vulnerability to lifestyle-related risk factors, such as physical inactivity and midlife insomnia may be part of the cause (Sindi et al., 2021). Women's longer life expectancy (Huque et al., 2023) and hormonal factors (see e.g. Savolainen-Peltonen et al., 2019) may also contribute to the observed differences.

Earlier studies have also detected a declining prevalence of dementia, mostly in younger old people (Crimmins, 2015; Harrison et al., 2019; Wu et al., 2016). A recent Swedish study reported a declining incidence and prevalence of dementia among people aged 85 to 90 years between the 1980s and 2010s (Wetterberg et al., 2023). It has been proposed that the reasons for the declining dementia prevalence lie in positive societal changes, such as rising education levels, improved early-life environments and lifestyle, and better management of cardiovascular risk factors (Wu et al., 2016). However, it is possible that dementia is still an underdiagnosed condition (Collerton et al., 2009; Gauthier et al., 2021), especially among the oldest people (Savva & Arthur, 2015). In the present study, despite the declining prevalence rate, the number of people with dementia increased over the study years.

Overall, participants with dementia showed an increase in the number of other diseases over time. This increase was relatively greater among those without dementia, but participants with dementia had a slightly higher overall disease count

than those without dementia. Similarly, in their register-based study among dementia patients in Finland, Vargese et al. (2021) found an increasing prevalence of comorbidities of dementia during the last years of life. Beerten et al. (2022) also reported an increasing trend of comorbid hypertension and diabetes in dementia patients based on register data.

In the present study, the most common diseases in participants with dementia were hypertension, heart disease, arthritis, depression, and diabetes. Similarly, Wang et al. (2018) found in a nested case-control setting that these diseases were the most common comorbidities in patients with Alzheimer's disease, and a recent register study found that hypertension and arthritis were the most prevalent morbidities in patients with dementia (Beerten et al., 2022). Indeed, given their high overall prevalence in old age, hypertension and arthritis are the most common comorbidities in several age-related major chronic diseases (Griffith et al., 2019). However, even though hypertension and arthritis were common diseases in participants with dementia, they were even more common in participants without dementia. These findings can in part be explained by the underdiagnosis or undertreatment of diseases in people with dementia. It has been suggested that dementia can affect the quality of care received (Bunn et al., 2014). The detection of other diseases besides dementia can be difficult for several reasons, as pointed out by Calderón-Larrañaga et al. (2019). People with dementia may not attend appointments (Calderón-Larrañaga et al., 2019) and they may have difficulty communicating symptoms (Baird et al., 2019). In addition, the high symptom burden caused by dementia, specifically its behavioral and psychological symptoms, requires so much attention that other diseases may remain unnoticed (Calderón-Larrañaga et al., 2019).

Conversely, depression was consistently more likely to occur in participants with dementia than in those without dementia. Previous studies have demonstrated the high prevalence of depression in older people and the the oldest old with dementia (Bauer et al., 2014; Sherzai et al., 2016; Vargese et al., 2021). Depressive and other mental health and neuropsychiatric conditions such as Parkinson's disease, which was found to be associated with dementia in the present study as well, have been found to cluster with cognitive decline and dementia (Jackson et al., 2015; Schäfer et al., 2010).

Overall, the prevalence of comorbidities with dementia is high (Bunn et al., 2014; Clague et al., 2016) and increasing (Beerten et al., 2022; Vargese et al., 2021). The increasing burden of dementia comorbidity poses challenges for those living with dementia, caregivers, and for the care system as a whole. Cognitive decline and multimorbidity seem to be bidirectionally connected as there is evidence that

multimorbidity may contribute to declining cognition, and preventing cognitive decline can also prevent new chronic diseases (Calderón-Larrañaga et al., 2019; Marengoni et al., 2018). It is not clear if people with dementia have the same access to health care services as the general population do, and like other people with multimorbidity, people with dementia and comorbidities may face a lack of continuity in their care (Bunn et al., 2014). Clinical guidelines for dementia do not provide sufficient guidance on comorbidities and specifically the treatment of very old people with dementia, mostly because there is a shortage of reliable research (Damiani et al., 2014). The Finnish Current Care Guidelines for dementia emphasize the need for coordinated and patient-centered care but offer no guidance for the treatment of comorbidities (Muistisairaudet: Käypä hoito-suositus, 2020).

10.3 Disability, self-rated health, and self-rated functioning

The present findings showed that dementia was strongly associated with both ADL and mobility disability in both women and men. Depression was associated with ADL disability and mobility disability in women and with ADL disability in men. In addition to dementia and depression, hip fracture was associated with ADL and mobility disability in women and stroke with ADL disability in both genders.

The results of the present study underline the contributory role of dementia and depression to ADL disability and mobility disability among the oldest old people. The association was stronger for ADL disability than for mobility disability. The strong association of these diseases with ADL disability reflects the progressive nature of disability, as mobility has been found to decline before daily activities such as those included in the Vitality 90+ Study, dressing and getting in and out of bed (Jagger et al., 2001).

Depression and other mental health conditions, such as anxiety have been strongly associated with disability among younger old people (Garin et al., 2014). The role of cognitive decline and dementia in causing disability has been established in follow-up studies (Helvik et al., 2014; Zahodne et al., 2013). A recent Vitality 90+ article found that the improved functioning seen in the study population from 2001 to 2018 was mostly attributable to improvements among participants without dementia (Vargese et al., 2023). As dementia and depression often co-occur (Asmer et al., 2018; Vargese et al., 2021) and are common diseases among the oldest old,

their contribution to disability is pronounced in this age group. Given the increasing number of people living with dementia and depression, it seems clear that care needs will continue to increase in the future. As for the other diseases studied, the association between hip fracture and disability highlights the need for ongoing efforts at more effective fall prevention in the oldest old.

The cumulative burden of several chronic diseases among the oldest old warrants serious attention. In the present study, more severe multimorbidity (i.e. at least three diseases in women and at least four diseases in men) was associated with ADL and mobility disability. According to Calderón-Larrañaga et al. (2019), the vast majority of studies indicate that multimorbidity is associated with poor physical functioning in older people. This association between multimorbidity and disability may be bidirectional: disability may further increase the risk of developing new chronic diseases (Calderón-Larrañaga et al., 2019). Among younger old people, Garin et al. (2014) found a strong and progressive association between an increasing number of chronic conditions and disability. Lu et al. (2016) also showed that among younger old people, multimorbidity increased the risk of incident disability. Among the oldest old, having only geriatric conditions (such as cognitive decline, falls, pain, incontinence, and depressive symptoms) but not multimorbidity increased the risk of incident disability. The association of multimorbidity and disability may be mediated by dementia and depression, which were common in the Vitality 90+ Study population, as it has been shown that neuropsychiatric diseases individually and in combination are important determinants of disability in old people (Calderón-Larrañaga et al., 2019). Mental conditions such as mood disorders and anxiety have been shown to exacerbate the contribution of multimorbidity on ADL and IADL functioning in community-dwelling older population (Fisher et al., 2021). There is evidence that the biological mechanisms of aging may impact both the susceptibility to diseases and declining physical functioning (Calderón-Larrañaga et al., 2019).

The associations of diseases and multimorbidity with disability were more pronounced in women than in men, a finding earlier reported by Kingston et al. (2014) and Garin et al. (2014). Another common finding in population studies is that women have higher disability levels than men, especially in IADL functions but also largely in ADL functions (Crimmins, Shim, et al., 2019). It has been found that the oldest old men have a somewhat larger proportion of fatal diseases than women, while women have more disabling, nonfatal diseases. (Kingston et al., 2014.) This was also seen in the present study, where the prevalence of arthritis and hip fracture was higher among women than among men, and men showed higher rates of heart disease and cancer than women.

It has been suggested that the prevalence of chronic diseases has increased to such an extent that this trend can be thought to support the expansion of morbidity hypothesis. Disability-related measures, on the other hand, lend support to the compression of morbidity hypothesis. (Chatterji et al., 2015; Crimmins, 2015.) Seeman et al. (2010) found an increasing prevalence of ADL and IADL disability, mobility disability, and functional limitations in the older US population from 1988-1994 to 1999-2004, except for the oldest old people. Improved functioning among the oldest old has also been observed by Falk Erhag et al. (2021) and Rasmussen et al. (2018). The Vitality 90+ Study found a similar improvement in ADL and mobility among women between 2001 and 2018, especially in the latest study waves in 2014 and 2018. (Enroth et al., 2020.) Hossin et al. (2019) reported an increasing disease prevalence but improving ADL and IADL functioning in Swedish people aged over 77 years. They suggested that these results may be explained by earlier diagnosis of diseases, better treatment, healthier lifestyles, and environmental adaptation to disability.

Self-rated health and self-rated functioning

Depression and dementia showed the strongest association with poor self-rated health and poor self-rated functioning in both genders, as also reported by Simonsson & Molarius (2020). Self-rated functioning, an outcome that is not widely used in research, was mostly associated with the same diseases as other outcomes. Depression showed a strong association with poor self-rated functioning in women, possibly reflecting the poor self-efficacy of people having depressive symptoms. Self-rated ability to take care of oneself has been found to be associated with higher mortality risk (Bernard et al., 1997). The role of depression as a determinant of self-rated health specifically among the oldest old has been also emphasized by French et al. (2012). Lisko et al. (2020) found that dementia was associated with self-rated health indirectly through depression in the oldest old.

Earlier studies have shown that with increasing age, people often adapt to age-related health changes and common age-related diseases (Galenkamp et al., 2011; Leinonen et al., 2002). However, in a follow-up study on Vitality 90+ population, Galenkamp et al. (2013) detected a decline in self-rated health with an increasing number of chronic diseases and increasing functional difficulty, with depression contributing significantly to the decline. In the present study, an increasing number of chronic diseases was found to be associated with poor self-rated health and poor self-rated functioning. This association is most likely mediated by symptoms and the impact these diseases exert on functional ability, particularly when contrasted with those in younger old age (Lisko et al., 2020; Nützel et al., 2014). Koroukian et al.

(2016) found that the most important factors affecting self-rated health were a combination of functional limitations and geriatric syndromes (i.e., poor cognitive functioning, depressive symptoms, pain, incontinence, and sensory impairment). In conclusion, studies into self-assessed health outcomes among the oldest old must adequately address the complex interplay of diseases, disabilities, and the symptom burden.

10.4 Long-term care and mortality

Parkinson's disease had the highest impact on LTC admission in women, followed by dementia, hip fracture, and depression. However, due to its low prevalence, Parkinson's disease accounted only for 0.6% of LTC admissions, whereas dementia accounted for 8% in women and 9% in men. None of the diseases were a statistically significant predictor of LTC admission in men; only functional ability served as a predictor of LTC admission among men. Overall, the PAFs for LTC admission were very low. A higher risk of LTC admission due by multimorbidity (Koller et al., 2014; Viljanen et al., 2021) was detected among women with at least three diseases.

The results imply that dementia and multimorbidity are the main drivers for the need of LTC in the oldest ages. This association is most likely mediated by functional ability, frailty, care received at home, and living arrangements, which are known risk factors for LTC admission in old age (Kauppi et al., 2018; Luppa et al., 2010; Rockwood et al., 2004). It is highly likely that care needs will continue to increase in the future as more people live to very old age. Based on a microsimulation model, Kingston et al. (2018) projected that in England, both low and high dependency among the oldest people will substantially increase in absolute terms by 2035, even though the prevalence of dependency will change only little. In Finland, the coverage of care for older people has declined because of the policy focus on reducing 24-hour care. At the same time, the availability of home care has not increased to the same extent (Mielikäinen & Kuronen, 2023). The use of LTC has also decreased among the oldest old, but living to the oldest ages and the presence of dementia remain the two most important factors associated with the use of LTC services (Aaltonen et al., 2019).

Results on the effects of gender on the risk for LTC admission are not entirely consistent (Luppa et al., 2010). In Finland, Viljanen et al. (2021) found that women enter LTC more frequently than men. The oldest old women more live alone more

often than men because of widowhood, a known risk factor for LTC admission (Luppa et al., 2010), but they also show higher rates of disability and for this reason are more likely to need LTC in the oldest ages. The results of the present study reflect the better functional ability of men compared to women, contributing to their lower care needs. Disabling diseases thus appear to be a greater contributor to LTC admission in women in the oldest old.

Baseline mortality is high in the oldest old. In the present study using a long follow-up time and the time-varying covariates to capture changes in functional ability and morbidity it was found that heart disease, dementia, and diabetes increased the risk of death in people aged over 90. Furthermore, multimorbidity was to some extent predictive of mortality as women with three or more diseases had an increased risk of death and the lowest mortality risk was seen in participants reporting no diseases.

CVDs are the leading cause of death in Finland in people aged over 75, with dementia the second leading cause (Official Statistics of Finland (OSF), 2021c). In younger old people, the most important predictors of death are CVDs and diabetes (Prince et al., 2015). With a shorter follow-up time and a smaller sample size, Nybo et al. (2003) found that diabetes and CVDs were predictive of mortality in the oldest old, and Ferrer et al. (2017) showed that COPD, atrial fibrillation, and cancer were predictive of mortality. In the present study, PAF was higher for dementia than for heart disease, highlighting the contribution of dementia to mortality in the oldest old. Similar results concerning the importance of dementia in the oldest old people have been presented before by Börjesson-Hanson et al. (2007). Depression increased the risk of death only in women, but its PAF was only 5%. Depression is a known predictor of mortality in younger people, but the association has been less evident among the oldest old (Rapp et al., 2008). Nybo et al. (2003) did not find the number of diseases to be predictive of mortality among the oldest old, and Rajamäki et al. (2021) reported that the association of mortality and Alzheimer's disease with comorbidities was weaker among people aged over 80 compared with younger old people.

This study confirmed earlier findings of the contribution of disability on mortality in the oldest ages (Landi et al., 2010; Lee et al., 2008; Rajamäki et al., 2021), as the impact of disability on mortality was prominent in both genders. Especially in men the impact of diseases was attenuated when disability was accounted for in the models. Limitations in mobility and ADL have been found to increase before death in old age (Lunney et al., 2018), while Lee et al. (2008) showed that in younger old

people, chronic diseases as such were stronger predictors of death than functional limitations.

10.5 Studying the oldest old individuals

The oldest old comprise a rather unique population in health research, in several respects. One is the size of the population: until recent decades, people aged over 85 or 90 years have been relatively few in numbers, representing the 'survivors' of their birth cohorts. In the 21st century, however, their absolute numbers and share of the adult population have risen sharply. This has facilitated research into this population group and underlined its importance. (Jylhä, 2020.) Although surveys have been the most popular method of data collection in health research, questions have lingered over whether the oldest old are in fact capable of providing reliable information about their health via questionnaires. There is still a scarcity of research into the reliability of survey information on diseases, i.e. the ability of an instrument to measure consistently what it is intended to measure (Strotmeyer & Ward, 2012). Yet this information is crucially important for public health purposes and for planning health and social care services in aging populations. Clinical examinations are often considered the gold standard for assessing the validity of disease information. However, it is often difficult and sometimes impossible to conduct clinical examinations in large population-based samples of the oldest old individuals. Given these constraints, the present study assessed the reliability of disease information by comparing it to national register data. This approach provides valuable insights into the consistency of self- and proxy-reported information in the oldest old.

In line with earlier studies, the results showed a high level of agreement between survey information and register data for Parkinson's disease, diabetes, and hip fracture (Guerra et al., 2019; Hansen et al., 2014; Okura et al., 2004). These diseases are characterized by clear definition in the survey, specific treatments (medication, surveillance of symptoms), and the need for inpatient or specialized care. Lower agreement was seen for hypertension, heart disease, depression, and arthritis, again in line with earlier studies (Andersen-Ranberg et al., 2013; Hale et al., 2019; K. R. Koller et al., 2014; Teh et al., 2013). These diseases do not often require specialized hospital care, and the medication used for these diseases can also have other indications. The survey items used in this study for heart disease and depression were more ambiguous than for those diseases showing high agreement with the register

data, that is Parkinson's disease, hip fracture, and diabetes. The heart disease item included coronary artery disease, arrhythmia, and myocardial infarction, and depression also included 'depressed mood'.

It is noteworthy that the survey results indicated a higher prevalence for the diseases than the register data, which is partly inconsistent with earlier research (Andersen-Ranberg et al., 2013). This is most likely due to differences in register characteristics. The care register used in the present study did not include primary care. As for the diagnosis recorded in the Care Register for Health Care (CRHC), only diseases with an effect on treatment or prognosis are usually recorded in addition to the main diagnosis (Finnish Institute for Health and Welfare, 2021; Sund, 2012.) Hence, CRHC is not complete and comprehensive with regard to secondary diagnoses. In order to obtain a reimbursement in the Finnish Prescription Register (FPR), a person needs to undergo a clinical examination. In addition, as the FPR does not cover drugs dispensed at institutional care, some cases can be missed for long-term institutional care residents. The requirement of clinical examination increases the likelihood that the recorded diseases are indeed correct, most likely contributing to the very high positive percent agreement between survey and FPR data in the present study. Dementia showed moderate to substantial agreement with the registers. The discrepancy was due to a higher rate of cases depicted from the survey compared with the registers. This is again most likely due to the register characteristics and the fact that the survey item also included 'problems with memory'. An earlier study assessing the validity of dementia diagnoses in CRHC found that it underreported dementia cases (Solomon et al., 2014).

The only diseases showing a higher prevalence in the register than the survey data were cancer and stroke, a finding most likely related to the rather long look-back time in the registers. It is possible that an earlier diagnosis of cancer or stroke has shown no symptoms at the time of the survey and was therefore not reported by the participants or proxy respondents. Cancer and stroke are also severe diseases that are likely to be treated in hospital settings and specialized care, which probably contributes to the higher prevalence in CRHC.

The proxy respondents in the present study reported a very high prevalence of dementia (86.3%), underscoring the importance of including proxy respondents in order to obtain representative results for the oldest old individuals with cognitive decline and dementia. The results confirm that proxy respondents are a necessity in studying the oldest old people (Gruber-Baldini et al., 2012; Kelfve et al., 2013). Otherwise, proxy-reported diseases showed a slightly lower level of agreement with register data than those reported by self-respondents. Rydén et al. (2019) found that

proxy respondents reported a lower prevalence for several diseases than self-respondents. Agreement between proxy and self-respondents was high for diabetes, angina pectoris, and myocardial infarction (Rydén et al., 2019). Since dementia was very common among participants who used a proxy respondent, it is possible that diseases other than dementia remained unreported due to the high symptom burden caused by dementia. Multimorbidity and frailty have been shown to increase the discrepancy between survey and register information (Hale et al., 2019). Furthermore, there is some evidence that proxy respondents may overestimate cognitive decline (Li et al., 2015).

The aim in the present study was to capture both inpatient and outpatient care using two different register sources. These registers did indeed complement each other as the kappa values were higher and disease prevalences were closer to the survey results when the information from the two registers was merged and used in combination. This finding highlights the importance of using registers that provide information on both inpatient and outpatient care in agreement studies and also if disease prevalence is to be assessed through register information. Moreover, it is important to know and understand the characteristics of the registers used, i.e. their population coverage, reporting requirements, and recording practices.

10.6 Ethical considerations

The Finnish Responsible Conduct of Research (RCR) guidelines were followed throughout this research process (Finnish Advisory Board of Research Integrity, 2013). The study participants were exceptionally old and some of them lived in LTC. Although high age does not itself affect the decision-making ability or increase the vulnerability of study participants (Nikander & Zechner, 2006), people living in LTC are nonetheless recognized as a vulnerable population due to their dependency on others and the high prevalence of cognitive decline, which may hinder their decision-making abilities and make them susceptible to coercion (Boult et al., 2003). Older people, people living in LTC, and people with cognitive decline have often been excluded from both clinical trials and epidemiologic studies, resulting in incomplete understanding of the fundamental epidemiologic factors that influence these populations (Boult et al., 2003). The exclusion of marginalized populations and its consequences are also discussed by Kuula (2011), who points out that sidelining these groups is bound to leave gaps in our knowledge.

Informed consent is a crucial component of research ethics, particularly in studies of older people where there may be an imbalanced power relationship between researchers and study participants (Nikander & Zechner, 2006). To provide genuine informed consent, study participants need to be adequately informed about the study (Kuula, 2011). If a participant is unable to give their informed consent, consent may be obtained from a close relative or a legal representative (Mäkinen, 2006). The person's ability to consent may be affected by cognitive decline, but as Mäki-Petäjä-Leinonen (2006) notes, there is no simple way to define the point where cognitive decline hinders the ability to make major decisions. It is also important in research settings to respect the autonomy of people with memory disorder. On the other hand, problems with overprotectiveness may occur if a representative declines an invitation to participate in research without even consulting the person's opinion (Boult et al., 2003; Kuula, 2011).

