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**Caring and Mental Health in Europe:
Cross-Sectional and Longitudinal Analysis of Care Situations
from the Survey of Health, Ageing and Retirement in Europe**

Dissertation

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Zusammenfassung

Die Pflege außerhalb eines formellen Kontextes kann verschiedene Arten der Pflege, beispielsweise körperbezogene Pflege, praktische Haushaltshilfe und Hilfe bei der Erledigung von Formalitäten, Orte der Pflege, beispielsweise die Pflege einer Person innerhalb oder außerhalb des eigenen Haushalts, und Beziehungen zwischen Pflegenden und Pflegebedürftigen, beispielsweise Pflege für Ehepartner, Eltern, Schwiegereltern, Kinder, andere Verwandte oder Nicht-Verwandte, umfassen, wobei diese Aspekte für die gesundheitlichen Auswirkungen auf den Pflegenden von Bedeutung sein können. Bisherige Untersuchungen zum Zusammenhang zwischen Pflege und Gesundheit haben jedoch nicht alle diese Aspekte berücksichtigt, was die bislang uneinheitlichen Ergebnisse erklären könnte. Vor diesem Hintergrund bietet diese Arbeit eine detaillierte Beschreibung der Pflege in Europa unter Berücksichtigung verschiedener Pflegearten, Orte und Beziehungen zwischen Pflegeperson und Pflegebedürftigen. Darüber hinaus untersucht die Arbeit diese Zusammenhänge im Querschnitts- und Längsschnitt. Die Analysen stützen sich auf mehrere Erhebungswellen der „Survey of Health, Ageing and Retirement in Europe“-Studie (SHARE).

Insgesamt kümmern sich Frauen häufiger als Männer um die körperbezogene Pflege von Menschen innerhalb oder außerhalb ihres Haushalts. Während die körperbezogene Pflege im eigenen Haushalt in der Regel für (Ehe)partner geleistet wird, gilt die Pflege außerhalb des Haushalts meist den Eltern. Im Gegensatz dazu ist praktische Haushaltshilfe wesentlich verbreiteter und weniger geschlechtsspezifisch, mit Werten von über 20 % für Männer und Frauen. Sowohl für Männer als auch für Frauen ist die körperbezogene Pflege im eigenen Haushalt, insbesondere wenn sie für nahe Verwandte geleistet wird, mit einer erhöhten Prävalenz für depressive Symptome verbunden, die auch langfristig bestehen bleiben können. Durch die systematische Unterscheidung zwischen den wesentlichen Aspekten von Pflegesituationen erweitert diese Arbeit die bestehende Forschung, indem sie Bedingungen herausarbeitet, unter denen Pflege besonders gesundheitsschädlich ist, und diejenigen identifiziert, die einem erhöhten Risiko ausgesetzt sind.

Abstract

Caring outside a formal setting can include various types of care, for example personal care, practical household help or help with paperwork, locations of care, for example care inside or outside the household and relationship types between carers and care recipients, for example a spouse, parent, parent-in-law, child, other relative or non-relative, and these aspects may be important for health-related consequences for the caring person. However, previous research on the association between caring and health has not addressed all these aspects, which may explain the mixed results to date. Against this background, this work provides a detailed description of caring across Europe considering different types of care, locations of care and relationship types between carer and care recipient. In addition, this work investigates their cross-sectional and longitudinal associations with mental health. For the analyses, several waves of the Survey of Health, Ageing and Retirement in Europe (SHARE) are used. Overall, women are more likely than men to engage in personal care for someone living inside or outside their household. While personal care inside the household is mostly provided for spouses, care outside the own household is mostly provided for parents. In contrast, practical household help is much more common and less gender-specific, with values above 20 % for men and women. For both men and women, personal care inside the household, especially when provided to primary relatives, is associated with an increased risk of developing depressive symptoms, which can even persist in the long run.

By systematically differentiating between key aspects of care situations, this work extends existing research by clarifying the conditions under which caring is especially detrimental to health and by identifying those who are at particular risk.