10.7 Strengths and limitations

The present study comprised a well-defined total population of people aged over 90 years within a specific geographic area. It involved repeated surveys with similar questions over a long period of time and linked the survey information collected with national register data. Other noteworthy strengths of the Vitality 90+ Study include the high response rate throughout the study period and the inclusion of proxy respondents (Enroth et al., 2023). The questionnaires were completed very carefully and there was only little missing data. The Tampere population aged over 90 is quite comparable to the Finnish population of the same age. Older populations in Finland are fairly homogenous in terms of their ethnic background, and the proportion of the oldest old in the total Tampere population is roughly the same as in the rest of Finland. Furthermore, the country's universal health care system covers the whole population, which means that people are on relatively equal footing with respect to the treatment of diseases, for example (Enroth et al., 2023; Jylhä et al., 2013). Even though the survey covered only a limited number of diseases, they are all common age-related chronic conditions included in several multimorbidity studies (Diederichs et al., 2011) and in the Functional Comorbidity Index (Groll et al. 2005), which was developed for use in studies measuring physical function as an outcome. The functional ability items used in the Vitality 90+ Study, even though limited in number, are well validated and widely used in studies on older people

(Hopman-Rock et al., 2019). Mobility is not systematically included in ADL or IADL measurements, but is an important aspect of physical capacity. The Short Form 36 Health Survey (SF-36) includes a physical functioning subscale (PF-10) which assesses capacity and mobility. The scale includes items such as carrying heavy objects, walking shorter and longer distances, climbing stairs, and bending and kneeling (Guralnik et al., 2012).

The Vitality 90+ surveys were conducted among people aged over 90 and therefore had a limited number of questions. The information was collected using self-reports. In addition to the finding that self-reported and register data were in adequate agreement, the validity of the present results can be estimated based on their plausibility (Strotmeyer & Ward, 2012). 'Conclusion validity' assesses if the association between a measure and an outcome is plausible (Strotmeyer & Ward, 2012), and the findings of the present study that diseases, multimorbidity, and functional ability did predict mortality and LTC admission can be considered to indicate strong conclusion validity.

The Vitality 90+ surveys did not assess the severity or onset of diseases, factors that might have given more insight into the associations detected. They also did not assess frailty, again failing to measure its impact on the outcomes studied. Furthermore, it is probable that a minority of participants who reported no diseases in the present study, had some disease(s) not included in the questionnaire.

The Vitality 90+ surveys had very high response rates, but two months after the survey non-respondents had a higher mortality rate than those who did participate (Enroth et al., 2023), suggesting that they were in poorer health. The health problems identified in the present study are therefore likely underestimated. Both the response rate and the proportion of proxy respondents declined over the study years. This adversely affects the certainty of the results of the trend analysis over time. In addition, the small number of male participants reduced the power of the statistical analysis and likely contributed to the weaker associations found in men throughout the present study.

The limitations of the registers used in this study include the lack of information from primary care (general practitioners) and the limited availability of FPR data. The use of drug reimbursement codes meant that some milder disease cases might have been missed from FPR because of the criteria used for the reimbursement. However, the registers used in the present study comprise routinely collected, population-based data with good coverage. Reporting to CRHC is mandatory and FPR covers all reimbursed prescription drugs dispensed at pharmacies (Finnish Institute for Health and Welfare, 2021; Furu et al., 2010; Laugesen et al., 2021).

10.8 Implications for practice and research

The morbidity profile of the oldest old population is characterized by a high and increasing number of chronic diseases and a high prevalence of cardiovascular diseases, dementia, and depression. Dementia, heart disease, and depression are strongly associated with poor health assessments, the need for long-term care, and mortality. These diseases and multimorbidity have important implications for the functional ability of the oldest old, a factor closely related to other outcomes and possibly mediating the associations discovered. This study also showed that survey methods can be used in population-based health studies to collect information on chronic diseases among the oldest old.

The growing number of people with chronic diseases and increasingly complex multimorbidity are going to need coordinated care. Dementia is a highly prevalent condition that is associated with disability and an increased need for LTC and that is predictive of mortality in the oldest old. Even though prevalence rates are on the decline, the absolute number of people with dementia and other age-related chronic diseases is continuing to rise and bound to present a major challenge for health and social care systems in the future. It is important that these increasing care needs are recognized and that adequate support and long-term care is available when needed.

To maintain or increase the quality of life of people with multiple co-occurring diseases, care and rehabilitation must be person-centered, tailored to the individual rather than to the disease. More research is needed on the specific care needs of the oldest old living with multimorbidity and on the care burden of both the professionals and the relatives caring for these people. For well-being and quality of life reasons it would be important to look into how people with multimorbidity and their carers experience the way they are encountered in the health and social care system. New practices and models of care are needed to treat the increasing number of old people with multimorbidity.

Research on the oldest old must work closely with administrators, care staff, family members, and relatives and conduct carefully designed surveys that have representative samples. The design and wording of survey items are particularly critical when it comes to studying diseases. Questions should mention specific diseases and preferably also specify time ranges. As most health registers do not contain information on other relevant outcomes such as functional ability, social relations, and self-rated health, and as both self and proxy reports from the oldest old seem to be sufficiently reliable data sources, it seems reasonable to argue that

surveys are a feasible method for collecting health-related information even among the oldest old.

With respect to the issue of healthy longevity, the increasing disease burden and the high burden of dementia and depression found in the present study suggest that life at the oldest ages is characterized by high chronic disease morbidity. There is reason to expect that heterogeneity in the health status of the oldest people will continue to increase in the future as larger proportions of birth cohorts live up to very old age. It is therefore important to continue to monitor trends in disease frequency and in disability and to study their association in different cohorts.

As long as there is no cure or no way to fully prevent chronic diseases and disability as a result of aging, the focus both in research and practice should be on maintaining the quality of life of the people living with diseases and disability and the people taking care of them, and on ensuring timely care, especially proper end of life care when it is needed.

10.9 Conclusions

- The increasing population of people aged over 90 has a high and rising prevalence of age-related conditions and multimorbidity. Those with dementia have high and increasing levels of other age-related diseases, but the prevalence of dementia has decreased.
- In particular, dementia, depression, and multimorbidity are associated with disability and poor health assessments.
- Dementia and disability are the most important predictors of long-term care admissions and together with heart disease the most important mortality predictors.
- Survey questionnaires are a sufficiently reliable method for data collection in health research among the oldest old, showing acceptable agreement with national register data.

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PUBLICATIONS

PUBLICATION I

Pitkäaikaissairaudet ja monisairastavuus hyvin vanhoilla sekä niiden yhteys toimintakykyyn ja itse arvioituun terveyteen – Tervaskannot 90+ -tutkimus

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Pitkäaikaissairaudet ja monisairastavuus hyvin vanhoilla sekä niiden yhteys toimintakykyyn ja itse arvioituun terveyteen – Tervaskannot 90+ -tutkimus

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Tutkimuksessa selvitettiin pitkäaikaissairauksien ja monisairastavuuden esiintyvyyttä 90-vuotiailla ja sitä vanhemmilla tamperelaisilla. Erityisenä mielenkiinnon kohteena oli sairastavuuden yhteys huonoon itse arvioituun terveyteen ja toimintakykyyn sekä avun tarpeeseen päivittäisissä toiminnoissa ja liikkumisessa. Tutkimuksessa käytettiin Tervaskannot 90+ -tutkimuksen vuoden 2014 postikyselyaineistoa, johon vastasi 1637 henkilöä ja vastausprosentti oli 80. Tutkimuksen mukaan miehistä 77 % ja naisista 82 % sairasti vähintään kahta pitkäaikaissairautta. Etenkin muistisairautta ja masennusta sairastavat henkilöt arvioivat terveytensä ja toimintakykynsä huonoksi, ja heillä avun tarve liikkumisessa ja päivittäisissä toiminnoissa oli lisääntynyt. Naisilla useampi yksittäinen sairaus oli yhteydessä huonoon itse arvioituun terveyteen ja toimintakykyyn kuin miehillä. Monisairaat henkilöt arvioivat terveytensä ja toimintakykynsä heikommaksi ja tarvitsivat enemmän apua liikkumisessa ja päivittäisissä toiminnoissa kuin ne henkilöt, joilla oli vain yksi sairaus. Hyvin vanhojen sairastavuutta ja monisairastavuutta tulisi selvittää lisää, jotta terveydenhuollossa ja yhä enemmän kotona tapahtuvassa hoidossa voitaisiin nykyistä paremmin huomioida monisairaiden henkilöiden tarpeet.

Johdanto

Suomalaisen väestön vanhetessa kaikkein vanhin väestönosa kasvaa. Vuoden 2016 lopussa Suomessa oli 47 417 yli 90-vuotiasta henkilöä (Suomen virallinen tilasto 2017). Pitkäaikaissairauksien ja monisairastavuuden tiedetään yleistyvän ikääntymisen myötä (Barnett ym. 2012; Koskinen, Manderbacka & Aromaa 2012, 77–81; Marengoni ym. 2011). Englannin kieli erottaa toisistaan käsitteet ”comorbidity” ja ”multimorbidity”, joista jälkimmäisellä yleensä viitataan siihen, että henkilö sairastaa useampaa kuin yhtä pitkäaikaissairautta samanaikaisesti. ”Comorbidity” puolestaan viittaa muiden sairauksien esiintymiseen yhdessä tietyn indeksisairauden kanssa (Valderas, Starfield, Sibbald, Salisbury & Roland 2009). Suomeksikin voidaan puhua lisäsairauksista (komorbiditeetista) ja moni-

sairastavuudesta (multimorbiditeetista), vaikka usein näillä tarkoitetaan samaa asiaa (Tilvis 2009). Tämä tutkimus keskittyy hyvin iäkkäiden henkilöiden multimorbiditeetin eli monisairastavuuden tarkasteluun.

Monisairastavuus on yleistä iäkkäillä, erityisesti naisilla (Bähler, Huber, Brüngger & Reich 2015; Barnett ym. 2012; Marengoni ym. 2011). Aikaisemmat tutkimukset osoittavat, että yli 65-vuotiaista 7–8:lla kymmenestä on ainakin kaksi pitkäaikaissairautta (Bähler ym. 2015; Jackson ym. 2015; Fried, Bandeen-Roche, Kasper & Guralnik 1999). Iäkkäillä yleiset sydän- ja verisuonisairaudet sekä dementia ja masennus esiintyvät usein yhdessä. Dementia ja masennus liittyvät usein myös muihin sairauksiin, kuten lonkkamurtumaan (Marengoni, Rizutto, Wang, Winblad & Fratiglioni 2009). Barnett ym. (2012) mukaan psyykkistä ja somaattista sairautta yhtäaikaisesti sairastavien osuus kasvaa iän myötä. Monisairaat sairastavat entistä useampaa sairautta samanaikaisesti (KonéPefoyo ym. 2015; Uijen & van de Lisdonk 2008). Hollantilainen tutkimus osoittaa, että erityisesti kolmea tai useampaa sairautta sairastavien osuus kasvoi vuosien 1985–2005 välillä (Uijen & van de Lisdonk 2008). Myös ruotsalaistutkimus raportoi vakavien oireiden ja sairauksien esiintyvyyden lisääntyneen vuosien 1992–2011 välillä (Meinow, Kåreholt, Thorslund & Parker 2015).

Hyvin vanhojen henkilöiden pitkäaikaissairauksista ja monisairastavuudesta on vain vähän tietoa. Vuoden 2010 Tervaskannot 90+ -tutkimuksen mukaan lähes kaikilla yli 90-vuotiailla oli vähintään yksi lääkärin toteama sairaus (Helminen, Sarkeala, Enroth, Hervonen & Jylhä 2012). Englantilaisen sairauskertomuksiin perustuvan tutkimuksen mukaan lähes 90 %:lla 85 vuotta täyttäneistä oli vähintään kolme sairautta (Collerton ym. 2009). Barnettin ja kumppaneiden (2012) tutkimuksessa yli 85-vuotiaista 82 % sairasti useampaa kuin yhtä sairautta. Kanadalaisessa tutkimuksessa, jossa selvitettiin yli 90-vuotiaiden monisairastavuutta, havaittiin, että 75 % oli monisairaita vuonna 2003 ja prosenttiosuus nousi 83:een vuonna 2009 (KonéPefoyo ym. 2015).

Monisairastavuuden on todettu heikentävän toimintakykyä (Marengoni ym. 2011; Ryan, Wallace, O'Hara & Smith 2015) ja elämänlaatua (Marengoni ym. 2011). Hollantilaisessa tutkimuksessa (Drewes ym. 2011) vähintään kahden sairauden sairastaminen oli yhteydessä heikentyneeseen toimintakykyyn yli 85-vuotiailla henkilöillä. Monisairastavuus lisäksi nopeutti toimintakyvyn heikkenemistä viisivuotisen seurannan aikana (emt.). Pitkäaikaissairaudet vaikuttavat myös henkilön omaan arvioon terveydestään. Galenkamp, Braam, Huisman ja Deeg (2011) sekä McDaid ym. (2013) tutkimuksissa itse arvioitu terveys oli heikoin niillä henkilöillä, joilla oli useita pitkäaikaissairauksia. Itse arvioitu terveys on kokonaisvaltainen terveydentilaa kuvaava, tutkimuksessa paljon käytetty terveyden mittari (Jylhä 2009), joka ennustaa kuolleisuutta vielä yli 90-vuotiaillakin (Vuorisalmi, Sarkeala, Hervonen & Jylhä 2012; Nybo ym. 2001).

Tämän tutkimuksen tarkoituksena on selvittää pitkäaikaissairauksien ja monisairastavuuden yleisyyttä hyvin vanhoilla sekä tarkastella niiden yhteyttä itse arvioituun terveyteen, itse arvioituun toimintakykyyn ja avun tarpeeseen päivittäisissä toiminnoissa ja liikkumisessa Tervaskannot 90+ -tutkimuksen vuoden 2014 kyselyaineiston perusteella.

Aineisto ja menetelmät

Tutkimuksessa käytettiin Tervaskannot 90+ -hankkeen vuoden 2014 postikyselyllä kerättyä aineistoa. Tervaskannot 90+ on vuodesta 1995 käynnissä ollut tutkimuskokonaisuus, jossa kohderyhmänä ovat tamperelaiset 90-vuotiaat ja sitä vanhemmat henkilöt (Jylhä, Pirttiniemi & Hervonen 1997). Vuoden 2014 kysely suunnattiin vuonna 1924 ja sitä aiemmin syntyneille tamperelaisille. Tampereen kaupungilta saatujen tietojen mukaan ikäryhmään kuului 2156 henkilöä. Ennen kyselylomakkeiden postitus-

ta 98 henkilöä kuoli ja kaksi henkilöä ei enää asunut Tampereella, joten lomake lähetettiin 2056 henkilölle. Kyselyyn vastasi 1637 henkilöä, ja vastausprosentti oli 80. Vastaajista 82 % (n=1320) oli vastannut kyselyyn itse tai valinnut vastaukset itse, vaikka toinen henkilö olisi avustanut lomakkeen täyttämisessä; lopuilla vastaukset saatiin sijaisvastaajalta.

Vuoden 2014 kysymykset olivat suurelta osin samoja kuin aikaisempina vuosina. Sairauksien esiintyvyyttä selvitettiin kysymällä, onko lääkäri todennut vastaajalla seuraavia sairauksia: verenpainetauti/korkea verenpaine, sydänsairaus (sepelvaltimotauti, rytmihäiriö tai sydäninfarkti), syöpä, muistisairaus (dementia, Alzheimerin tauti tai muistin heikkeneminen), aivohalvaus, diabetes/sokeritauti, nivelrikko/artroosi, Parkinsonin tauti, lonkkamurtuma tai masennus/masentuneisuus.

Monisairastavuuden kuvaamiseksi sairauksien määrä luokiteltiin viiteen luokkaan: 0–1, 2, 3, 4 ja 5 tai useampi sairautta. Tutkittavat, joilla ei ollut yhtään sairautta tai oli yksi sairaus, yhdistettiin samaan luokkaan, sillä täysin ilman sairauksia olevia tutkittavia oli vähän.

Toimintakyvyn tasoa selvitettäessä tutkittavilta kysyttiin kykenivätkö he: 1) pukeutumaan ja riisuutumaan, 2) nousemaan vuoteesta ja menemään vuoteeseen, 3) kävelemään 400 metriä, 4) liikkumaan sisätiloissa ja 5) kulkemaan portaita. Vastausvaihtoehdot olivat: a) kyllä, vaikeuksitta, b) kyllä, mutta se on vaikeaa, c) vain jos joku auttaa ja d) en kykene. Mikäli vastaaja selviytyi ilman apua kahdesta ensimmäisestä toiminnosta (1–2), hänen katsottiin olevan itsenäinen päivittäisissä toiminnoissaan; mikäli hän selviytyi itsenäisesti kolmesta jälkimmäisestä (3–5), hänet katsottiin liikkumiskyvyltään itsenäiseksi.

Itse arvioitua terveyttä ja itse arvioitua toimintakykyä selvitettiin kysymyksillä ”Millaiseksi itse arvioitte nykyisen terveydentilanne?” ja ”Millaiseksi itse arvioitte nykyisen toimintakykynne?”. Vastausvaihtoehdot molempiin kysymyksiin olivat a) erittäin hyvä, b) melko hyvä, c) keskiverto, d) melko huono ja e) huono. Analyysia varten vastausvaihtoehdot melko huono ja huono yhdistettiin kuvaamaan huonoa itse arvioitua terveyttä ja toimintakykyä ja muut vastaukset yhdistettiin kuvaamaan hyvää terveyttä ja toimintakykyä. Omia arviointeja koskevista vastauksista huomioitiin ne, joissa tutkittavat olivat vastanneet kysymyksiin täysin itsenäisesti tai he olivat vastanneet kysymyksiin itse, vaikka olivat saaneet apua lomakkeen täyttämisessä (= itse vastanneet).

Analyysit tehtiin erikseen miehille ja naisille, koska terveyden tiedettiin olennaisesti eroavan sukupuolten välillä (Helminen ym. 2012; Jylhä ym. 1997). Analyysimenetelminä käytettiin aineiston kuvailuun frekvenssijakaumia ja ryhmien välisten tilastollisten erojen testaamiseen khiin neliö-testiä sekä Parkinsonin taudin kohdalla itse vastanneilla Fisherin testiä pienten luokkafrekvenssien vuoksi. Lisääntyneeseen avun tarpeeseen päivittäisissä toiminnoissa ja liikkumisessa sekä itse arvioituun terveyteen ja itse arvioituun toimintakykyyn yhteydessä olevia tekijöitä selvitettiin logistisen regressioanalyysin avulla. Vastemuuttujia regressioanalyysissä olivat huono itse arvioitu terveys, huono itse arvioitu toimintakyky, avun tarve päivittäisissä toiminnoissa sekä avun tarve liikkumisessa. Analyyseissa tarkasteltiin ensin kaikkien yksittäisten sairauksien yhteyttä vastemuuttujiin. Parkinsonin tauti jätettiin pois regressioanalyysistä taudin harvinaisuuden vuoksi. Seuraavaksi tarkasteltiin monisairastavuuden yhteyttä vastemuuttujiin. Kaikki edellä kuvatut mallit vakioitiin iällä ja lisäksi yksittäisten sairauksien mallit vakioitiin tutkimuksen muilla yksittäisillä sairauksilla. Referenssikategoriana yksittäisten sairauksien malleissa olivat vastaajat, jotka eivät sairastaneet kyseistä sairautta ja monisairastavuutta koskevissa malleissa ne, joilla oli 0–1 sairautta.

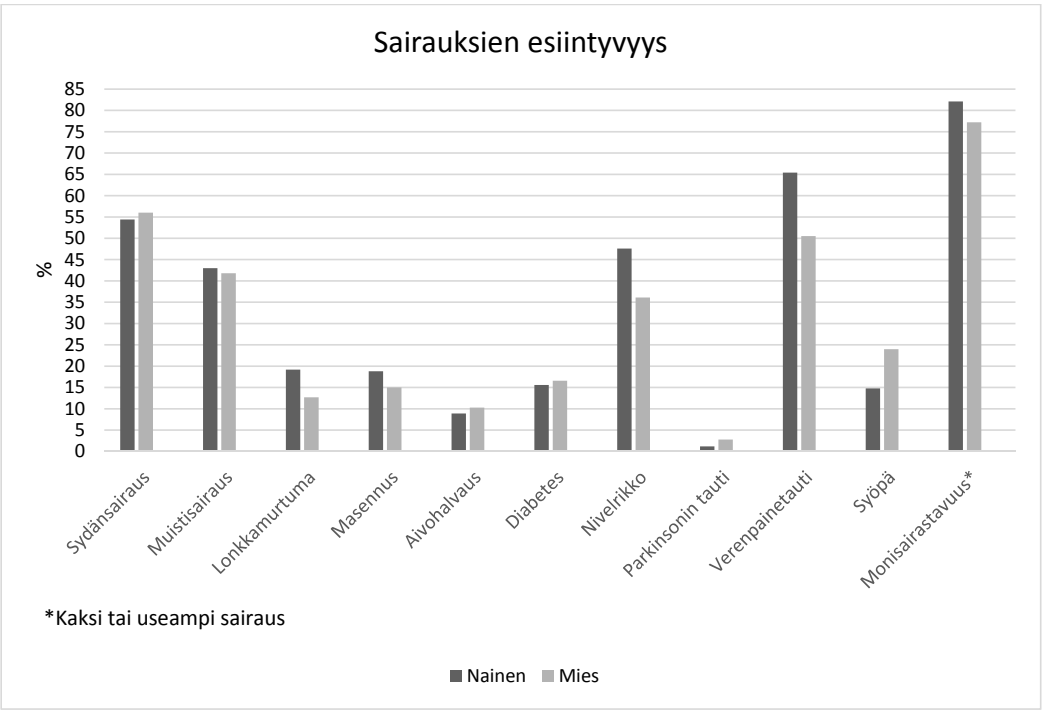
Tilastollisen merkitsevyyden rajana pidettiin p-arvoa 0,05. Logistisen regressioanalyysin tuloksista esitetään vetosuhde (OR) ja 95 %:n luottamusväli (LV). Tilastoanalyysit tehtiin IBM SPSS Statistics 23 -ohjelmalla.

Tulokset

Taustatiedot ja sairastavuus

Tutkittavista suurin osa oli naisia (77 %). Naisten keskimääräinen ikä oli 92,8 vuotta (vaihteluväli 90–106 vuotta) ja miesten 92,2 vuotta (vaihteluväli 90–103 vuotta). Tutkittavista 61 % asui kotona ja 39 % asumisyksiköissä, joissa henkilökuntaa on paikalla ympäri vuorokauden. Tutkittavilla oli keskimäärin 2,8 sairautta. Kokonaan ilman sairauksia oli miehistä 3 % ja naisista 2,9 %.

Naisten yleisin sairaus oli verenpainetauti (65,4 %) ja miesten sydänsairaus (56 %). Näiden lisäksi nivelrikko ja muistisairaus olivat molemmilla sukupuolilla yleisiä sairauksia. Miehistä 77,2 % ja naisista 82,1 % sairasti vähintään kahta sairautta. (Kuvio 1 ja Taulukko 1.) Vaikka sairauksien lukumäärä ei eronnut sukupuolten välillä tilastollisesti merkitsevästi, eroja havaittiin yksittäisissä sairauksissa. Miehet sairastivat sydänsairautta, Parkinsonin tautia ja syöpää useammin kuin naiset, ja heillä oli naisia vähemmän lonkkamurtumia, nivelrikkoa sekä verenpainetautia. Kun analyysissä huomioitiin vain tutkimukseen itse vastanneet, sukupuolten väliset erot olivat samankaltaiset kuin koko tutkittavien joukossa, vaikka lonkkamurtumissa ja sydänsairauksissa ero ei ollut tilastollisesti merkitsevä (Taulukko 1). Muistisairauden esiintyvyys itse vastanneiden joukossa oli 32,6 % ja koko tutkittavien joukossa 42,7 %.



Kuvio 1. Sairauksien esiintyvyys sukupuolittain Tervaskannot 90+ -aineistossa (%).

Taulukko 1. Yksittäisten sairauksien ja monisairastavuuden esiintyvyys sekä toimintakyky ja itse arvioitu terveys kaikilla vastaajilla ja itse vastanneilla sukupuolittain Tervaskannot 90+ -aineistossa (%).

	Kaikki vastaajat			Itse vastanneet		
	Naiset N=1117–1249	Miehet N=329–375		Naiset N=884–997	Miehet N=273–315	
	%	%	p-arvo	%	%	p-arvo
Sydänsairaus	54,4	56,0	**<0,001**	54,3	55,8	0,628
Muistisairaus	43,0	41,8	0,672	32,5	32,8	0,928
Lonkkamurtuma	19,2	12,7	**0,005**	18,2	13,8	0,081
Masennus	18,8	15,0	0,098	17,1	12,9	0,087
Aivohalvaus	8,9	10,3	0,401	8,2	10,0	0,336
Diabetes	15,6	16,6	0,647	14,9	17,5	0,286
Nivelrikko	47,6	36,1	**<0,001**	50,2	37,4	**<0,001**
Parkinsonin tauti	1,2	2,8	**0,024**	0,8	3,0	**0,008***
Verenpainetauti	65,4	50,5	**<0,001**	66,6	51,8	**<0,001**
Syöpä	14,8	24,0	**<0,001**	14,8	25,1	**<0,001**
Ei yhtään tai yksi sairaus	17,9	22,8	0,163	19,3	24,2	0,440
Kaksi sairautta	25,3	28,0		27,4	28,2	
Kolme sairautta	27,4	23,7		26,7	23,8	
Neljä sairautta	17,1	15,2		16,4	15,0	
Viisi tai useampi sairaus	12,3	10,3		10,2	8,8	
Tarvitsee apua liikkumisessa	60,6	40,3	**<0,001**	52,1	32,3	**<0,001**
Tarvitsee apua päivittäisissä toiminnoissa	26,8	17,6	**<0,001**	14,8	10,2	**0,035**
Huono itse arvioitu terveys				25,6	25,0	0,829
Huono itse arvioitu toimintakyky				33,9	29,3	0,133

*Fisherin tarkka testi

Tilastollisesti merkitsevät yhteydet lihavoitu

Sairauksien yhteys itse arvioituun terveyteen ja itse arvioituun toimintakykyyn

Yksittäisistä sairauksista muistisairaus oli yhteydessä huonoon itse arvioituun terveyteen ja huonoon itse arvioituun toimintakykyyn molemmilla sukupuolilla. Masennus heikensi itse arvioitua terveyttä molemmilla sukupuolilla ja naisilla myös itse arvioitua toimintakykyä. Naisilla sydänsairaus ja lonkkamurtuma heikensivät sekä itse arvioitua terveyttä että itse arvioitua toimintakykyä. Miehillä nivelrikko oli yhteydessä heikentyneeseen itse arvioituun terveyteen (Taulukko 2).

Kahden sairauden sairastaminen heikensi itse arvioitua terveyttä ja itse arvioitua toimintakykyä miehillä, mutta naisilla vasta kolmen sairauden sairastaminen heikensi arvioita merkitsevästi. Naisilla itsearvioinnit olivat sitä huonompia mitä useampaa sairautta he sairastivat, miehillä sairauksien määrän vaikutus itsearviointeihin ei ollut yhtä johdonmukainen (Kuvio 2).

Sairauksien yhteys avun tarpeeseen päivittäisissä toiminnoissa ja liikkumisessa

Yksittäisistä sairauksista muistisairaus, aivohalvaus ja masennus lisäsivät avun tarvetta päivittäisissä toiminnoissa sekä naisilla että miehillä. Lisäksi naisilla lonkkamurtuma oli yhteydessä lisääntyneeseen avun tarpeeseen päivittäisissä toiminnoissa. Osalla sairauksista yhteys oli päinvastainen: miehissä diabetesta ja syöpää sairastavat selviytyivät useammin itsenäisesti päivittäisistä toiminnoista verrattaessa miehiin, joilla juuri näitä sairauksia ei ollut (Taulukko 2).

Sydänsairaus, muistisairaus, lonkkamurtuma ja masennus lisäsivät avun tarvetta liikkumisessa naisilla. Miehillä avun tarvetta liikkumisessa lisäsi ainoastaan muistisairaus. Naisissa syöpää sairastavat olivat liikkumisessaan itsenäisempiä verrattuna naisiin, joilla syöpää ei ollut (Taulukko 2).

Naisilla kolmen sairauden sairastaminen ja miehillä viiden tai useamman sairauden sairastaminen lisäsi avun tarvetta päivittäisissä toiminnoissa. Liikkumisessa avun tarvetta lisäsi naisilla kolmen ja miehillä neljän sairauden yhtäaikainen sairastaminen (Kuvio 2).

Pohdinta

Tässä tutkimuksessa selvitettiin pitkäaikaissairauksien ja monisairastavuuden esiintyvyyttä sekä niiden yhteyttä itse arvioituun terveyteen ja toimintakykyyn sekä avun tarpeeseen päivittäisissä toiminnoissa ja liikkumisessa hyvin vanhoilla henkilöillä. Lähes jokaisella tutkittavalla oli vähintään yksi pitkäaikaissairaus, ja suurin osa oli monisairaita. Naisilla useampi yksittäinen sairaus oli yhteydessä heikkoon itse arvioituun terveyteen ja toimintakykyyn kuin miehillä. Monisairastavuus heikensi itse arvioitua terveyttä ja toimintakykyä sekä miehillä että naisilla.

Tutkituista sairauksista yleisimpiä olivat muistisairaudet ja nivelrikko sekä verenpainetauti ja sydänsairaus. Näistä muistisairaudet olivat yhteydessä heikompaan toimintakykyyn ja arvioon omasta terveydestä sekä miehillä että naisilla. Myös masennus oli yhteydessä heikompaan terveyteen ja toimintakykyyn miesten itse arvioitua toimintakykyä ja liikkumiskykyä lukuun ottamatta. Aikaisemmat tutkimukset osoittavat, että dementia ja masennus (Marventano, Ayala, Gonzalez, Garcia-Gutierrez & Forjaz 2014; Garin ym. 2014) sekä tuki-ja liikuntaelinsairaudet, sydän- ja verisuonisairaudet, diabetes ja syöpä (Marventano ym. 2014; Forjaz ym. 2015) heikentävät toimintakykyä yli 65-vuotiailla. Lisäksi masennus sekä tuki- ja liikuntaelinsairaudet heikentävät elämänlaatua (Garin ym. 2014; Forjaz ym. 2015). Itse arvioidun terveyden kannalta yksittäisten sairauksien merkitystä ei ole juurikaan aiemmin tutkittu hyvin vanhoilla. Saksalaisessa tutkimuksessa (Nützel ym. 2014) 65–85 -vuotiailla monisairailla henkilöillä ainoastaan masen-

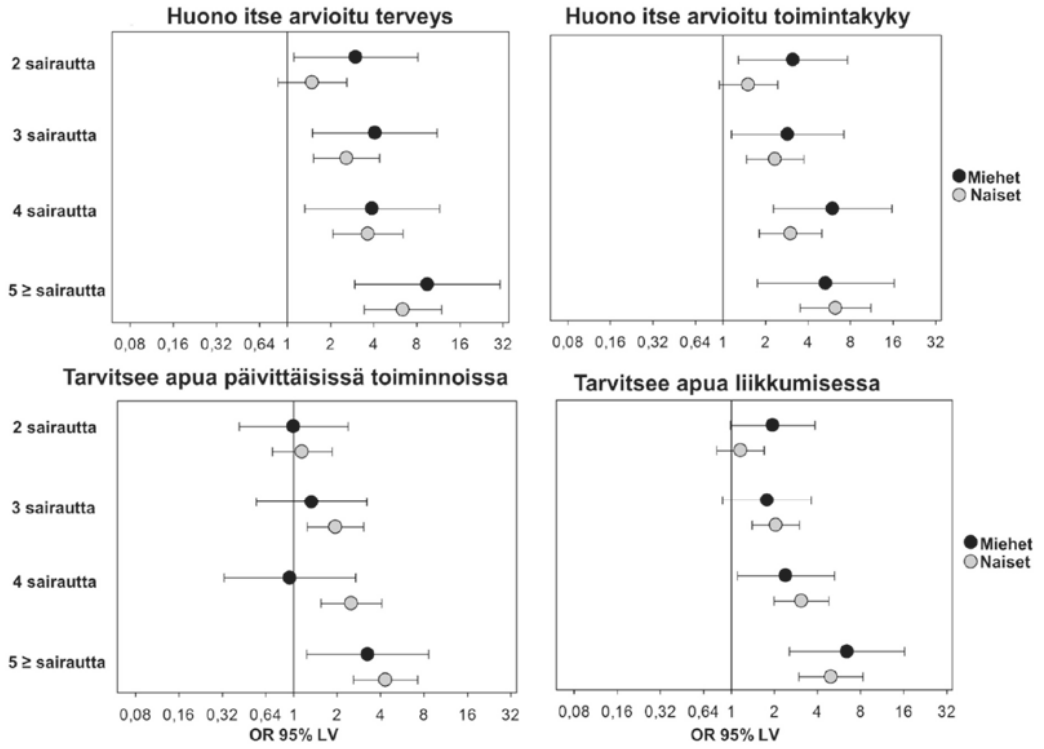
Taulukko 2. Logistinen regressioanalyysi sairauksien yhteydestä itse arvioituun terveyteen, itse arvioituun toimintakykyyn, avun tarpeeseen päivittäisissä toiminnoissa ja liikkumisessa sekä osuudet eri sairauksia sairastavista vasteiden mukaan Tervaskannot 90+ -aineistossa naisilla ja miehillä.

	Huono itse arvioitu terveys			Huono itse arvioitu toimintakyky			Tarvitsee apua päivittäisissä toiminnoissa			Tarvitsee apua liikkumisessa		
	%	OR	95 % LV	%	OR	95 % LV	%	OR	95 % LV	%	OR	95 % LV
Naiset												
Sydänsairaus	31,4	**2,02**	**1,44–2,82**	39,2	**1,69**	**1,24–2,31**	25,5	0,96	0,70–1,32	64,7	**1,55**	1,17–2,05
Muistisairaus	35,9	**1,79**	**1,27–2,52**	47,0	**2,07**	**1,49–2,87**	51,0	**10,67**	**7,59–15,07**	77,6	**3,76**	**2,80–5,05**
Lonkkamurtuma	34,5	**1,57**	**1,06–2,34**	48,9	**1,93**	**1,32–2,84**	36,5	**1,50**	**1,02–2,21**	75,2	**2,08**	**1,42–3,05**
Masennus	46,8	**2,84**	**1,90–4,21**	60,4	**3,50**	**2,35–5,23**	41,2	**1,82**	**1,25–2,65**	77,4	**2,23**	**1,50–3,32**
Aivohalvaus	34,7	1,38	0,80–2,37	42,1	1,23	0,72–2,10	39,3	**1,70**	**1,03–2,81**	74,5	1,47	0,88–2,47
Diabetes	28,5	1,04	0,67–1,63	34,0	0,84	0,54–1,31	28,7	1,18	0,76–1,82	64,1	1,34	0,91–1,97
Nivelrikko	27,6	1,12	0,81–1,55	37,2	1,30	0,95–1,77	23,5	0,86	0,62–1,19	62,7	1,31	0,99–1,73
Verenpainetauti	25,5	1,16	0,82–1,65	32,9	1,03	0,74–1,42	23,2	0,85	0,61–1,18	57,4	0,77	0,58–1,04
Syöpä	26,6	0,80	0,50–1,27	28,4	0,52	0,32–0,83	24,6	0,88	0,56–1,39	53,4	**0,55**	**0,37–0,81**
Miehet												
Sydänsairaus	29,1	1,29	0,69–2,39	32,9	1,35	0,76–2,40	16,2	0,55	0,27–1,12	41,1	0,87	0,52–1,44
Muistisairaus	38,8	**2,82**	**1,51–5,27**	44,4	**2,69**	**1,50–4,82**	36,7	**16,15**	**6,78–38,47**	61,3	**4,85**	**2,90–8,12**
Lonkkamurtuma	25,6	0,82	0,33–2,04	30,0	0,71	0,31–1,65	15,9	0,87	0,28–2,68	47,7	1,42	0,67–2,99
Masennus	46,2	**2,33**	**1,04–5,24**	46,2	1,59	0,72–3,52	37,0	**3,53**	**1,51–8,24**	57,4	1,44	0,71–2,89
Aivohalvaus	24,1	0,59	0,20–1,75	36,7	1,05	0,42–2,63	32,4	**2,96**	**1,07–8,18**	51,4	1,47	0,64–3,37
Diabetes	26,9	1,01	0,46–2,23	26,9	0,79	0,37–1,68	10,2	**0,29**	**0,09–0,96**	40,7	1,09	0,55–2,17
Nivelrikko	33,6	**1,84**	**1,01–3,35**	35,7	1,39	0,78–2,47	14,5	0,60	0,27–1,30	45,4	1,31	0,77–2,21
Verenpainetauti	28,5	1,44	0,78–2,66	31,0	1,06	0,60–1,88	16,3	1,07	0,51–2,23	37,7	0,82	0,50–1,38
Syöpä	28,4	1,37	0,71–2,64	36,5	1,68	0,91–3,09	10,6	**0,27**	**0,10–0,70**	44,0	1,30	0,73–2,33

Mallit vakioitu iällä ja yksittäisillä sairauksilla

Tilastollisesti merkitsevät yhteydet lihavoitu

OR=Odds ratio, vetosuhde, LV=Luottamusväli



Kuvio 2. Monisairastavuuden yhteys huonoon itse arvioituun terveyteen ja toimintakykyyn sekä avun tarpeeseen päivittäisissä toiminnoissa ja liikkumisessa. Ikävakioitu vetosuhde (OR=Odds ratio) ja 95 % luottamusvälit (LV) logistisesta regressioanalyysistä. Vertailuryhmänä 0–1 sairautta sairastavat.

nus ja Parkinsonin tauti sekä neuropatiat olivat yhteydessä huonoon itse arvioituun terveyteen.

Miehillä kahden ja naisilla kolmen yhtäaikaisen sairauden havaittiin olevan yhteydessä heikompiin itsearviointeihin, kun taas toimintakykyä heikensi naisilla kolme ja miehillä neljä–viisi yhtäaikaista sairautta. Monisairastavuuden ja heikentyneen toimintakyvyn välinen yhteys on osoitettu aiemmissa tutkimuksissa jo kahden samanaikaisesti sairastetun sairauden kohdalla (Garin ym. 2014; Drewes ym. 2011). Tutkimukset eroavat kuitenkin siinä, että Garinin ja kumppaneiden (2014) tutkimuksen kohderyhmä oli tämän tutkimuksen kohderyhmää nuorempi, ja toisaalta tutkimuksissa käytetyt toimintakyvyn mittarit sekä kysyttyjen sairauksien lukumäärä eroavat Tervaskannot 90+ -tutkimuksesta. Itse arvioidun terveyden on todettu heikkenevän hyvin vanhoilla suoraviivaisesti sairauksien lukumäärän mukaan, kun taas nuoremmilla ikäryhmillä yhden pitkäaikaissairauden sairastaminen heikentää itse arvioitua terveyttä suhteellisesti enemmän kuin monisairastavuus (Galenkamp ym. 2011). Eron taustalla saattavat olla erilainen sopeutuminen heikompaan terveydentilaan ja mahdollinen eri sairauksien oireiden päällekkäisyys (Galenkamp ym. 2011). Koska sairauksista johtuvat oireet, kuten kipu ja toimintakyvyn rajoitukset ovat vahvasti yhteydessä huonompaan itse arvioituun terveyteen, monisairailla iäkkäillä henkilöillä päällekkäisistä sairauksista johtuva oireiden kumuloituminen saattaa olla merkittävämpää itse arvioidun terveyden kannalta kuin yksittäiset sairaudet sinänsä (Nützel ym. 2014).

Tässä tutkimuksessa naisilla oli heikompi toimintakyky, ja heillä useampi sairaus oli yh-

teydessä itse arviointeihin kuin miehillä, mutta huonoksi terveytensä ja toimintakykynsä arvioivien naisten ja miesten osuudet eivät eronneet toisistaan. Samansuuntaisia tuloksia on aiemmin saanut Arber ja Cooper (1999), joiden tutkimuksessa naisilla todettiin miehiä huonompi toimintakyky, mutta miehiä pienempi todennäköisyys raportoida itse arvioitu terveys huonoksi. Tutkimuksessamme sairauksien yhteys itse arvioituun toimintakykyyn oli naisilla hyvin samanlainen kuin niiden yhteys itse arvioituun terveyteen. Miehillä useampi yksittäinen sairaus oli yhteydessä huonoon itse arvioituun terveyteen kuin huonoon itse arvioituun toimintakykyyn. Itse arvioitua toimintakykyä on tietojemme mukaan aiemmin käytetty vain vähän toimintakyvyn mittarina, mutta esimerkiksi Parkatti (1990) on tutkinut itse arvioitua toimintakykyä väitöskirjatyössään.