List of Abbreviations

AME	Average Marginal Effects
ABS	Affects Balance Scale
BDI	Back Depression Inventory
BHPS	British Household Panel Survey
CAPI	Computer-Assisted Personal Interviews
CES-D	Center for Epidemiologic Studies Depression (Scale)
CHARLS	Chinese Health and Retirement Survey
CI	Confidence intervals
CSHA	Canadian Study of Health and Ageing
DEAD	German Ageing Survey (“Deutscher Alterssurvey”)
DPS	Dementia Progression Study
DSM	Diagnostic and Statistical Manual of Mental Disorders
EHIS	European Health Interview Survey
ELSA	English Longitudinal Study of Ageing
ELSA-Brasil	Brazilian Longitudinal Study of Adult Health
EPD	Northern Ireland Enhanced Prescribing Database
ESS	European Social Survey
EU (27)	European Union (with 27 member states)
EURO-D	European Depression (Scale)
GAD	Generative anxiety disorders
GHQ	General Health Questionnaire-12
HRS	Health and Retirement Study
(I)ADL	(Instrumental) Activities of Daily Living
ICD	International Classification of Diseases and Related Health Problems
ICM	Informal care model
ISCED	International Standard Classification of Educational Degrees
JSTAR	Japanese Study of Aging and Retirement
KLoSA	Korea Longitudinal Study of Ageing

LASI	Longitudinal Ageing Study in India
LOGG	Norwegian Life-Course, Generation and Gender Study
LTC	Long-term care
MBPC	Memory and Behaviour Problem Checklist
MDD	Major Depressive Disorder
MHAS	Mexican Health and Aging Study
MHS	Mental Health Stigma
NHATS	National Health and Aging Trends Study
NILS	Northern Ireland Longitudinal Study
NKPS	Netherlands Kinship Panel Study
NorLAG	Norwegian Life Course, Ageing and Generation Study
NSFH	National Survey of Families and Households
NSOC	National Study of Caregiving
OECD	Organisation for Economic Co-operation and Development
PADL	Personal care (Help with personal hygiene, feeding, and getting dressed)
PHQ	Patient Health Questionnaire
pp	Percentage points
PSM	Propensity Score Matching
QoL	Quality of Life
REACH	Resources for Enhancing Alzheimer's Carer Health
REGARDS	Reasons for Geographic and Racial Differences in Stroke
sd	Standard deviation
SF	Short Form Health Survey
SHARE	Survey of Health, Ageing and Retirement in Europe
SOEP	German Socio-Economic Panel
TILDA	Irish Longitudinal Study on Ageing
UKHLS	United Kingdom Household Longitudinal Study
UN	United Nations
WHO	World Health Organization

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1 Introduction

1.1 Research background

In the upcoming years and decades, demographic change will affect the global and particularly the European population. Especially the age composition of populations is going to be characterized by major changes. Due to medical progress, higher hygiene standard, better screening and prevention and more knowledge regarding a healthy lifestyle, the life expectancy of people in Europe has increased since the 1950s, mostly caused by a decline in mortality in later life (Gruenberg, 1977; Klenk et al., 2016; Organisation for Economic Co-operation and Development/European Commission, 2024).

As life expectancy continues to rise, societies around the world are seeing a growing number of older individuals. This is possibly accompanied by an increasing demand for care, as aging is often associated with health-related suffering and the need for daily support (GBD 2021 Europe Life Expectancy Collaborators, 2025; Klenk et al., 2016). According to concrete forecasts in several countries, the proportion and absolute number of people with health-related suffering, in particular dementia will increase in the upcoming decades (Belmonte & Nedee, 2024; Doblhammer et al., 2022). Recent forecasts indicate that the number of people requiring long-term care (LTC) in Europe in 2070 will be 21 % higher than in 2020 (Belmonte & Nedee, 2024). Furthermore, a worldwide study estimates that 48 million people will die having experienced serious health-related suffering by 2060, compared with only 26 million people in 2016, with the most rapid increases among people older than 70 years and those with dementia (Sleeman et al., 2019). As a result, new challenges in providing adequate and sustainable care solutions for an aging population are an important public health issue today and in the near future (Ophir & Polos, 2022; Pavolini & Ranci, 2008). Since caring outside a formal setting remains the most important source of care, these carers are an indispensable part of current care provision. Therefore, it is essential to maintain this source in order to meet the demand for care in Europe (European Commission, 2021).

Overall, the spectrum of tasks associated with caring is broad and varies from physical activities that must be performed very frequently, for example feeding and bathing, to more flexible and infrequent tasks, for example assistance with gardening. In most cases, carers are individuals the person in need of care has a social relationship with. A large proportions of care recipients are close family member, such as spouses or partners, parents, parents-in-

law or children (Bertogg & Strauss, 2020; De Klerk et al., 2021; Litwin et al., 2014; Pinquart & Sorensen, 2011; Swinkels et al., 2022). Caring for more distant relatives or non-relatives is less common and their role in caring has rarely been investigated in previous research (Barker, 2002; Burns et al., 2011; De Klerk et al., 2021). Regardless of gender, socioeconomic position and national welfare policies, the spouse provides an important level of care. Throughout Europe around 80 % of persons living together with a care-dependent spouse are engaged in care for this spouse (Bertogg & Strauss, 2020). While carers of a spouse usually live with them and are no longer in paid work, the second large group of carers, namely children, typically do not live together with their care-dependent parents (Pinquart & Sorensen, 2011). Beyond that, many children are caring alongside their paid work or other family commitments like childcare (De Klerk et al., 2021; Pinquart & Sorensen, 2011; Suh, 2016). Thus, next to the tasks associated with caring, the relationship type between carer and the person in need of care and the location where caring takes place, for example inside or outside the carer's household, can differ a lot. Despite changes in traditional gender roles, which have led to more and more men entering care work, the majority of care is still performed by women (Almeida-Meza et al., 2025; Quashie et al., 2022).

Considering these differences, there is a broad range of terminologies and definitions for caring outside a formal setting. For example, terms like “unpaid care”, “informal care” or “family care” are used. In addition to these different terminologies there are differences in how caring is defined. While some studies only look at personal care for a cohabiting spouse (Swinkels et al., 2022), other studies also refer to less intensive tasks such as shopping, housekeeping and help with paperwork provided for friends, neighbours or other non-kin living in another household (Barker, 2002).

Whether caring is positively or negatively associated with the carers health and well-being has been discussed frequently. On the one hand, findings from previous research show that caring is associated with positive feelings of reward, growth, satisfaction or an increased closeness to the care recipient (Broese van Groenou et al., 2013; Mackenzie & Greenwood, 2012; Tarlow et al., 2004). On the other hand, caring can be mentally, physically, emotionally, socially and financially demanding and many carers feel stressed or rather depressed more often than non-carers (Pinquart & Sorensen, 2003; Schulz et al., 1997; Verbakel et al., 2017). Previous research for example revealed that people providing high-intensity care (Verbakel et al., 2017) and those who face limited opportunities for leisure activities and time with family and friends are at higher risk of suffering from depressive symptoms than non-carers (Stratmann et al., 2021).

1.2 Aim of this work

To get more knowledge about the depth of caring outside a formal setting, the first aim of this work is to provide highly differentiated information on the prevalence of caring in Europe regarding different care situations. Here, the focus is placed on whether care is for someone living inside or outside the own household, on different types of care, such as personal care, practical household help and help with paperwork, and different relationship types between carer and care recipient, for example if they are spouses, parents, parents-in-law, children, other relatives or non-relatives. Since a good mental health of the carers is an important factor for high-quality and dignified care (Zygouri et al., 2021) and the results to date are inconsistent, the second aim of this work involves an in-depth examination of the associations between mental health and location, type and carer-care recipient relationship type and the identification of care situations that are particularly challenging. In addition to cross-sectional analyses, longitudinal associations between caring and mental health are presented, as these have often been overlooked in previous research. Since earlier studies point to gender differences, all analysis are calculated separately for men and women.