Monisairastavuuden määritelmä vaihtelee tutkimusten välillä, niin kysyttyjen yksittäisten sairauksien, niiden lukumäärän samoin kuin vakavuusasteen suhteen. Määritelmien vaihtelun vuoksi tutkimustulosten suora vertailu on vaikeaa (Marengoni ym. 2011). Monisairastavuus on yleistä hyvin iäkkäillä ja yleisempää naisilla kuin miehillä (KonéPefeyo ym. 2015; Formiga ym. 2013). Naisten miehiä yleisempi monisairastavuus (Kirchberger ym. 2012; Marengoni ym. 2011) ei kuitenkaan tullut Tervaskannot 90+ -aineistossa esille tilastollisesti merkitsevänä, vaikka naisilla oli prosentuaalisesti enemmän sairauksia.

Aikaisemmista tutkimustuloksista (Nützel ym.2014) poiketen Tervaskannot 90+ -aineistossa ei havaittu sydänsairauksien, verenpainetaudin, diabeteksen tai syövän yhteyttä heikkoon itsearvioituun terveyteen tai toimintakykyyn. Tutkimustulosten eroavaisuuksiin Tervaskannot 90+ -aineiston ja aiemman tutkimuksen välillä voi osaltaan vaikuttaa Tervaskannot-kyselyssä käytetty kysymyksenasettelu, jonka vuoksi tiedossa ei ollut milloin tutkittava sairaus oli todettu tai oliko sairaus akuutti vai hyvässä hoitotasapainossa oleva pitkäaikaissairaus. Lisäksi tässä tutkimuksessa tutkittavaa sairautta sairastavia henkilöitä verrattiin henkilöihin, joilla ei ollut juuri kyseistä sairautta, vaikka heillä saattoi olla muita sairauksia. Koska diabeteksen tai syövän sairastaminen näytti ”suojaavan” terveys- ja toimintakykyongelmilta, analyysit tehtiin myös siten, että mallit vakioitiin ainoastaan iällä. Naisilla yhteydet yksittäisten sairauksien ja vastemuuttujien välillä eivät muuttuneet. Miehillä pelkkä ikävakiointi muutti tuloksia siten, että syöpä ja diabetes eivät enää olleet terveys- ja toimintakykyongelmilta ”suojaavia” tekijöitä. Lähes kaikilla tutkittavilla oli jokin pitkäaikaissairaus, joten vertailuryhmän henkilötkään eivät olleet täysin terveitä. Saatu tulos viittaa siihen, että vertailuryhmällä oli muita vakavia sairauksia, vaikka ei juuri syöpää tai diabetesta.

Tutkimuksen vahvuudet ja rajoitukset

Tervaskannot 90+ -tutkimus on jo 20 vuoden ajan selvittänyt tutkimuksissa vähälle huomiolle jääneen ikäryhmän terveyttä ja hyvinvointia. Tervaskannot 90+ -tutkimuksen kyselyissä vastausprosentti on ollut korkea, keskimäärin 80 %, joten tutkittavien voidaan olettaa edustavan hyvin ikäryhmäänsä. Kyselyyn vastaamattomat ovat varsinkin tässä ikäryhmässä kaikkein sairaimpia ja huonokuntoisimpia. Tutkimuksen vahvuuksiin lukeutuu myös se, että mukana kyselyssä olivat sekä kotona asuvat että laitoshoidossa olevat. Tutkittavien asuinpaikan moninaisuus lisää terveydentilassa ja toimintakyvyssä havaittua vaihtelua sekä samalla myös vahvistaa tutkimustulosten yleistettävyyttä.

Tutkimuksen tulokset perustuvat kyselylomakkeella kerättyyn tutkittavien itse raportoimaan tietoon. Muistisairaudet yleistyvät iän myötä, joten tulosten luotettavuutta arvioitaessa täytyy pohtia, kuinka hyvin vastaukset kuvaavat todellisuutta. Goebeler, Jylhä ja Hervonen (2007) ovat selvittäneet Tervaskannot 90+ -aineistolla itse raportoitujen sairauksien esiintyvyyden yhteneväisyyttä potilastietojen kanssa.

Tutkimuksessa (Goebeler ym. 2007) havaittiin, että vastaajat aliraportoivat monia sairauksia, mutta olivat taipuvaisia yliraportoimaan masennusta, nivelrikkoa ja muistisairautta. Huomattavaa Goebelerin ja kumppaneiden (2007) tutkimuksessa oli myös se, että lääkärin toteama muistivaikeus ei lisännyt itse raportointien ja sairauskertomustietojen epäyhtenäisyyttä. Tämänkin tutkimuksen tulokset tukevat käsitystä siitä, että muistisairauksia sairastavat henkilöt kykenevät melko hyvin arvioimaan omaa terveyttään. Itse vastanneilla raportoitu muistisairaus oli yhteydessä huonoon itse arvioituun terveyteen. Vaikeasti muistisairaiden puolesta kysymyksiin kuitenkin vastasi usein joku toinen henkilö, jolloin omaa arviota terveydestä ei ollut käytettävissä.

Kyselylomake pyrittiin pitämään mahdollisimman selkeänä ja lyhyenä, jotta iäkkäiden tutkittavien vastaaminen helpottuisi. Tämä on edesauttanut korkean vastausprosentin saavuttamista, mutta haittapuolena on, ettei sairauksien vaikeusasteesta tai sairastumisajankohdasta saatu tietoa. Etenkin syövän kohdalla tämä saattaa olla olennaista: emme tiedä, onko sairaus ollut tutkimushetkellä aktiivinen vai onko tutkittava kenties toipunut sairaudesta täysin.

Vuoden 2014 kysymykset olivat suurelta osin samoja kuin aikaisempina vuosina Tervaskannot 90+ -tutkimuksessa käytetyt kysymykset. Suurempi kysyttyjen sairauksien määrä olisi antanut vieläkin monipuolisemman kuvan hyvin iäkkäiden monisairastavuudesta. Esimerkiksi hengityselinsairauksien vaikutukset toimintakykyyn ja terveyteen voivat olla hyvinkin merkittäviä. Huolimatta sairauksien rajallisuudesta, kyselylomakkeessa on kuitenkin kysytty iäkkäiden tärkeimpiä sairauksia. Tutkimuksessa mukana olevat sairaudet sisältyvät muun muassa Functional Comorbidity Index -kokonaisuuteen, johon kuuluu yhteensä 18 sairautta. (Groll, To, Bombardier & Wright 2005). Functional Comorbidity Index on kehitetty ajatellen erityisesti toimintakykyyn yhteydessä olevia sairauksia.

Päätelmät

Tutkimus antaa tietoa siitä, minkälainen rooli pitkäaikaissairauksilla ja monisairastavuudella on hyvin vanhojen elämässä ja miten sairastavuus on yhteydessä terveyden eri ulottuvuuksiin. Tutkimuksemme kertoo, että erityisesti muistisairaudet ja masennus ovat merkittäviä hyvin vanhojen toimintakykyyn ja itse arvioituun terveyteen yhteydessä olevia sairauksia. Ne esiintyvät usein yhdessä muiden pitkäaikaissairauksien kanssa, ja yhdessä muiden sairauksien kanssa niiden haitat saattavat olla suurempia (Onder ym. 2015). Ylipäätään monisairastavuus on hyvin vanhoilla enemmän sääntö kuin poikkeus, ja sillä on suuri merkitys itsenäisen elämän kannalta.

Monisairastavuus on nykyisin vilkkaan tutkimuksen kohteena. Tiedetään, että kun iäkkäällä ihmisellä on samanaikaisesti useita sairauksia, niiden yhteisvaikutus terveydentilaan on suurempi kuin erillisten sairauksien oletettu yhteenlaskettu vaikutus (WHO 2015, 58; Cesari ym. 2016a). Hyvin vanhojen ihmisten monisairastavuustilanteesta ei ole toistaiseksi paljon tutkimuksia. On kuitenkin ilmeistä, että mitä vanhemmasta ikäryhmästä on kyse, sitä enemmän terveydentila muotoutuu useiden sairauksien ja vanhenemisen aiheuttaman elimistön muutosten yhteisvaikutuksen kautta. Juuri hyvin vanhojen nopeasti kasvavan ryhmän hoidossa ja terveyden edistämisessä tarvitaan kokonaistilanteen, toimintakyvyn, ja haurauden ja raihnaisuuden (frailty) arviointia (Cesari ym. 2016b) ja niihin kohdistuvia toimia. Tämä on suuri haaste niin perusterveydenhuollolle, geriatrialle kuin kaikille muillekin iäkkäitä ihmisiä hoitaville.

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PUBLICATION II

Dementia and related comorbidities in the population aged 90 and over in the Vitality 90+ Study, Finland: patterns and trends from 2001 to 2018

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Article

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Abstract

Objectives: To examine trends in the prevalence of dementia and related comorbidities among the oldest old.

Methods: Six repeated cross-sectional surveys were conducted between 2001 and 2018, each including all inhabitants aged over 90 in Tampere, Finland (n = 5386). Co-occurring conditions and their time trends among participants with dementia were examined using logistic regression and generalized estimating equations.

Results: The prevalence of dementia decreased from 47% in 2007 to 41% in 2018. Throughout the study period, depression was more common among people with dementia compared to those without. The prevalence of hypertension, diabetes, and osteoarthritis increased and the prevalence of depression decreased among people with dementia. The mean number of comorbidities increased from 2.0 in 2001 to 2.3 in 2018.

Discussion: Dementia remains highly prevalent among the oldest old and it is accompanied by an increasing burden of comorbidities, posing a challenge to people with dementia, their caregivers, and care systems.

Keywords

dementia, comorbidity, oldest old, time trends

Introduction

Dementia is associated with increased mortality, disability, lower quality of life (Andersen et al., 2004; Doblhammer & Barth, 2018; Halonen et al., 2019; Tonelli et al., 2017), and long-term care use (Forma et al., 2011; Halonen et al., 2019). It is a highly age-related condition: the incidence of dementia is highest in people aged over 90 years (Lucca et al., 2020; Olfson et al., 2021). Several recent studies imply that the incidence and prevalence of dementia are decreasing (Gao et al., 2019; Sullivan et al., 2019), but trends among the oldest old have received less research attention.

Chronic conditions rarely occur alone in old age, and dementia too is usually accompanied by other conditions. In research and clinical practice, the term comorbidity is used to refer to additional conditions coexisting with an index disease (Feinstein, 1970; Nicholson et al., 2019), while multimorbidity is defined as co-occurring diseases with no special interest on any single condition (Nicholson et al., 2019). Frequent comorbidities in dementia include hypertension, coronary heart disease, and other cardiovascular diseases, cerebrovascular diseases, diabetes, connective tissue disease (Clague et al., 2016; Jørgensen et al., 2018; Nelis et al., 2018; Wang et al., 2018), and depression (Nelis et al., 2018; Wang et al., 2018). Earlier studies using different samples and designs have found approximately as many (Schubert et al., 2006; Zekry et al., 2008), less (Forma et al., 2011; Jørgensen et al., 2018; Sherzai et al., 2016), and more (Clague et al., 2016; Wang et al., 2018) comorbidities among people with dementia than among those without.

In studies examining clusters or patterns of comorbidity, dementia is often associated with neuropsychiatric or

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psychogeriatric disorders (Nguyen et al., 2018; Prados-Torres et al., 2012; Schäfer et al., 2010). A history of multimorbidity has also been found to predict dementia. Grande et al. (2021) showed that individuals with neuropsychiatric and cardiovascular multimorbidity and those with sensory impairment or cancer were at increased risk for dementia, but no association was found between the patterns of respiratory, metabolic, and musculoskeletal conditions and dementia development. With the exception of Sherzai et al. (2016), earlier studies have been conducted in samples combining age groups of people aged over 65 years, either in care settings or using insurance registers. A recent Finnish study based on national population register data showed that among people who died at the age of 70 or over, the proportion of those with a dementia diagnosis during the last 5 years of life increased from 24.5% in 2001 to 35.6% in 2013, and within this group, the number of comorbidities increased. An increasing trend was seen for hypertension, cardiac insufficiency, osteoporosis, insomnia, diabetes, cancer, lipoprotein disorders, renal insufficiency, and thyroid disorders. These growth trends are likely due to increasing age at death, longer survival with chronic diseases, and improving diagnostic practices (Vargese et al., 2021).

This study focuses on persons aged over 90, who show the highest prevalence and incidence of dementia. This population segment has not yet been extensively researched, mainly because it has only emerged quite recently as a major population group, but also because of the challenges involved in studying individuals with multiple health problems and the rather large numbers living in residential care (Jylhä et al., 2020). The rapid absolute and relative growth of this population segment worldwide nonetheless makes it one of great interest and importance. In Finland, the number of people aged 90 and over is projected to rise from around 23,000 (.4% of the total population) in 2000 to over 130,000 (2.3%) by 2040 (Official Statistics of Finland, 2021). In the US, the size of this age group is expected to quadruple from 2000 to 2040 and its proportion of the total population to grow from .5% to 1.6% (United Nations, Department of Economic and Social Affairs, Population Division, 2019). Prior research shows that the morbidity profile of the oldest old differs from that of the younger olds, showing high rates of dementia, cerebrovascular diseases, arthritis, and diabetes (Doblhammer & Barth, 2018; Salminen et al., 2012). Furthermore, it is not clear to what extent the trend of increasing morbidity in older people is seen in the oldest old people with dementia.

This study uses six repeated population-based cross-sectional surveys with the exact same methods to investigate the trend in the prevalence of dementia, and the patterns of related comorbidity among people aged 90 and older. We analyzed (1) the prevalence of dementia, (2) the number of chronic conditions among people with and without dementia, and (3) the prevalence of the most common comorbidities among people with dementia between 2001 and 2018.

Methods

Data

The data came from the Vitality 90+ Study, a population-based survey in Tampere, Finland (2019 population 238,140, of whom .9% were over 90 years). Tampere is Finland's third-largest city, located in the Pirkanmaa region where life expectancy is close to national average (81.85 vs 81.46 in 2018) (Official Statistics of Finland, 2018). Mailed questionnaires were sent to all inhabitants aged 90 or over, irrespective of health or place of living in Tampere in 2001, 2003, 2007, 2010, 2014, and 2018. The response rates were 84%, 86%, 82%, 80%, 80%, and 77%, respectively. Proxy respondents were used in order to obtain information from individuals with cognitive problems or other health issues and so to make the study more representative. Participants were categorized as self-respondents if they chose the response options themselves (even if they received help with writing from a family member, relative or acquaintance, or home care worker/nursing staff). Respondents were considered proxy if a family member, relative or acquaintance, or home care worker/nursing staff answered on behalf of the participant.

In each survey year, the questionnaire included an item about chronic conditions: "Has a doctor told you that you have…?". Dementia was considered to be present in participants who answered "yes" to the question about having "dementia, Alzheimer's disease, or worsening of memory." Once a participant had reported dementia that was assumed to apply for the next study rounds as well because of the chronic nature of dementia. Altogether 136 (2.5%) participants reported no dementia in at least one round of data collection after reporting it in a previous round.

In addition to dementia, the presence of hypertension (high blood pressure), heart disease (coronary artery disease, arrhythmia, or myocardial infarction), stroke, diabetes, arthritis, hip fracture, and depression (depressed mood) was asked every study year. Cancer was not included in 2010 and Parkinson's disease was not included in 2018. Chronic lung disease was listed only in the latest survey in 2018. These conditions were excluded from trend analysis.

The Vitality 90+ Study has obtained ethical permission for every survey round from the regional ethics committee of Tampere University Hospital (in 2018 approval number R18041) or the City of Tampere, depending on the year of the survey. Written informed consent was obtained from the participants or their representative.

Statistical Analysis

The data were first analyzed cross-sectionally separately in each survey year to define the frequency of each condition. In

order to identify the most common combinations of chronic conditions among participants with dementia, we determined the prevalence of pairs of conditions among them. We then formed triads of conditions that belonged to the pairs that had a prevalence higher than 10% and further analyzed the most common pairs and triads among participants with dementia (Supplement Table 1). Logistic regression analysis was performed for each survey year, with dementia as the dependent variable. The analysis was done first with individual chronic conditions and the number of conditions (multimorbidity), and then with pairs and triads of chronic conditions as independent variables.

Trend analysis was then performed to examine linear trends in the prevalence of chronic conditions over time with a generalized estimating equation (GEE). With this approach, it is possible to model the changes in the population mean over time with repeated cross-sectional measurements, representing the population at each time point. Since all individuals aged over 90 in the area were included in the study at all six time points, two-thirds (69%) of the participants responded in one survey round, 25% in two rounds, and 6% in three or more rounds. An independent 'working' correlation structure was used to account for repeated responses by the same individuals across several study years (Raitanen et al., 2020). A binomial distribution family with logit link function, reporting odds ratios (ORs) with 95% confidence intervals (CIs), was used to analyze the trend in the prevalence of chronic conditions. A negative binomial distribution family with log link function, reporting incidence rate ratio (IRR) with CIs, was used to analyze the trend in the number of chronic conditions over time. In this latter model, the number of chronic conditions was used as a continuous variable. All models included study year as the independent variable and were first run without adjustments and then adjusted for age and gender. With no major differences between the unadjusted and adjusted models, only the age- and gender-adjusted models are presented. The figures show fitted lines derived from the age- and gender-adjusted models and the observed prevalence for each study year, with a *p*-value for the differences between the years. A *p*-value of .05 or lower was considered statistically significant. The analysis was performed with Stata 15 (StataCorp LLC).

Results

Characteristics of the Study Population and the Prevalence of Dementia

After the removal of 105 observations with missing information on dementia, 7483 observations and 5386 participants were included in the analysis. Most of the participants were women, but the proportion of men increased over the years. The study population grew over the years from 874 participants to 1856 participants. The prevalence of dementia was 43% in 2001, 47% in 2003, 47% in 2007, 43% in 2010, 43% 2014, and 41% in 2018, showing a decreasing trend from 2007 onwards (*p* .007) (Table 1 & Figure 1(a)). The absolute number of participants with dementia increased despite the proportional decrease. Participants with dementia were slightly older than those without dementia. No gender differences were found in dementia prevalence in any survey year. People with dementia lived in long-term care more often than those without dementia.

The use of a proxy respondent was considerably more common among participants with dementia compared to participants without dementia. Around 30%–40% of participants reporting dementia had answers provided by a proxy respondent, while among participants without dementia proxy respondents were rare: between 2% and 10% depending on the survey year (Table 1). Proxies were most often relatives, but survey answers were also provided by staff in nursing homes.

Chronic Conditions Among Participants with and without Dementia

The mean number of chronic conditions was in most survey years higher for participants with dementia compared to those without. In all survey years the most common chronic conditions among participants with dementia were heart disease and hypertension, followed by osteoarthritis and depression (Table 1). In most survey years, depression, stroke, Parkinson's disease, and hip fracture were more prevalent among participants with dementia than those without. In contrast, osteoarthritis and hypertension were more prevalent among those without dementia (Table 1).

Hypertension, heart disease, and osteoarthritis formed the most prevalent combinations of two and three conditions among participants with dementia (Supplement Table 1).

Age- and gender-adjusted logistic regression showed that the odds of depression and Parkinson's disease were more than twice as high among participants with dementia than among those without. In most survey years the odds of having a stroke and a hip fracture with dementia were above 1.00 compared with participants without dementia, but not always statistically significant. The odds of hypertension and osteoarthritis, on the other hand, were lower for participants with dementia compared to those without dementia. Participants with and without dementia did not differ in the odds of having heart disease, diabetes, or cancer. The association of the number of other morbidities with dementia fluctuated from one study year to another but was positive in the beginning and at the end of the study period (Table 2).

The results of the regression models for combinations (pairs and triads) of comorbid conditions were closely similar to those of single conditions comorbid with dementia. The pair of hypertension and osteoarthritis was less likely to co-occur with dementia throughout the survey years, with odds ranging from .44 (CI 0.32–.62) in 2007 to .74 (CI 0.60–.91) in

Table 1. Characteristics of the Study Population With and Without Dementia From 2001 to 2018 in the Vitality 90+ Study.

	2001		2003		2007		2010		2014		2018	
	(*n* = 874)		(*n* = 937)		(*n* = 932)		(*n* = 1263)		(*n* = 1621)		(*n* = 1856)	
	Dementia *n* (%)	No dementia *n* (%)	Dementia *n* (%)	No dementia *n* (%)	Dementia *n* (%)	No dementia *n* (%)	Dementia *n* (%)	No dementia *n* (%)	Dementia *n* (%)	No dementia *n* (%)	Dementia *n* (%)	No dementia *n* (%)
	375 (42.9)	499 (57.1)	438 (46.7)	499 (53.3)	439 (47.1)	493 (52.9)	541 (42.8)	722 (57.2)	698 (43.1)	923 (56.9)	768 (41.4)	1088 (58.6)
Age (years), mean	92.5	92.2*	92.8	92.1***	92.9	92.3**	93.1	92.2***	93.0	92.3***	93.0	92.5***
Range	90–106	90–104	90–103	90–106	90–105	90–104	90–107	90–107	90–106	90–103	90–105	90–107
Gender												
Women	309 (82.4)	395 (79.2)	360 (82.2)	396 (79.4)	351 (80.0)	392 (79.5)	577 (79.9)	449 (83.0)	542 (77.7)	707 (76.6)	575 (74.9)	793 (72.9)
Men	66 (17.6)	104 (20.8)	78 (17.8)	103 (20.6)	88 (20.1)	101 (20.5)	92 (17.0)	145 (20.1)	156 (22.4)	216 (23.4)	193 (25.1)	295 (27.1)
Proxy	158 (42.1)	47 (9.5) ***	154 (35.2)	53 (10.6) ***	130 (29.8)	12 (2.4) ***	238 (44.2)	41 (5.7) ***	270 (39.2)	39 (4.3) ***	251 (32.7)	34 (3.1) ***
In long-term care	223 (59.5)	116 (23.3) ***	226 (51.6)	116 (23.3) ***	238 (54.3)	83 (16.9) ***	327 (60.9)	142 (19.8) ***	404 (58.2)	164 (18.0)***	408 (53.5)	143 (13.2) ***
Chronic conditions												
Hypertension	120 (32.0)	158 (31.7)	158 (36.1)	200 (40.1)	169 (38.5)	253 (51.3) ***	233 (43.1)	427 (59.1) ***	384 (55.0)	606 (65.7) ***	463 (60.3)	731 (67.2)**
Heart disease	208 (55.5)	259 (51.9)	248 (56.6)	270 (54.1)	216 (49.2)	275 (55.8) **	280 (51.8)	409 (56.7)	369 (52.9)	499 (54.1)	401 (52.2)	565 (51.9)
Cancer	47 (12.5)	49 (9.8)	52 (11.9)	62 (12.4)	61 (13.9)	62 (12.6)			110 (15.8)	155 (16.8)	110 (14.3)	225 (20.7) ***
Stroke	38 (10.1)	31 (6.2)*	42 (9.6)	29 (5.8)*	28 (6.4)	24 (4.9)	37 (6.8)	30 (4.2) *	82 (11.8)	63 (6.8) **	63 (8.2)	67 (6.2)
Diabetes	48 (12.8)	47 (9.4)	50 (11.4)	45 (9.0)	48 (10.9)	55 (11.2)	56 (10.4)	93 (12.9)	109 (15.6)	141 (15.3)	153 (19.9)	194 (17.8)
Osteoarthritis	119 (31.7)	194 (38.9)*	144 (32.9)	177 (35.5)	140 (31.9)	229 (46.5) ***	205 (37.9)	339 (47.0) **	276 (39.5)	434 (47.0) **	321 (41.8)	505 (46.4)*
Chronic lung disease											64 (8.3)	89 (8.2)
Parkinson's disease	14 (3.7)	7 (1.4)*	12 (2.7)	6 (1.2)	11 (2.5)	5 (1.0)	8 (1.5)	10 (1.4)	18 (2.6)	6 (.7) **		
Hip fracture	75 (20.0)	77 (15.4)	95 (21.7)	78 (15.6)*	61 (13.9)	105 (21.3) **	101 (18.7)	116 (16.1)	136 (19.5)	142 (15.4)*	145 (18.9)	128 (11.8) ***
Depression	123 (32.8)	85 (17.0) ***	144 (32.9)	82 (16.4) ***	120 (27.3)	82 (16.6) ***	147 (27.2)	93 (12.9) ***	172 (24.6)	109 (11.8) ***	201 (26.2)	107 (9.8) ***
No. of chronic conditions (0–7)												
Mean	2.0	1.7**	2.0	1.8**	1.8	2.1***	2.0	2.1*	2.2	2.2	2.3	2.1*
SD	1.2	1.2	1.3	1.2	1.2	1.3	1.3	1.2	1.3	1.2	1.4	1.2

p-value for chi-square test (categorical variables) and Mann–Whitney-U test (age and no. of chronic conditions).
Notes: Dementia not included in the number of conditions.
SD = Standard deviation.
*$p < .05$; **$p < .01$; ***$p < .001$.

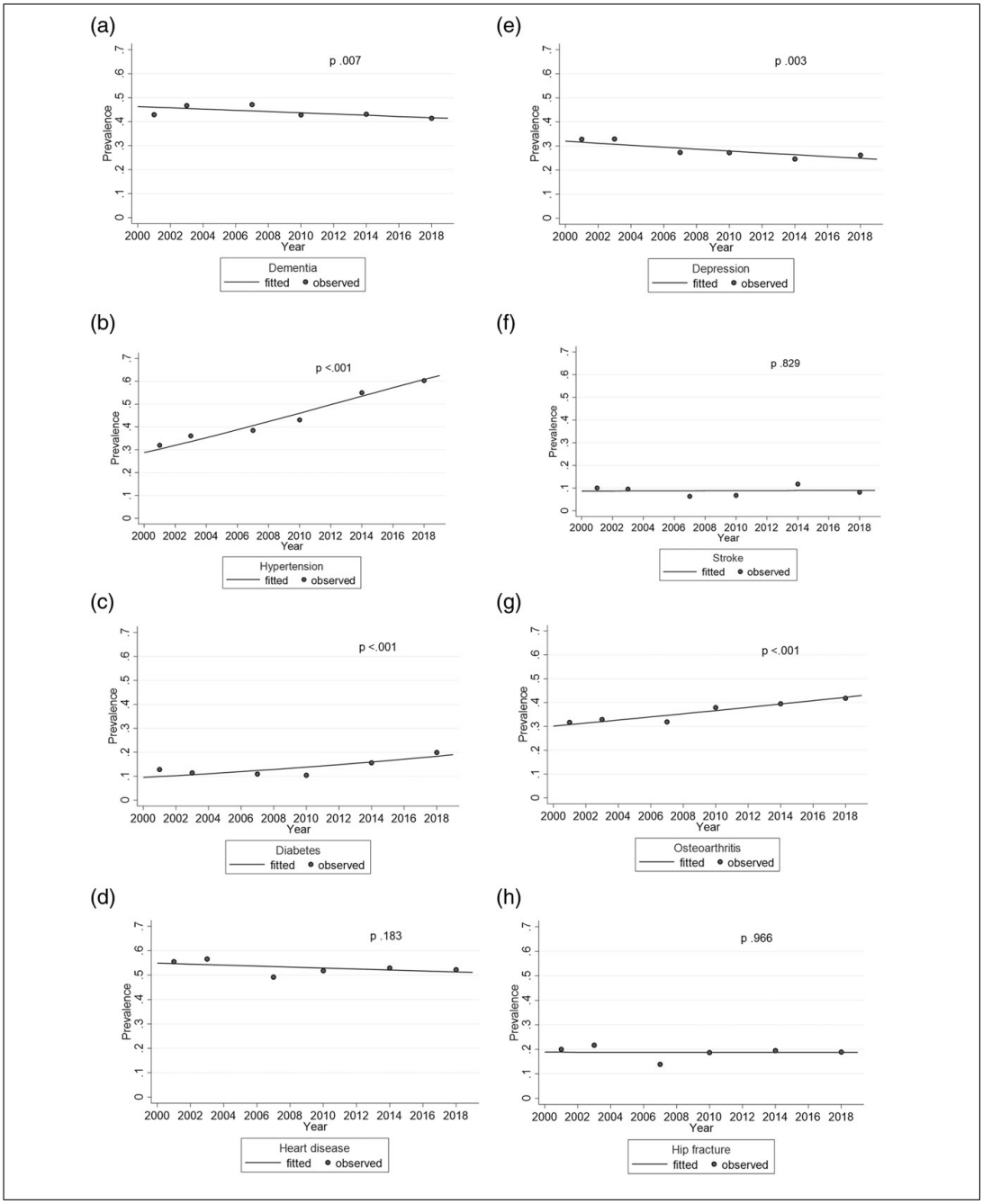

Figure 1. Trends for dementia and comorbid chronic conditions among participants with dementia between 2001 and 2018, adjusted for age and gender.

Table 2. Association of Chronic Conditions and Multimorbidity With Dementia in the Six Study Rounds. Logistic Regression Analysis With Odds Ratios (OR) and 95% Confidence Intervals (CI) Adjusted for Age and Gender.

	2001		2003		2007		2010		2014		2018	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Comorbid condition												
Hypertension	1.00	0.75–1.34	.84	.64–1.11	**.61**	**.47–.79**	**.54**	**.43–.68**	**.64**	**.52–.78**	**.74**	**.61–.89**
Heart disease	1.15	0.88–1.50	1.12	.86–1.46	**.76**	**.59–.99**	.83	.66–1.05	.95	.78–1.15	1.00	.83–1.20
Cancer	1.36	.89–2.08	.94	.63–1.41	1.13	.77–1.67	—	—	.93	.71–1.22	**.64**	**.50–.82**
Stroke	**1.73**	**1.06–2.85**	**1.82**	**1.11–2.98**	1.34	.76–2.36	**1.67**	**1.01–2.76**	**1.85**	**1.31–2.62**	1.40	.98–2.01
Diabetes	1.44	.94–2.21	1.32	.86–2.03	.99	.64–1.46	.83	.58–1.19	1.11	.84–1.46	1.20	.94–1.52
Osteoarthritis	**.72**	**.54–.96**	.90	.68–1.18	**.54**	**.41–.71**	**.66**	**.53–.84**	**.74**	**.61–.91**	**.79**	**.65–.96**
Chronic lung disease	—	—	—	—	—	—	—	—	—	—	1.04	.74–1.46
Parkinson's disease	**2.64**	**1.05–6.62**	2.25	.83–6.12	2.74	.94–8.00	1.01	.39–2.61	**4.19**	**1.64–10.67**	—	—
Hip fracture	1.31	.92–1.86	**1.42**	**1.02–1.99**	**.56**	**.39–.79**	1.11	.82–1.50	**1.31**	**1.01–1.70**	**1.69**	**1.30–2.19**
Depression	**2.42**	**1.76–3.34**	**2.50**	**1.83–3.41**	**2.05**	**1.48–2.83**	**2.54**	**1.89–3.40**	**2.54**	**1.94–3.32**	**3.25**	**2.51–4.20**
No. of comorbidities												
	1.18	**1.06–1.33**	**1.18**	**1.06–1.31**	**.83**	**.75–.93**	.92	.84–1.01	1.03	.95–1.11	**1.10**	**1.02–1.19**

Notes: Analyses were conducted for each condition and the number of comorbidities separately.
No. of comorbidities range between 0 and 7.
Bolding indicates a statistically significant association.

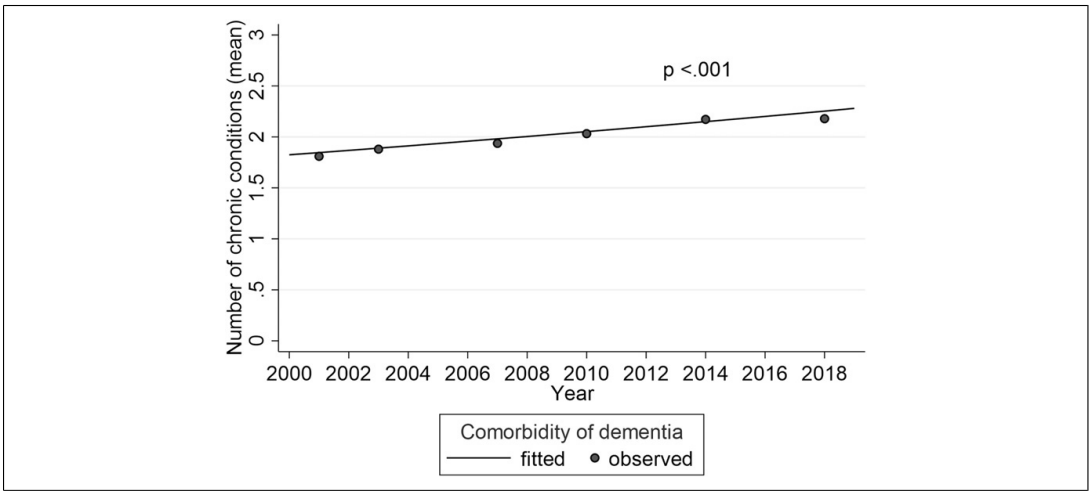

Figure 2. Trend for number of comorbidities with dementia between 2001 and 2018, adjusted for age and gender.

2018. Pairs and triads including depression showed higher odds to occur with dementia in later study years (Supplement Table 2).

Trends for Comorbidities of Dementia

Figure 1 shows the trends for dementia and conditions comorbid with dementia from GEE models (fitted lines). The adjusted prevalence of hypertension and diabetes comorbid with dementia nearly doubled during the study period (p <.001) and that of osteoarthritis also increased markedly (p <.001), particularly in later survey years. The prevalence of heart disease, stroke, and hip fracture comorbid with dementia was steady throughout the study years (p .183, p .829, p .966, respectively). The only condition showing a decreasing trend over time was depression (p .003) (Figure 1). The mean number of conditions comorbid with dementia increased from 2.0 to 2.3 during the study period (p <.001) (Figure 2). It is of note that despite the stable or decreasing proportions, the absolute number of people with heart

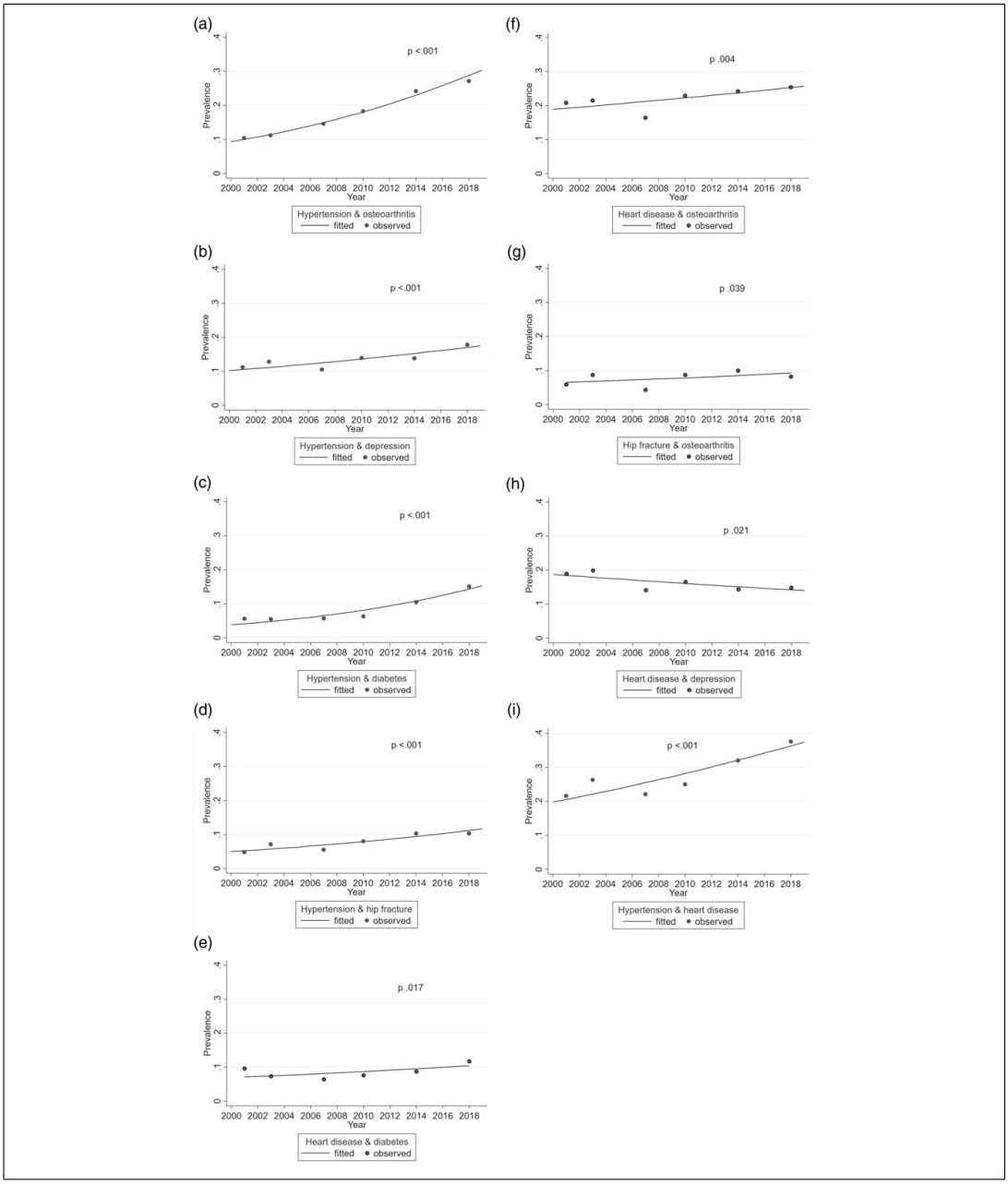

Figure 3. Trends for pairs of comorbid chronic conditions among participants with dementia between 2001 and 2018, adjusted for age and gender.

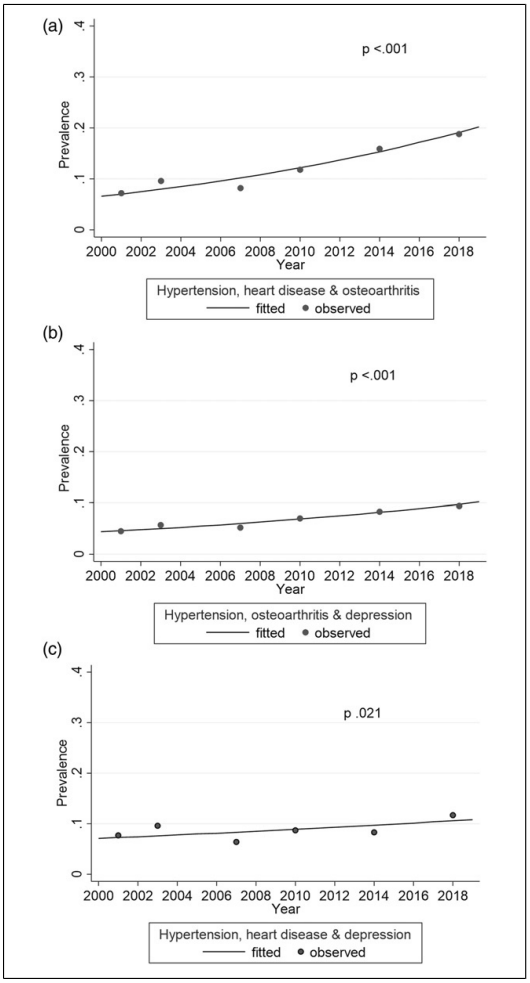

Figure 4. Trends for triads of comorbid chronic conditions among participants with dementia between 2001 and 2018, adjusted for age and gender.

disease, hip fracture, and depression increased throughout the study years due to the increasing size of the basic population (Table 1).

Figure 3 and Figure 4 present combinations of conditions comorbid with dementia that demonstrated a significant trend over the study years. Driven by the large increase in hypertension, all combinations including hypertension became more prevalent over time. The largest increases were seen for a combination of hypertension and osteoarthritis (p <.001) and hypertension and diabetes (p <.001). The only combination with a decreasing trend was heart disease and depression (p .021).

Discussion

This study examined time trends of dementia and its comorbidities in people aged 90 and over during a 17-year period. Parkinson's disease, depression, hip fracture, and stroke were more likely to co-occur with dementia than to occur without it, while hypertension and osteoarthritis were more prevalent among those without dementia. In particular, the prevalence of hypertension, diabetes, and osteoarthritis increased in time, whereas the prevalence of hip fracture, stroke, and heart disease remained stable. The only condition showing a decreasing trend was depression. The number of chronic conditions comorbid with dementia increased over the study period. To our knowledge, this is the first population-based study examining time trends in dementia comorbidity in the oldest old population.

The prevalence of dementia was higher than 40% in each survey year, which is in line with former studies that have reported prevalence rates between 40% and 50% in the oldest old people (Corrada et al., 2008; Doblhammer & Barth, 2018). The evidence indicates decreasing prevalence (Harrison et al., 2020; Wu et al., 2016) and incidence rates for dementia among younger old people in Western countries (Gao et al., 2019; Sullivan et al., 2019), but we are not aware of any such results for the oldest age groups. Our study suggests that the prevalence of dementia remains high among very old people, even though it may be slightly declining. Factors underlying this decline likely include reduced cardiovascular risk factors and a rising level of education (Satizabal et al., 2016). A recent study among 70-year-old Finnish people found a decline in the proportion of people with cardiovascular risk factors for dementia, improved educational level, and better performance in cognitive tests, suggesting a positive development in subsequent cohorts regarding the risk of dementia (Vire et al., 2020). Yet, as age is by far the strongest risk factor for dementia, the impact of these changes on the oldest old is difficult to predict. However, since the oldest old is the fastest growing population segment in Finland, as it is in several other countries worldwide, the absolute number of people having dementia is increasing and will most likely continue to increase in the future.