The presented work was done as part of a European consortium project called “Inequalities in informal caring over the adult life course in Europe” (EUROCARE). The main objective of the project was to investigate the association between caring and paid work, social participation and mental and physical health by taken into account gender, socioeconomic and ethnic differences in these associations across European countries and from a life course perspective. The consortium consists of researchers from the United Kingdom (Research Department of Epidemiology & Public Health, University College London and Institute of Population Health, St George’s University of London), Spain (Centre for Demographic Studies, Autonomous University of Barcelona), Norway (Norwegian Institute of Public Health) and Germany (Department of Social Studies, TU Dortmund University and Institute of Medical Sociology, University Hospital Düsseldorf and Heinrich-Heine University of Dusseldorf) with different research priorities (EUROCARE-Project, 2025). The overarching research focus in Düsseldorf was to take a closer look at different care situations in later life and its cross-sectional and longitudinal association with mental health.

In the following, I will provide an overview of two key concepts of interest in this work: Caring (Chapter 2) and mental health (Chapter 3). I will then provide an overview of existing knowledge on the association between caring and mental health, highlight areas where further research is needed and present my research questions (Chapter 4). Chapter 5 will explain

the methods in more detail, considering the data source, how independent, dependent and additional variables are measured and the analytical strategy. Chapter 6 lists the three papers that form the basis of my doctoral thesis alongside a brief summary of each paper. Finally, the last chapter summarises the key findings of my work along with its strengths and limitations and provides concrete suggestions for what needs to be done in the future.

2 Caring

The following part will provide an overview of different terms and definitions of caring, give insights into current prevalence rates for caring and examine the potential and necessity of care in the future.

2.1 Definition

The provision of care for the growing number of older people is an important public health issue today and in the near future. In this context, a general distinction between care inside or outside a formal setting is made.

Formal LTC generally refers to paid services provided to a person in need of care by a trained person in a formal setting such as a health care facility or nursing home (Bieber et al., 2018; Li & Song, 2019; Triantafyllou et al., 2010). Formal care is provided by trained, licensed and qualified professionals with work contracts specifying their care responsibilities according to their specific professions and their professional experience. However, the depth of training can vary widely. Typical formal carers are professional such as nurses, occupational therapists, home or social workers, physical therapists or general practitioners and other physicians (Li & Song, 2019; Triantafyllou et al., 2010). Other key aspects are that formal carers are paid and entitled to work arrangements with regulated working hours and regulated possibilities to turn off from the care situation (Triantafyllou et al., 2010).

While it is quite clear what is meant by formal care, there is a lack of a standardized definition and there are many ways to term and define caring outside a formal setting. In many cases, terms like “informal care”, “family care” or “unpaid care” are used. Also the term “support” often has a similar meaning. In line with this, there are many aspects that constitute a care situation, including for example the location of care, the type of care and the relationship type between carer and care recipient.

For example, a study from the Netherlands using data from the European Social Survey (ESS) defined persons as “informal carers” if they indicated that they spend any time looking after or giving help to family members, friends, neighbours or others because of long-term physical or mental ill health, disability or problems related to old age (Verbakel, 2018). A Spanish study using data from the Survey on Disabilities, Personal Autonomy and Dependency Situation defines “informal care” as “the care provided to an individual with limited autonomy to conduct one or more daily activities by one or more members of the social