It is not straightforward to compare our findings with earlier results because most studies also include younger people and the types and number of morbidities included in these studies vary. In addition, most studies are conducted either in care settings or exclude long-term care residents, while our research is population-based and includes long-term care residents. In our study, the participants with dementia had more chronic conditions than participants without dementia in most years, and the number of conditions in this group increased over the study period (2001–2018). This is in line with previous research which shows an increasing prevalence of major age-related chronic conditions in the general older population (Christensen et al., 2009; Crimmins

et al., 2019). Also, a recent register-based nationwide study on comorbidity trends during the last years of life in Finnish dementia patients aged 70 years and over, found an increasing burden of comorbidities from 2001 to 2013 (Vargese et al., 2021). The number of comorbidities is highly dependent on the range of conditions included in the analysis, and therefore it is understandable that some earlier studies have found more comorbid chronic conditions with dementia than we did (Clague et al., 2016; Nelis et al., 2018).

The participants in our study were exceptionally old; therefore, the findings cannot be generalized to younger age groups with dementia. Yet our results showed rather similar comorbidities of dementia as reported in previous studies. Hypertension and osteoarthritis are the most common comorbidities in major age-related conditions such as stroke, diabetes, and dementia (Griffith et al., 2019), and they also occurred frequently in our study. Both conditions were more likely to occur among participants without dementia, but their frequency increased over the study period especially among participants with dementia, as did the frequency of diabetes. Also, hip fracture was in most years more prevalent among participants with dementia, possibly reflecting the lowered functional ability associated with dementia and the increased risk for falls (Lach et al., 2017).

Finland has a universal health care system that largely remained unchanged throughout our study period, although diagnostic and therapeutic practices have improved. Even so, it is possible that particularly the results from the early years of our study reflect underdiagnosis of some chronic conditions with less prominent symptoms such as hypertension, especially among people with advanced dementia (Bauer et al., 2014). It has been pointed out that people with dementia may lack access to care and the quality of their care tends to be poorer (Bunn et al., 2014). In addition, cognitive impairment may lead to underreporting of symptoms (Doraiswamy et al., 2002). Both clinical practice and research are currently paying increasing attention to chronic conditions among the oldest old and those with dementia as well as to the importance of early diagnosis of cognitive problems. This refocus is in response to the sharp rise in the number of the oldest old, increasing life expectancy even at very old age, and a health policy emphasis on supporting the functioning and independence of older individuals. In addition, there is growing evidence of the benefits of active treatment of conditions such as hypertension in older individuals (Beckett et al., 2008). Therefore, it is likely that improved diagnostic practices together with longer survival with chronic disease (Enroth et al., 2020) are major contributing factors behind the increasing prevalence of hypertension and diabetes. It is noteworthy that despite these developments, our findings showed not an increase but rather a slightly decreasing trend in the frequency of dementia.

Most conditions included in this study have been found to be associated with dementia, either as a risk factor (Grande et al., 2021) or as a consequence of dementia. These conditions include stroke, Parkinson's disease, and depression, which are more likely to occur in people with dementia than in those without dementia (Bauer et al., 2014; Clague et al., 2016; Sherzai et al., 2016). Disabling conditions, such as stroke, Parkinson's disease, depression, and hip fracture were also in our study more prevalent among people with dementia. Depression showed high odds to occur with dementia throughout the study period, whereas the association of stroke, Parkinson's disease, and hip fracture with dementia varied. Diabetes has been identified as a risk factor for dementia (Rastas et al., 2010), but in our study, its prevalence was not higher among participants with dementia. The role of hypertension in the onset of dementia among the oldest old is controversial even if there is strong evidence of its significance in midlife (Ou et al., 2020). In one study, late-onset hypertension (over 80 years of age) has been associated with a lower risk for dementia in people aged over 90 (Corrada et al., 2017), yet the causal associations are difficult to establish, as the pathological changes develop for several years, even decades, before the diagnosis. As long-living individuals are known to be healthier at younger old age than their age peers who die earlier (Doblhammer & Barth, 2018), it is likely that most of our study population have survived to a rather old age free from dementia or other major conditions, and their comorbidity profile may to some extent differ from that of younger old people.

We found a rather high prevalence of depression (over 24%) in people with dementia in every study year. This is at the same level (Lyketsos et al., 2002; Savva et al., 2009) or higher (Sherzai et al., 2016) than the figures reported for people aged over 65 years. Depression is one of the conditions often associated with dementia, since depression earlier in life has been found to be a risk factor for dementia, and depression can also be a prodrome for dementia (Enache et al., 2011; Grande et al., 2021). In line with Sherzai et al. (2016), we found that depression was more common among participants with dementia than those without, but it showed a tendency to decrease over time, as also indicated by a recent Finnish register-based study (Vargese et al., 2021). Severe clinical depression is quite rare in very old age, but the prevalence of depressive disorders is known to be relatively high (Luppa et al., 2012). The wording of the item in the Vitality 90+ survey (depression, depressed mood) likely has contributed to the rather high prevalence of depression seen in this study.

Our study consisted of six identical cross-sectional surveys spanning a long, 17-year timeline which enabled us to study trends during a reasonably long period. The study population was exceptionally old, and the exhaustive population registers available in Finland allowed us to include all inhabitants in a defined area, irrespective of their place of residence or health status. Excluding long-term care residents and people with poor health from surveys is known to result in underestimated prevalence rates for chronic conditions in older populations (Kelfve et al., 2013). The decision to allow

proxy responses meant we also obtained information from participants who would not have been able to answer themselves. As expected, proxy responses were more common among those living in long-term care and having dementia. The response rate was high in every survey year. Even though the range of chronic conditions included was limited, all the most significant and most common diseases were covered. Given the high response rate and the inclusion of long-term care residents and proxy respondents, it is reasonable to assume that our study also includes severe cases of dementia. Since we did not have information on the onset of dementia or comorbidities, we were not in the position to draw conclusions about the stage of dementia and its consequences. Also, the study focused solely on population-based time trends using independent cross-sections and did not follow the incidence or change in morbidity at the individual level.

We had access to dates of death for the total basic population and hence were able to compare mortality between respondents and non-respondents two, three, and 4 months after each Vitality 90+ survey. In each survey round, mortality was higher for non-respondents than for respondents (data not shown). Therefore, the prevalence rate reported for dementia and other chronic conditions is most likely an underestimate since those who did not answer the survey were probably in poorer health than the respondents. The response rate, although high in every round, was slightly lower in 2018. However, the mortality rate after the survey in 2018 was similar to that in previous survey years, suggesting no greater mortality selection in 2018. Therefore, in our understanding, the findings are comparable across the study years.

The data for this study was based on self-reports, the method of choice in most surveys estimating the prevalence of chronic conditions in older populations (Christensen et al., 2009). Self-reports are the most feasible and often the only available method for collecting representative population-based information. It is often assumed that self-reports underestimate the prevalence of chronic conditions, but Christensen et al. (2009) suggest that certain conditions are in fact overreported. The increasing trend in prevalence rates for most chronic conditions is seen in both self-reported data and medical records (Christensen et al., 2009).

We are aware that cognitive decline may undermine the reliability of information collected from the oldest old people, and we have done our utmost to evaluate and limit the extent of this potential problem. First, it should be noted that the majority of our sample did not have cognitive decline, which is consistent with earlier studies in this age group (Corrada et al., 2008; Doblhammer & Barth, 2018). Prior research also suggests that people with mild to moderate cognitive decline are able to assess their health status (Walker et al., 2004) and most of those with diagnosed dementia do report their memory problems (Campbell et al., 2008). Second, for participants with more severe dementia, information was received from family members or care staff. In addition to the 30–44% of proxy respondents for participants with dementia, 16–30% received help from others in answering the survey (data not shown). Thus, less than half of the participants with dementia gave the information entirely independently. Third, in an earlier round of the Vitality 90+ survey, we have compared self-reports of chronic conditions with medical records (Goebeler et al., 2007). We found that participants had a tendency to overreport rather than underreport dementia, depression, and osteoarthritis. Agreement between the survey and medical records was greatest for Parkinson's disease, hip fracture, and diabetes. Inter-source agreement on chronic conditions was not dependent on cognitive decline recorded by a physician. Compared to studies on self-reported morbidity in younger old people, the disagreement followed the same pattern but was larger in the Vitality 90+ sample. In all, we certainly recognize the uncertainties in the self-reported information collected among the oldest old, but on the balance of evidence we believe that our data is sufficiently reliable and can usefully contribute to our understanding of the health and morbidity of this age group.

As for our results on time trends, possible sources of uncertainty from self-reported information in a trend study include changes in diagnostic practices and reporting behavior, and respondents' awareness of the conditions queried (Galenkamp et al., 2014). However, these challenges apply to every study conducted over extended period of time and are effectively beyond the control of research teams.

The results of this study contribute to our understanding of the health of the rapidly growing oldest old population, which has an exceptional morbidity profile. As dementia is most often accompanied by other chronic conditions, new clinical phenotypes may occur. Current clinical guidelines usually focus on single diseases, and where guidelines for multimorbidity do exist (Boyd et al, 2019), they do not take into account the specific characteristics of dementia. Comorbidities affect the lives of people with dementia and their caregivers (Bunn et al., 2014) since they are associated with problems in self-care and mobility and with lower quality of life (Doraiswamy et al., 2002; Nelis et al., 2018). Hence, comorbidities aggravate the negative effects of dementia. The increasing number of people with dementia and the increasing comorbidity burden pose new challenges not only for clinical guidelines and practice, but also for research.

Conclusions

Dementia remains a highly prevalent condition among the oldest old people and it is associated with an increasing comorbidity burden. This presents a significant challenge for the people living with dementia, their caregivers, and the care system. Our results show an increasing prevalence of hypertension, diabetes, and osteoarthritis which likely reflects improved diagnostics and treatment of these conditions in general and especially among individuals with dementia, and longer survivorship with these conditions. Depression, even though it is showing a slightly declining trend, is notably more common among individuals suffering from dementia than others. Yet it is possible that some conditions, particularly those with fewer symptoms, are still underdiagnosed in people with dementia. This is a question that warrants closer

investigation. This study implies that increasing longevity likely leads to an increasing number of chronic conditions comorbid with dementia and a growing prevalence of multimorbidity. It is therefore crucial that further epidemiological, clinical, and social research is conducted on dementia comorbidity among the most rapidly growing population group, the oldest old.

Authors' Note

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Author Contributions

PH and MJ initiated the article. PH, LE, MJ and EJ designed the study and analysis. PH conducted the analysis and drafted the article. PH, LE, EJ, SV and MJ contributed to the interpretation of the data and results, and to the revision of the article and accepted the final version of the manuscript.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethical Statement

The Vitality 90+ Study has obtained ethical permission for every survey round from the regional ethics committee of Tampere University Hospital (in 2018 approval number R18041) or the City of Tampere, depending on the year of the survey. Written informed consent was obtained from the participants or their representative.

Data Availability

https://services.fsd.tuni.fi/catalogue/series/64?tab=description&lang=en

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Supplemental Material

Supplemental material for this article is available online.

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PUBLICATION III

Chronic conditions and multimorbidity in population aged 90 years and over: associations with mortality and long-term care admission

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Chronic conditions and multimorbidity in population aged 90 years and over: associations with mortality and long-term care admission

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Abstract

Background: prevalence of many chronic conditions is rising in the aging population worldwide. However, the long-term impact of these conditions and multimorbidity on other health outcomes in very old age is rarely studied.
Methods: the data were based on four waves of the Vitality 90+ Study conducted in 2001, 2003, 2007 and 2010. Associations of chronic conditions and multimorbidity with mortality were analysed in a total sample of 2,862 people aged over 90, and associations with long-term care (LTC) admission in a subsample of 1,954 participants living at home in baseline. Risk of death and LTC admission were assessed with Cox and competing risks regression with time-dependent covariates. Population attributable fractions (PAF) for mortality and LTC admission were calculated for chronic conditions based on the regression models.
Results: heart disease, diabetes and dementia predicted mortality in men and women. In addition, depression was associated with increased mortality in women. Parkinson's disease, dementia and hip fracture predicted LTC admission in women. Multimorbidity increased the risk of death and LTC admission in women but not in men. For both genders, dementia had the highest PAF for mortality and LTC admission.
Conclusion: heart disease and diabetes are still important predictors of mortality in very old age. However, the role of dementia is pronounced in this age group. Of the studied conditions, dementia is the main contributor both to mortality and LTC admission. Multimorbidity has predictive value concerning both mortality and LTC admission, at least in oldest old women.

Keywords

nonagenarians, chronic conditions, multimorbidity, mortality, long-term care, older people

Key points

- Dementia accounts for more deaths than heart disease or diabetes in population aged 90+.
- Chronic conditions account for small fractions of LTC admission.
- Predictors of mortality and LTC admission are more evident in nonagenarian women than men.
- Dementia is the most important condition leading to LTC admission in the oldest old.
- Certain chronic conditions and multimorbidity increase the risk of death and LTC admission in the oldest old.

Introduction

Increases in longevity along with improved management of chronic conditions have led to more people living to very old ages with one or more chronic conditions [1]. The prevalence of most chronic conditions is projected to increase; by 2035, over half the population aged over 85 years will have four or more chronic conditions [2]. Consequently, interest is increasing in the associations of chronic conditions and multimorbidity with different health outcomes.

The prevalence of multimorbidity, defined as having more than one chronic condition, peaks around age 85, with reported prevalence rates ranging from 82 to 95% [3–5]. In studies mostly concerning younger people, multimorbidity has been associated with declining functional ability, lower quality of life and high need for health care services [6].

Most studies have shown higher mortality for people with several chronic conditions, but in old age, this association is thought to be mediated by functional ability [7]. Disability and chronic conditions are closely related and often co-occur in old age, reflecting the severity of chronic conditions. However, functioning seems to decrease in old age irrespective of a person's disease status [8]. Currently, knowledge about the predictors of mortality among the oldest old is limited. In a Danish study, chronic conditions had little effect on mortality [9], whereas in another study low baseline comorbidity was associated with low 5-year mortality [10].

The need for long-term care (LTC) rises during the last years or months of life. Time spent in LTC during the end of life seems to have increased, possibly since people are living longer and suffering from more chronic conditions than before [11]. In younger old people, dementia and Parkinson's disease, as well as multimorbidity, have been associated with the need for LTC [12, 13]. Prior research is scarce on chronic conditions or multimorbidity as predictors of LTC use in the oldest old population.

The study examines to what extent chronic conditions and multimorbidity predict mortality and LTC admission in the population aged 90 and over, and assesses the population attributable fractions (PAFs) of mortality and LTC admission for individual chronic conditions.

Methods

Sample

The data were based on four cross-sectional waves of the Vitality 90+ Study conducted in 2001, 2003, 2007 and 2010 [14]. Each study year the mailed survey included both community-dwelling and institutionalised residents aged 90 years and over in the city of Tampere, Finland (in 2017 with 231,853 inhabitants, of whom 19% were aged over 65 and 0.9% aged over 90 [15]). The response rate varied between 79 and 86%. Due to high mortality, most participants (n = 1,650) responded to only one survey. Of the remainder, 1,004 participated in two surveys, 176 three surveys and 32 all four surveys. The sample used in the analysis concerning mortality included 2,862 participants (79.5% women). The LTC analysis used a subsample of 1,954 respondents living in their own homes at baseline. Proxy answers were included for participants who could not answer the questionnaire themselves.

Chronic conditions

Information on chronic conditions was based on self-reports. Participants were asked whether a doctor had told them they had any of nine chronic conditions: hypertension, heart disease, dementia, stroke, diabetes, arthritis, Parkinson's disease, hip fracture and depression. To describe multimorbidity, the respondents were categorised as having 0, 1, 2, 3 and 4+ conditions.

Covariates

Functional ability was included in the analysis as a sum of five variables measuring activities of daily living and mobility. Participants were asked 'Are you able to…' move indoors, walk at least 400 m, use stairs, dress, and get in and out of bed. The answer choices were 'Yes, without difficulty', 'Yes, but it's difficult', 'Not without help' and 'Unable'. Answers were scored from 1 (able without difficulty) to 4 (unable). Hence, the total score for functional ability ranged from 5 (i.e. able to perform all activities without difficulty) to 20 (unable for all activities).

Occupational class was used as a covariate since multimorbidity and certain chronic conditions tend to be more prevalent in people with lower socioeconomic status [3, 16]. The participant's main occupation during working life was coded according to the Statistics Finland occupation classification [17] as upper non-manual, lower non-manual, skilled manual, unskilled manual, housewives and unknown occupation.

Other covariates used in the analysis were age and year entering the study. Additionally, living alone vs. with others was included as a covariate in LTC analysis.

Outcomes

The main outcomes in this study were death and entering LTC. LTC was defined as an approval for LTC admission from the municipal authorities or being at least 90 days in a residential home, service home with 24-h assistance or inpatient ward of a health centre or hospital. Data for mortality and LTC were retrieved from the Finnish Population Register and the National Care Registers for Health and Social Welfare and were linked to the survey data using unique personal identity codes. The follow-up began on the index date of every study year and ended on 31 December 2012 at the latest.

Permission to use pseudonymized register data was obtained from the National Institute for Health and Welfare and the data were formed with Statistics Finland. The ethics committees of Pirkanmaa Hospital District or the City of Tampere, depending on the study year, gave ethical statements for the Vitality 90+ Study.

Statistical analysis

Cox proportional hazard regression was used to estimate risk of death. In the analysis concerning LTC admission, competing risk regression [18] with death as a competing risk was used. Chronic conditions, functional ability and living arrangements were considered as time-dependent covariates using data from each participants' all available survey rounds. Number of chronic conditions was also considered as a time-dependent covariate. However, if a participant reported fewer conditions on a later survey round, the former number (i.e. the higher number) of conditions remained unchanged.

First, the associations of each chronic condition and functional ability separately, with mortality, adjusted for age and year of entry, were analysed. Second, all chronic conditions, functional ability, and occupational class, together with age and year of entry were included in the same model. The analyses concerning association between chronic conditions and entering LTC followed the same patterns but living alone was also included in the second model. Then similar analyses were performed to test the effects of multimorbidity. All analyses were conducted separately for men and women. Hazard ratios (HR) and subhazard ratios (SHR) with 95% confidence intervals are presented.

PAF was used to describe the burden of chronic conditions. PAF was computed based on the Cox and competing risk regression analyses [19]. These models, however, were adjusted only for age, year of entry and all conditions, in order to estimate purely the attribution of the chronic conditions. PAF takes into account not only the strength of a relationship between risk factor and outcome but also the prevalence of the risk factor in a population. Therefore, it describes the importance of certain risk factors at population level [20].

P-values < 0.5 were considered significant. Stata version 15.1 was used in all analyses.

Results

In total, 2,862 participants were included in the analyses concerning mortality. Of them 2,165 died (75.2% of women and 77.3% of men) during the follow-up. The average time to death was 2.5 years (range 9 days–11.6 years). Of those living outside institutions at baseline (n = 1,954), 46.1% of women and 33.8% of men moved to LTC. The average follow-up time to LTC admission was 2.1 years (range 4 days–11 years). Characteristics of participants at baseline are shown in Table 1.

Chronic conditions and multimorbidity as predictors of mortality

In the first model, dementia, stroke, diabetes, heart disease and depression increased the risk of death, whereas participants with arthritis had lower mortality. In addition, worse functional ability predicted mortality. The findings were similar for both genders (Table 2).

In the fully adjusted model, heart disease, dementia and diabetes, but not stroke, increased the risk of death for both genders. In addition, depression was associated with an increased risk of death in women. In men, arthritis and Parkinson's disease were associated with lower risk of death (Table 2).

In the model adjusted for age and year of entry, there was a graded association between the number of conditions and the risk of death in both genders. When functional ability and occupational class were added, HRs declined but women with 3 or 4+ conditions still had increased risk of death (53 and 59%, respectively). In the final model, having three or more conditions predicted mortality in women whereas the association was found in men only for those with one condition compared to men with no conditions (Table 2).

Chronic conditions and multimorbidity as predictors of LTC admission

Women with Parkinson's disease, dementia, hip fracture or depression had an increased risk of LTC admission in both the first and fully adjusted models. In men, none of the conditions was associated with LTC admission; the only significant predictor was worse functional ability (Table 3).

Having at least two conditions increased the risk of LTC admission in women when only age and year of entry were adjusted for. When functional ability, living alone and occupational class were taken into account, the risk of entering LTC increased by 64% for women having 3 conditions and 99% for women having 4+ conditions. In men, multimorbidity was not associated with LTC admission (Table 3).

PAF of mortality and LTC admission

In women 16% of deaths, and in men 14%, were attributable to heart disease. Corresponding numbers for dementia were 19% for women and 20% for men, and for diabetes, 3% for women and 5% for men. Depression accounted for 5% and stroke for 3% of deaths in women and hip fracture for 3% of deaths in men.

In both genders, dementia had the highest PAF for entering LTC (8% in women and 9% in men). In women, Parkinson's disease had the lowest PAF (0.6%), though it was the strongest predictor of LTC admission in regression model (Table 3). PAF for hip fracture was 5% and for depression 4% (Supplementary Table S1, available in *Age and Ageing* online.).

Discussion

This follow-up study describes the associations of chronic conditions and multimorbidity with mortality and LTC admission in the fastest growing population segment in Europe: people aged over 90 years. The results show that certain individual conditions, as well as multimorbidity, predict mortality and LTC admission in this population

Table 1. Baseline characteristics of the study population. % (*n*) of each variable if not stated otherwise.

	All		Home at baseline	
	Women	Men	Women	Men
Total number of participants	2,276	586	1,489	465
Proxy answers	20.1 (456)	13.2 (77)	4.1 (60)	4.3 (20)
Missing *n*	11	4	7	3
Median age (range)	91 (90–107)	91 (90–102)	91 (90–107)	91 (90–102)
Year of entry				
2001	31.6 (720)	29.4 (172)	27.5 (409)	28.8 (134)
2003	16.3 (370)	18.1 (106)	16.7 (249)	16.8 (78)
2007	23.9 (543)	24.6 (144)	24.0 (358)	24.7 (115)
2010	28.3 (643)	28.0 (164)	31.8 (473)	29.7 (138)
Occupation				
Upper non-manual	5.5 (125)	17.9 (105)	5.4 (80)	17.9 (83)
Lower non-manual	28.6 (651)	25.6 (150)	30.4 (452)	27.1 (126)
Skilled manual	33.3 (758)	44.5 (261)	34.6 (515)	43.7 (203)
Unskilled manual	9.6 (219)	2.2 (13)	8.9 (132)	1.7 (8)
Housewives	11.2 (254)		12.6 (188)	
Unknown occupation	11.8 (269)	9.7 (57)	8.2 (122)	9.7 (45)
Living arrangements				
Living alone	53.1 (1,203)	37.6 (220)	78.3 (1,160)	47.2 (219)
Living with someone	11.7 (264)	39.7 (232)	21.7 (321)	52.8 (245)
in LTC	35.2 (797)	22.7 (133)		
Missing *n*	12	1	8	1
Functional ability score median (IQR)	9 (6–13)	7 (5–11)	8 (6–14)	6 (5–14)
Missing *n*	69	21	40	16
Chronic conditions				
Hypertension	45.9 (1,030)	31.5 (182)	51.3 (753)	33.2 (152)
Heart disease	54.1 (1,213)	51.6 (298)	53.8 (790)	51.3 (235)
Dementia	41.6 (932)	38.6 (223)	26.7 (392)	32.2 (148)
Stroke	7.1 (158)	6.1 (35)	4.4 (64)	4.4 (20)
Diabetes	11.7 (262)	10.7 (62)	10.4 (153)	9.8 (45)
Arthritis	41.3 (926)	28.0 (162)	45.8 (672)	28.6 (131)
Parkinson's disease	2.1 (47)	1.0 (6)	1.2 (18)	0.7 (3)
Hip fracture	17.6 (395)	11.1 (64)	14.4 (212)	10.0 (46)
Depression	23.3 (522)	18.3 (106)	16.8 (246)	15.5 (71)
Missing *n*	32	8	21	7
Number of conditions				
0	6.0 (134)	13.2 (76)	8.0 (117)	15.3 (70)
1	19.7 (442)	26.6 (154)	22.1 (324)	28.2 (129)
2	28.2 (633)	26.5 (153)	29.9 (439)	26.4 (121)
3	24.9 (559)	23.0 (133)	23.8 (350)	21.2 (97)
4+	21.1 (474)	10.7 (62)	16.2 (238)	9.0 (41)
Median (range)	2 (0–7)	2 (0–7)	2 (0–7)	2 (0–7)
Missing *n*	32	8	21	7

Functional ability score ranges from 5 to 20, higher score representing worse functional ability.

independent of functional ability, age, living arrangements, socioeconomic status and cohort effect. Furthermore, a notable fraction of deaths is attributed to dementia, which also has the greatest effect on LTC admission. In men, chronic conditions and multimorbidity had weaker effects on the outcomes, at least partly due to the small number of male participants.

In this study, heart disease in women and diabetes in men had the strongest association with mortality, in line with previous studies considering younger old people [21, 22]. Our findings support previous evidence that cardiovascular diseases are a significant cause of death still in old age [23]. However, in oldest old, dementia was a greater determinant of death than heart disease or diabetes at population level. An even greater PAF of dementia was observed in a previous study including people over 95 years old [24]. As advances in prevention and treatment of cardiovascular diseases improve survival and decrease cardiovascular mortality [23], increasing numbers of the oldest will be expected to suffer and die from dementia.

Besides dementia and cardiovascular disease, depression was associated with mortality in women. Such an association has not been reported before in this age group. As causes of death were not studied, the mechanisms underlying the association between depression and mortality in the oldest old remain unknown. The lower risk of death for

Table 2. Associations of chronic conditions, multimorbidity and functional ability with mortality. Hazard ratios (HR) and 95% confidence intervals (CI) from Cox regression models.

	Women				Men			
	Model 1[a] (*n* = 2,216–2,255)		Model 2[b] (*n* = 2,216)		Model 1[a] (*n* = 566–581)		Model 2[b] (*n* = 566)	
	HR	95% CI	HR	95% CI	HR	95% CI	HR	95% CI
Functional ability	1.12	1.10–1.13	1.10	1.09–1.12	1.15	1.13–1.17	1.15	1.12–1.18
Hypertension	0.91	0.82–1.01	0.93	0.84–1.04	1.06	0.85–1.32	1.03	0.82–1.30
Heart disease	1.34	1.21–1.48	1.35	1.22–1.50	1.46	1.20–1.77	1.25	1.02–1.54
Dementia	1.68	1.52–1.86	1.20	1.07–1.33	1.75	1.44–2.12	1.30	1.05–1.61
Stroke	1.66	1.40–1.98	1.18	0.98–1.41	1.59	1.08–2.33	0.90	0.60–1.36
Diabetes	1.39	1.20–1.61	1.27	1.09–1.48	1.64	1.23–2.20	1.67	1.24–2.25
Arthritis	0.84	0.76–0.93	0.80	0.72–0.90	0.78	0.62–0.97	0.68	0.53–0.85
Parkinson's disease	1.26	0.91–1.76	1.02	0.73–1.43	1.11	0.52–2.36	0.37	0.17–0.82
Hip fracture	1.12	0.99–1.26	0.91	0.80–1.03	1.24	0.94–1.63	0.94	0.70–1.27
Depression	1.41	1.26–1.58	1.15	1.02–1.29	1.30	1.02–1.65	0.96	0.74–1.25
	Model 3[a] (*n* = 2,255)		Model 4[c] (*n* = 2,216)		Model 3[a] (*n* = 581)		Model 4[c] (*n* = 566)	
Functional ability	1.12	1.10–1.13	1.11	1.10–1.12	1.15	1.13–1.17	1.15	1.12–1.18
Multimorbidity								
0 conditions	Ref.		Ref.		Ref.		Ref.	
1 condition	1.64	1.20–2.24	1.38	1.01–1.90	1.63	1.10–2.43	1.56	1.03–2.35
2 conditions	1.69	1.25–2.29	1.32	0.96–1.79	1.85	1.25–2.74	1.42	0.94–2.14
3 conditions	2.27	1.68–3.07	1.53	1.12–2.08	2.08	1.40–3.08	1.40	0.92–2.12
4+ conditions	2.64	1.95–3.57	1.59	1.16–2.16	3.06	2.00–4.69	1.57	0.99–2.49

[a]Separate model for each variable, adjusted for age and year of entry.
[b]All conditions and functional ability adjusted for age, year of entry and occupational status.
[c]Multimorbidity and functional ability adjusted for age, year of entry and occupational status.

Table 3. Associations of chronic conditions, multimorbidity and functional ability with entering LTC. Regression models with mortality as a competing risk for LTC. Subhazard ratios (SHR) and 95% confidence intervals (CI).

	Women				Men			
	Model 1[a] (*n* = 1,458–1,476)		Model 2[b] (*n* = 1,444)		Model 1[a] (*n* = 450–461)		Model 2[b] (*n* = 447)	
	SHR	95% CI	SHR	95% CI	SHR	95% CI	SHR	95% CI
Functional ability	1.08	1.06–1.11	1.07	1.04–1.10	1.14	1.08–1.20	1.11	1.05–1.18
Hypertension	0.98	0.84–1.15	0.98	0.83–1.17	0.97	0.64–1.45	1.07	0.68–1.68
Heart disease	0.90	0.77–1.06	0.86	0.73–1.02	1.33	0.93–1.91	1.31	0.90–1.92
Dementia	1.58	1.33–1.87	1.50	1.25–1.79	1.44	1.01–2.06	1.23	0.80–1.89
Stroke	1.11	0.74–1.67	0.97	0.63–1.50	0.93	0.36–2.36	0.68	0.24–1.93
Diabetes	1.01	0.78–1.32	1.01	0.77–1.34	0.82	0.43–1.55	0.74	0.36–1.50
Arthritis	1.16	0.99–1.35	1.08	0.91–1.27	1.40	0.96–2.06	1.34	0.90–2.00
Parkinson's disease	3.05	1.92–4.82	2.36	1.40–3.97	0.41	0.48–3.49	0.51	0.05–4.88
Hip fracture	1.52	1.24–1.86	1.42	1.14–1.75	1.21	0.71–2.06	1.27	0.72–2.24
Depression	1.56	1.27–1.91	1.27	1.01–1.59	1.21	0.76–1.92	1.05	0.65–1.70
	Model 3[a] (*n* = 1,458–1,476)		Model 4[c] (*n* = 1,444)		Model 3[a] (*n* = 450–461)		Model 4[c] (*n* = 447)	
Functional ability	1.08	1.06–1.11	1.08	1.05–1.11	1.14	1.08–1.20	1.10	1.04–1.17
Multimorbidity								
0 conditions	Ref.		Ref.		Ref.		Ref.	
1 condition	1.32	0.92–1.91	1.34	0.91–1.97	0.84	0.48–1.49	0.90	0.49–1.66
2 conditions	1.46	1.03–2.08	1.43	0.98–2.08	1.51	0.88–2.60	1.52	0.82–2.78
3 conditions	1.76	1.23–2.51	1.64	1.12–2.40	1.52	0.84–2.74	1.57	0.83–3.00
4+ conditions	2.21	1.53–3.20	1.99	1.34–2.95	1.78	0.88–3.59	1.56	0.72–3.37

[a]Separate model for each variable, adjusted for age and year of entry.
[b]All conditions and functional ability adjusted for age, year of entry, occupational status and living arrangements.
[c]Multimorbidity and functional ability adjusted for age, year of entry, occupational status and living arrangements.

arthritis sufferers is not an unprecedented finding [22] yet contrasts with most studies on younger old people [25]. Both depression and arthritis in the oldest old should be studied further.

Previous evidence on the association between multimorbidity and mortality in nonagenarians has been inconsistent [9, 10]. In line with our findings, a study with younger old people indicated that having at least three diseases increases the risk of death, and the effect is more pronounced in those with five or more diseases [22]. Comparisons between studies are difficult because of different ways of defining and measuring multimorbidity. However, our findings suggest that multimorbidity should be considered a predictor of mortality in the oldest old population.

Due to their disabling effects, Parkinson's disease, dementia, hip fracture and depression understandably increased the need for LTC as they do in younger old people [12, 13]. Our results emphasise the importance of dementia as the most important condition leading to LTC in the oldest old. Certain conditions previously associated with institutionalisation (stroke, diabetes, heart disease, arthritis) [12, 13] did not affect LTC admission in our study, reflecting the importance of more disabling conditions in this age group: dementia, Parkinson's disease and hip fracture. Multimorbidity as predictor of LTC admission [13] seems to hold in the oldest old women, as our results suggest. Consonant with previous studies [9, 13, 26, 27], our results also show that LTC admissions are more common in women than men whereas mortality is higher in men in this age group. This might be one reason why we did not find associations between chronic conditions or multimorbidity and LTC admission in men.

The strength of this study is the study design, rarely used in studying the oldest old. A maximum of over 11 years' follow-up and use of time-dependent covariates provided information on the changes in morbidity and functional status. PAF added to this information by describing the significance of analysed conditions. It is also noteworthy that the sample included both community-dwelling and institutionalised participants. Using proxy answers, data were available from those not able to answer themselves. The response rates in the Vitality 90+ Study have been very high.

The most important limitation is that the information was mostly self-reported and except for data about functional status, there was no way to estimate the severity of conditions. However, it has been shown that even the oldest old are able to give sufficiently reliable information on their health status [28]. Another restriction is that to maintain sufficient response rates, the number of questions, including the number of conditions, was limited.

Our findings indicate that even though baseline mortality in very old people is high, certain chronic conditions, such as heart disease, diabetes, dementia and depression, in addition to multimorbidity, are still significant predictors of mortality in nonagenarians. In general, morbidity is associated with disability, but in this study, multimorbidity, dementia, hip fracture and depression increased the risk of LTC admission in women independent of functioning. Future research should focus on comorbidities with dementia since its prevalence is expected to increase [23]. In addition, updated information on the progression of the prevalence and incidence of other chronic conditions in the oldest old population is needed.

Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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ORIGINAL RESEARCH

Agreement Between Self-Reported Information and Health Register Data on Chronic Diseases in the Oldest Old

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Purpose: To study the agreement on disease prevalence between survey data and national health register data among people aged over 90.

Patients and Methods: The survey data were from the Vitality 90+ Study conducted among 1637 community dwellers and persons in long-term care aged 90 and over in Tampere, Finland. The survey was linked with two national health registers, including hospital discharge data and prescription information. The prevalence of 10 age-related chronic diseases was calculated for each data source and the agreement between the survey and the registers was estimated using Cohen's kappa statistics and positive and negative percent agreement.

Results: The prevalence of most diseases was higher in the survey than in the registers. The level of agreement was highest when the survey was compared with information combined from both registers. Agreement was almost perfect for Parkinson's disease (κ=0.81) and substantial for diabetes (κ=0.75) and dementia (κ=0.66). For heart disease, hypertension, stroke, cancer, osteoarthritis, depression, and hip fracture, the agreement ranged from fair to moderate.

Conclusion: Self-reported information on chronic diseases shows acceptable agreement with health register data to warrant the use of survey methods in population-based health studies among the oldest old. It is important to acknowledge the gaps in health registers when validating self-reported information against register data.

Keywords: chronic condition, reliability, survey, prevalence, health registers

Introduction

Self-report surveys are the most common and feasible method for acquiring information from large population-based samples in health research. However, electronic health registers have paved the way for the use of register information compiled by administrators or insurance providers. These registers typically cover either general practice records or inpatient care, but the variation is wide.[1] Thorough clinical and laboratory examinations, regarded as the gold standard, are seldom possible in large population studies.

In younger adults, self-report and health register data show high agreement for clearly defined diseases that require constant medication.[2,3] Yet studies have suggested that self-reports underestimate disease prevalence.[4–6] In the fast-growing group of the oldest old, multimorbidity and cognitive problems may compromise the reliability of self-reported health information.[7–9] Self-reports and register data on hypertension and heart disease have shown poor or moderate agreement in the few studies including the oldest old.[8,10] A study of Swedish people aged 80 found that the prevalence of cardiovascular diseases and diabetes was lower in a patient register than in interviews.[11] In an earlier analysis of community-dwelling Vitality 90+ Study participants in Finland, depression, dementia, and arthritis occurred more frequently in self-reports than in local medical records, while other diseases were underreported.[12]

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The Nordic countries have publicly funded universal health-care systems, providing the basis for reliable and comprehensive health registers.[13] These registers are accurate for diseases that require continuous care and medication, such as diabetes, but potentially less so for risk factors (eg, high blood pressure, obesity, hyperlipidemia).[14] However, most registers are not designed and intended for research, but for administrative purposes.[1,13]

The number of the oldest old is continuing to grow worldwide[15] and therefore reliable and accurate information on morbidity is essential for informed policy-making and planning.[16] This study evaluates the reliability of self- and proxy-reported survey information on chronic diseases in the oldest old by comparing it with national health register data. We use two registers, one covering hospital treatment and the other prescription data. Our research questions are: (1) To what extent are self-reports consistent with register data on the prevalence of selected chronic diseases, and (2) How does the level of agreement vary between different diseases?

Materials and Methods

Survey Data

The Vitality 90+ Study is a multidisciplinary population-based research project focused on the health, functioning, and life circumstances of people aged 90 and over.[17] Its main component is a postal survey among both community-dwelling and long-term care residents in the city of Tampere, Finland (2019 population 238,140, of which 0.9% were over 90 years). This study uses data from a survey conducted in 2014 among people born in 1924 or earlier. Responses were received from 1637 participants, giving a response rate of 80%.

The survey included a question on chronic diseases. Respondents were asked, "Has a doctor told you that you have…?", followed by a list of 10 diseases: 1) hypertension, high blood pressure, 2) heart disease (coronary artery disease, arrhythmia, myocardial infarction), 3) dementia, Alzheimer's disease or worsening of memory, 4) diabetes 5) Parkinson's disease, 6) stroke, 7) osteoarthritis 8) hip fracture, 9) depression, depressed mood, and 10) cancer. Information was also collected on place of residence (home, long-term care facility) and the use of proxy respondents. Proxy respondents (287; 16 participants had missing information on proxy status) were used for those who were unable to respond themselves. Most of the proxy responses were given by a relative/acquaintance (76.7% of proxy responses) and the rest by a member of staff in health or social care (23.2%).

Register Data

Care Register for Health Care

The Care Register for Health Care (CRHC) compiled by the National Institute for Health and Welfare is an administrative register containing nationwide information on inpatient care, specialized outpatient care, and day surgery.[13] It provides one primary diagnosis for every care episode (ie, the main reason for the care episode) and possible secondary diagnoses (ie, other relevant diagnoses with implications for prognosis, treatment, or health status) with ICD-10 code. Reporting to the register is mandatory and the main diagnosis must be specified for every care episode.[18] A review assessing the validity of the register found that the main diagnoses were complete, but information on secondary diagnoses was often incomplete.[19] In our study, data from CRHC was obtained for 1563 survey participants; 74 participants declined to give permission for the linkage.

Finnish Prescription Register

The Finnish Prescription Register (FPR) maintained by the Social Insurance Institution of Finland is a nationwide register covering all prescription drugs dispensed at pharmacies. It identifies the Anatomical Therapeutic Chemical (ATC) code for each purchase and a reimbursement code, if applicable. In Finland, most prescription drugs are partly or fully reimbursed, depending on the indication. We used the reimbursement codes to identify hypertension, heart disease (including cardiac insufficiency, chronic coronary artery disease and related fat metabolism disorders, and chronic arrhythmias), Alzheimer's disease (AD), diabetes, and Parkinson's disease from the register. To be eligible for reimbursement, patients must undergo a thorough clinical examination. Hence, the code confirms the indication of the drug and is therefore a highly reliable indicator for a disease. FPR does not cover drugs administered during hospital or other institutional care, or over-the-counter drugs.[20] The validity of FPR concerning psychotropic drug use has been shown to

be adequate.[21,22] For our study, we only had permission to use FPR data for participants who had deceased before the linkage of the registers, December 31, 2018 (1117 individuals).

Data Matching and Linkage

The matching of survey variables with ICD-10 codes from the CRHC and ATC-codes from the FPR is shown in Table 1. All events with ICD-10 diagnoses from CRHC and all medication dispenses with a reimbursement code from FPR were drawn until the beginning of survey data collection in 2014 (January 17, 2014). CRHC included information from January 1, 1996, and FPR from January 1, 2010, onwards.

The register data were linked with the survey data using the personal identification code, a unique identifier assigned to all residents in Finland.[23] The linkage was done by Statistics Finland. All data accessed were handled according to relevant data protection and privacy regulations.

The protocol for Vitality 90+ Study has been approved by the Regional Ethics Committee of Tampere University Hospital and the study has a research permit from the City of Tampere. Permission to use the register data was obtained from the register keepers. All survey participants or their representatives provided written informed consent and were asked for permission to link the survey information with the health registers.

Statistical Analysis

First, the analyses were conducted for all survey respondents with complete information on chronic diseases (n = 1548), comparing all reported diagnoses in the survey with diagnosis information from CRHC. Second, information from both CRHC and FPR was used. The comparison of survey data with both registers was carried out among the 1107 participants for whom we had information from both CRHC and FPR and complete data on chronic diseases in the survey (Figure 1).

We first calculated the frequency of all 10 diseases from the survey and CRHC for the whole sample (n = 1548) and then for the five diseases with a reimbursement code in FPR (n = 1107). Among participants in the latter sample, information from the two registers was used in combination, and a participant was considered to have the disease if it was recorded in either register.

Cohen's kappa statistic was used to test the agreement for each disease between survey and CRHC, between survey and FPR, and between survey and combined data from both registers. Level of agreement was evaluated on a scale from 0.00 to 1.00 as defined by Landis & Koch:[24] <0.00 poor, 0.00–0.20 slight, 0.21–0.40 fair, 0.41–0.60 moderate, 0.61–0.80

Table 1 Matching of Survey Items, ICD-10, ATC, and Reimbursement Codes

Survey item	ICD-10	ATC code	Reimbursement code
Cancer	C00-C97	n.a.	n.a.
Diabetes	E10-E14	A10	Diabetes, insulin treatment (103), diabetes, other than insulin treatment (215)
Dementia or Alzheimer's disease, loss of memory	F00-F03, G30	N06D	Donepezil, Galantamine, memantine, rivastigmine (307)
Depression, depressed mood	F31-F34, F38-F39	n.a.	n.a.
Parkinson's disease	G20	N04	Parkinson's disease (110)
Hypertension, high blood pressure	I10-I15	C02C, C03A, C03B, C03C, C03D, C03E, C07A, C07B, C07F, C08C, C08D, C09A, C09B, C09C, C09D	Chronic hypertension (205)
Heart disease (coronary artery disease, arrhythmia, myocardial infarction)	I20-I25, I47-I50	C01A, C01D, C03A, C03C, C03D, C03E, C07A, C07B, C08C, C08D, C09A, C09B, C09C, C09D, C10A	Heart failure (201), chronic coronary artery disease and related fat metabolism disorders (206), chronic arrhythmias (207)
Hip fracture	S72.0, S72.1, S72.2	n.a.	n.a.
Stroke	I60-I64, I69	n.a.	n.a.
Osteoarthritis	M15-M19	n.a.	n.a.

Abbreviations: ICD-10, International Classification of Diseases, Tenth Revision; ATC code, Anatomical Therapeutic Chemical code; n.a, not available.

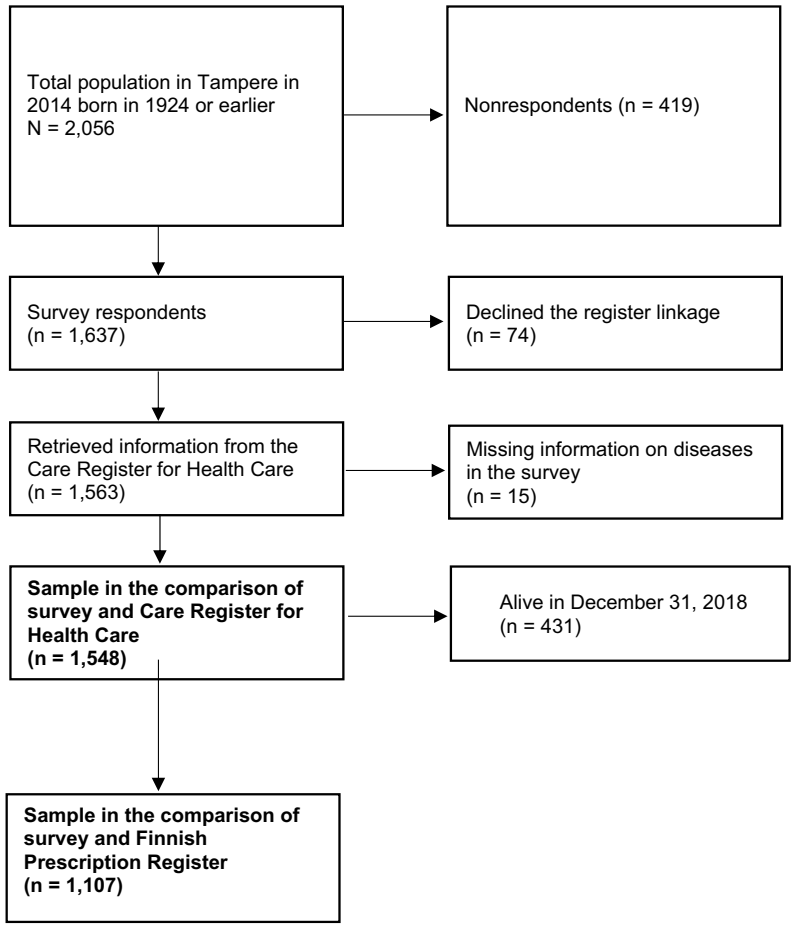

Figure 1 Flowchart of the study participants.

substantial, and 0.81–1.00 almost perfect. Positive and negative percent agreement were calculated to assess whether the discrepancy between the data sources originated from mismatch in positive or negative ratings.[25] Using the register as a reference, PPA denotes the proportion of matching positive ratings in the register and the survey out of all positive ratings in the register, and NPA denotes the proportion of matching negative ratings in the register and the survey out of all negative ratings in the register.

Analysis was performed with IBM SPSS Statistics version 28.0.

Results

Participant Characteristics

Mean age of the participants with complete disease information from the survey and CRHC was 92.7 (range 90–106), while in the sub-sample with information available from FPR it was 93.0 (range 90–106). The proportion of women was about the same in the whole study sample (76.5%) and in the sub-sample (76.6%) but the share of proxy respondents (18.6% and 24.6%, respectively) and residents in long-term care (36.4% vs 44.4%) was higher in the sub-sample.

Disease Prevalence in the Survey and the Registers

Among all respondents (n = 1548), the survey showed a higher prevalence than CRHC for all diseases, except for cancer and stroke, which had a higher prevalence in the register. Hypertension and heart disease were the two most prevalent diseases in both the survey and CRHC. The prevalence of osteoarthritis (43.9%) and dementia (42.4%) were also high in the survey, but much lower (24.9% and 26.0%, respectively) in CRHC (Table 2).

In the sub-sample (n = 1107), the survey showed a higher prevalence for all five diseases than either CRHC or FPR. The lowest prevalence rates for all diseases were obtained from FPR. When information from both registers was combined, the prevalence of all five diseases was closer to the figure from the survey (Table 3).

Agreement Between Survey Data and the Registers

Cohen's Kappa

Hip fracture (κ=0.65), diabetes (κ=0.63), and Parkinson's disease (κ=0.61) showed substantial agreement between the survey and CRHC among all survey participants. Stroke (κ=0.59), cancer (κ=0.57), dementia (κ=0.57), and heart disease (κ=0.52) showed moderate agreement and hypertension (κ=0.33), depression (κ=0.23), and osteoarthritis (κ=0.21) showed fair agreement (Table 2).

In the sub-sample, hypertension and Parkinson's disease showed higher agreement with FPR than CRHC. For heart disease, dementia, and diabetes, the agreement between survey and CRHC was higher than between survey and FRP. For

Table 2 Disease Prevalence in Survey and CRHC, Kappa Coefficients, Positive and Negative Percent Agreement Between Survey and CRHC and Two-by-Two Table of Frequencies (n = 1548)

	Survey % (n)	CRHC % (n)	κ	PPA %	NPA %	CHRC - Survey - n (%)	CRHC - Survey + n (%)	CRHC + Survey - n (%)	CRHC + Survey + n (%)
Osteoarthritis	43.9 (680)	24.9 (386)	0.21	63.5	62.6	727 (47)	435 (28)	141 (9)	245 (15.8)
Depression	17.1 (264)	5.7 (88)	0.23	59.1	85.5	1248 (80.6)	212 (13.7)	36 (2.3)	52 (3.4)
Hypertension	60.8 (941)	44.3 (685)	0.33	80.0	54.5	470 (30.4)	393 (25.4)	137 (8.9)	548 (35.4)
Heart disease	53.8 (833)	51.4 (796)	0.52	78.9	72.7	547 (35.3)	205 (13.2)	168 (10.9)	628 (40.6)
Cancer	16.5 (255)	24.9 (386)	0.57	54.4	96.1	1117 (72.2)	45 (2.9)	176 (11.4)	210 (13.6)
Dementia	42.4 (656)	26.0 (403)	0.57	93.3	75.5	865 (55.9)	280 (18.1)	27 (1.7)	376 (24.3)
Stroke	9.0 (140)	14.6 (226)	0.59	51.3	98.2	1298 (83.9)	24 (1.6)	110 (7.1)	116 (7.5)
Parkinson's disease	1.6 (24)	0.8 (12)	0.61	91.7	99.2	1523 (98.4)	13 (0.8)	1 (0.1)	11 (0.7)
Diabetes	15.4 (238)	10.4 (161)	0.63	83.9	92.6	1284 (82.9)	103 (6.7)	26 (1.7)	238 (15.4)
Hip fracture	17.2 (267)	13.1 (203)	0.65	81.3	92.4	1243 (80.3)	102 (6.6)	38 (2.5)	165 (10.7)

Notes: κ = Cohen's kappa. PPA is the percentage of positive ratings in CRHC and survey out of all positive ratings in CRHC. NPA is the percentage of negative ratings in CRHC and survey out of all negative ratings in CRHC. Percentages in the last four columns are proportions out of total observations.
Abbreviations: CRHC, Care Register for Health Care; PPA, positive percent agreement; NPA, negative percent agreement.

Table 3 Disease Prevalence in Survey, CRHC, FPR, and in Both Registers Combined Information, Kappa Coefficients and Positive and Negative Percent Agreement Across All Data Sources (n = 1107)

	Survey % (n)	CRHC % (n)	κ^a	PPA %	NPA %	FPR % (n)	κ^b	PPA	NPA	Both Registers % (n)	κ^c	PPA	NPA
Hypertension	58.0 (642)	48.0 (531)	0.37	77.2	59.7	34.5 (382)	0.42	89.8	58.8	58.0 (642)	0.51	79.4	71.6
Heart disease	56.6 (627)	56.3 (623)	0.48	77.4	70.0	21.2 (235)	0.26	89.8	52.3	59.8 (662)	0.51	77.5	74.4
Dementia	50.3 (557)	33.5 (371)	0.59	94.1	71.7	20.2 (224)	0.38	96.9	61.5	37.4 (414)	0.66	94.7	76.2
Diabetes	15.0 (166)	11.8 (131)	0.68	81.7	94.0	7.6 (84)	0.62	97.6	92	13.3 (147)	0.75	83.7	95.5
Parkinson's disease	1.6 (18)	1.0 (11)	0.69	90.9	99.3	1.0 (11)	0.76	100	99.4	1.3 (14)	0.81	92.9	99.5

Notes: [a]Kappa coefficient between survey and CRHC. [b]Kappa coefficient between survey and FPR. [c]Kappa coefficient between survey and both registers' information combined. PPA is the percentage of positive ratings in a register and survey out of all positive ratings in the register. NPA is the percentage of negative ratings in a register and survey out of all negative ratings in the register.
Abbreviations: CRHC, Care Register for Health Care; FPR, Finnish Prescription Register; PPA, positive percent agreement; NPA, negative percent agreement.

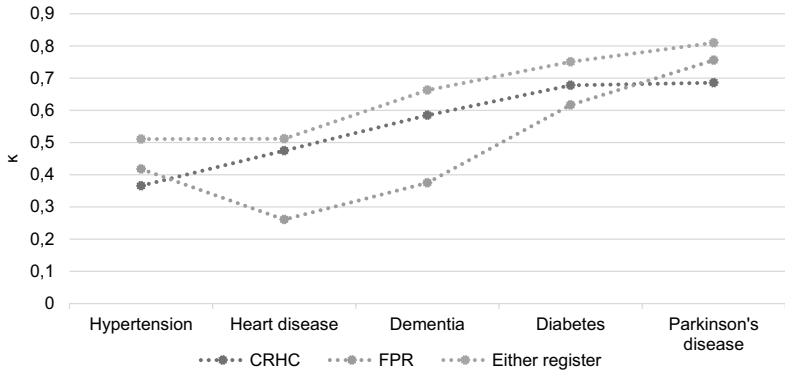

Figure 2 Kappa coefficients (κ) between survey and Care Register for Health Care (CRHC), survey and Finnish Prescription Register (FPR), and survey and either register in the sub-sample of 1107 respondents.

all five diseases, the agreement was highest when the two registers were combined. Parkinson's disease showed almost perfect agreement (κ=0.81); diabetes (κ=0.75) and dementia (κ=0.66) substantial agreement; and heart disease (κ=0.51) and hypertension (κ=0.51) moderate agreement (Table 3 and Figure 2).

For most diseases, agreement was slightly higher among proxy respondents than self-respondents between survey and CRHC. Agreement was substantial for Parkinson's disease, diabetes, and hip fracture. However, the agreement for dementia ranged from slight to moderate among proxy respondents, and agreement between proxy respondents and FPR was lower than between self-respondents and FPR (Supplementary Tables 1 and 2).

Positive and Negative Percent Agreement

Both PPA and NPA were high for diseases showing high agreement: Parkinson's disease, diabetes, and hip fracture. For hypertension and dementia, PPA was markedly higher than NPA, as in these diseases the discrepancy stemmed from a mismatch in negative ratings. A large number of hypertension and dementia cases reported in the survey were lacking from the register. Stroke and cancer showed high NPA and low PPA. Thus, some cases recorded in CRHC were lacking from the survey. Depression showed a very low prevalence in CRHC, and the mismatch was due to most survey-reported cases lacking from CRHC (Table 2).

Among participants with information available from both registers, all diseases showed higher PPA than NPA between the survey and FPR. PPA for FPR was higher than for CRHC, since there were very few cases that were registered in FPR but not reported in the survey. PPA for Parkinson's disease between FPR and the survey was 100%, indicating that all participants with a register entry of Parkinson's disease reported it in the survey (Table 4).

In proxy responses, NPA for dementia was low. Proxy respondents reported dementia far more frequently than either one of the registers (Supplementary Tables 1 and 2).

Discussion

This study assessed the agreement of disease information between a population-based survey and two national administrative health registers in a population aged over 90. Prevalence rates varied quite widely between the data sources. Agreement was high for clear, well-defined physical diseases: hip fracture, Parkinson's disease, and diabetes, and higher when information from the two registers was combined.

We used two Finnish national registers that are designed for administrative rather than research purposes yet nonetheless commonly used in research.[13] They cover the whole population and are therefore valuable sources of information. Our aim was to capture both inpatient and outpatient care by using one register with information originating from specialized care and hospitalization data, and the other with information on medication dispended from pharmacies, representing outpatient care.

Table 4 Two-by-Two Tables of Frequencies for Each Disease in the Comparison Between Survey and CRHC, Survey and FPR, and Survey and both Registers Information Combined. Percentages are Proportions Out of Total Observations for Each Disease (n = 1107)

	CRHC - Survey -	CRHC - Survey +	CRHC + Survey -	CRHC + Survey +	FPR - Survey -	FPR - Survey +	FPR + Survey -	FPR + Survey +	Registers - Survey -	Registers - Survey +	Registers + Survey -	Registers + Survey +
Hypertension n (%)	344 (31.1)	232 (21.0)	121 (10.9)	410 (37.0)	426 (38.5)	299 (27.0)	39 (3.5)	343 (31.0)	333 (30.1)	132 (11.9)	132 (11.9)	510 (46.1)
Heart disease n (%)	339 (30.6)	145 (13.1)	141 (12.7)	482 (43.5)	456 (41.2)	416 (37.6)	24 (2.2)	211 (19.1)	331 (29.9)	114 (10.3)	149 (13.5)	513 (46.3)
Dementia n (%)	528 (47.7)	208 (18.8)	22 (2.0)	349 (31.5)	543 (49.1)	340 (30.7)	7 (0.6)	217 (19.6)	528 (47.7)	165 (14.9)	22 (2.0)	392 (35.4)
Diabetes n (%)	917 (82.8)	59 (5.3)	24 (2.2)	107 (9.7)	939 (84.8)	84 (7.6)	2 (0.2)	82 (7.4)	917 (82.8)	43 (3.9)	24 (2.2)	123 (11.1)
Parkinson's disease n (%)	1088 (98.3)	8 (0.7)	1 (0.1)	10 (0.9)	1089 (98.4)	7 (0.6)	0 (0)	11 (1.0)	1088 (98.3)	5 (0.5)	1 (0.1)	13 (1.2)

Abbreviations: CRHC, Care Register for Health Care; FPR, Finnish Prescription Register.

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For most of the diseases studied, self-reports showed a higher prevalence than the registers, which is consistent with an earlier study among octogenarians.[11] The only exceptions were cancer and stroke, which showed a higher register prevalence, probably because our data dated back several years and at the time of the survey, the diseases may not have been active or shown any symptoms. It is also possible that cancer and stroke are more often recorded in CRHC since they can lead to hospitalization more often than other diseases included. Some studies have found higher prevalence rates in registers than in self-reports.[9,10] These studies used general practice records[9] and clinical examination[10] as a reference for self-reported information, whereas we used a patient register in which the diagnoses are based on the need for inpatient treatment or specialized care, possibly explaining the differing findings. Furthermore, as multimorbidity is high among the oldest old,[26] it is reasonable to assume that not all diseases are recorded during every care episode. To cover outpatient care, we used FPR data and indeed, the two registers seemed to complement each other well: the prevalence rates were closer to those reported in the survey and the agreement was better when the information from the two registers was combined. Similar findings have been presented concerning the identification of dementia from CRHC and FPR.[27]

In line with earlier studies with the oldest old,[8,10] we found that agreement between self-reports and health registers is fair to moderate for hypertension and heart disease. Likewise, our results are consistent with studies among younger old people, which have found that registers and survey data show high agreement for clearly defined diseases that require specific medication.[2,3,28] In our study, these diseases included Parkinson's disease, diabetes, and hip fracture, which showed an agreement ranging from substantial to almost perfect.

The level of agreement was lower for osteoarthritis and depression, which rarely lead to hospitalization and are not always treated with prescription drugs. Again, this is consistent with earlier studies.[5,9] Reimbursement for antidepressants is limited to severe depression, whereas in the survey we included any depression and depressed mood.

Dementia showed moderate to substantial agreement but was more frequently reported in the survey than in the registers. A previous Finnish study found that the register cases could be verified in clinical examinations, but all the cases diagnosed in clinical examinations were not recorded in registers. Thus, CRHC underestimated the prevalence of dementia.[27] Reimbursement in FPR only covers medication for AD, but among the oldest old cognitive impairment may be due to other conditions as well.[29] It is also possible that cases of early dementia are missed and hence not recorded in a register,[27] or that diagnostic examinations are not conducted because of the patient's overall clinical situation. Importantly, the wording used for dementia in our survey included "dementia, Alzheimer's disease or weakening of memory", and even though the question concerned diseases diagnosed by a doctor, it is possible that respondents also reported their own experiences and perceptions of a weakening of memory.

Our results confirm the importance of allowing the use of proxy respondents in studies of the oldest old.[30] Most of the participants who used a proxy in our study had dementia, and they more often lived in long-term care than those who responded independently. Consistent with earlier findings, we found high agreement between proxy-reported information and health register data on well-defined diseases.[11] Proxies may have underreported diseases not requiring active treatment or not showing prominent symptoms, such as hypertension and osteoarthritis. However, they reported a clearly higher prevalence of dementia than indicated by the registers. In addition to the wording of the question, another possible explanation is the tendency of proxies to overrate the level of disabilities, especially cognitive problems.[31]

The strengths of our study include the linking of survey data with two different nationwide registers covering inpatient and specialized care and all reimbursed drug purchases from pharmacies. The survey included all residents of Tampere aged over 90, regardless of their health or place of living, and it had a high response rate. The 90+ population in Tampere is rather homogenous in terms of ethnic background and represents well the overall 90+ population in Finland in terms of life expectancy and sociodemographic factors.[32] Limitations include the lack of register information on primary outpatient care and the fact that FPR data were only available for part of our survey respondents. Moreover, because the criteria for drug reimbursement are sometimes stricter than the diagnostic criteria, we have missed some cases with at least milder hypertension and heart failure. On the other hand, as only drug purchases eligible for reimbursement were included, we know they represent true clinically confirmed cases.

Conclusion

Self-reported disease data show acceptable agreement with register data among the oldest old people. Yet the use of proxy respondents is necessary in order to gain information on representative population samples, including people with cognitive decline. It is also important to acknowledge the gaps in health registers when validating self-reports against register information. In all, our study implies that also in the oldest old, survey data can be reliably used in population studies where clinical examinations are not feasible.

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Disclosure

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