environment of the care recipient” (Oliva-Moreno et al., 2015). A postal survey from Sweden defined seven activities as “informal care”. These included being prepared if something happened, having regular contact to prevent problems, helping in contact with the hospital, helping with instrumental activities of daily living (IADL), personal activities of daily living, medical care and helping to improve functions (Ekwall et al., 2004). In another study using data from the Reasons for Geographic and Racial Differences in Stroke Study (REGARDS) the term “family caregiving” was used and participants were asked “Are you currently providing care on an on-going basis to a family member with a chronic illness or disability? This would include any kind of help such as watching your family member, dressing or bathing this person, arranging care, or providing transportation” (Roth et al., 2009). According to Lacey et al. (2024), using data from the United Kingdom Household Longitudinal Study (UKHLS), an “unpaid carer” is a person providing some regular service or help for any sick, disabled or elderly person who either lives with them or not (Lacey et al., 2024). Lin (2008) uses data from the Health and Retirement Study (HRS) and defines “support” as providing assistance with time and money. Time transfers include activities of daily living (ADL), for example help with walking across the room, dressing, bathing, eating, getting in and out of bed and using the toilet, and IADL, for example help preparing meals, shopping for groceries, making phone calls, taking medicine and money management, while money transfers are defined as financial support of \$500 or more in the past two years (Lin, 2008). Kalmijn (2007) uses the Netherlands Kinship Panel Study (NKPS) and defined “support” as giving advice to parents, doing household work such as cooking, cleaning, groceries and laundry, giving practical help such as running errands, transportation, lending things and repairs, giving emotional support, attending the birthday of the parent, face-to-face contact and phone contact (Kalmijn, 2007).

Next to these studies, other research also takes the location where caring takes place into consideration. One larger strand of research exclusively focuses on care that takes place inside the household of the carer. For example, a study with data from the British Household Panel Survey (BHPS) exclusively focuses on co-resident caring by asking “Is there anyone living with you who is sick, handicapped or elderly whom you look after or give special help to?” (Mentzakis et al., 2009). Also a study using the term “informal care” analysing data from the Survey of Health, Ageing and Retirement in Europe (SHARE, “Is there someone living in this household whom you have helped regularly during the last twelve months with personal care, such as washing, getting out of bed, or dressing?”) and the English Longitudinal Study of Ageing (ELSA, “Did you look after someone in the past week (including your

partner or other person in the household? By ‘look after’ we mean the active provision of care”) only concentrates on care that takes place inside the household of the carer (Quashie et al., 2022). However, other studies consider care both inside and outside the household of the carer. For example, in a study by Marks et al. (2002) with data from the National Survey of Families and Household (NSFH) two questions, one on caring inside the household and one on caring outside the household, are included to identify carers.

Most studies agree that carers are individuals with whom the person in need of care has a social relationship with, such as spouses, parents, parents-in-law, children, other relatives, friends or other non-kin (De Klerk et al., 2021; Haberkern et al., 2013; Pinquart & Sorensen, 2011; Swinkels et al., 2022). In particular, spouses and partners are important sources of caring in later life. Regardless of gender, socioeconomic position and national welfare policies, a high level of care throughout Europe is provided by a spouse or partner (Bertogg & Strauss, 2020). Secondly, primary relatives like children are an important pillar of care (De Klerk et al., 2021).

In addition to researchers, also organizations deal with the definition of care outside a formal setting. In a policy brief, the World Health Organisation (WHO) uses the term “informal caregiving” and states “Informal caregivers generally provide care to those with whom they have an existing relationship, such as a family member, friend or neighbour. They provide care mostly to help with personal tasks, including ADL (i.e. bathing, toileting, dressing, mobility, eating and continence) and IADL (i.e. housekeeping, laundry, managing money, managing medication, preparing meals, shopping, taking transportation, using communication devices)” (World Health Organization, 2024b). The European Commission uses the term “informal care” which includes “any care or help provided to older people (family or otherwise), care provided to working age adults, young people and children with disability as well as people living with mental health problems” (European Union, 2018). An expert group of the United Nations (UN) says that “unpaid care entails the provision of both direct – or person-to-person – care (e.g. helping with bathing) and indirect care (e.g. preparing food or cleaning)” and highlights that “there is some confusion around the terms ‘informal’ and ‘unpaid’, which are sometimes used interchangeably” (United Nations, 2017). The annual publication “Health at a Glance” of the Organisation for Economic Co-operation and Development (OECD) says that “informal carers (typically family members or friends) play an important role in supporting older people to manage their chronic conditions. These carers often assist them with medications (e.g. helping with medication schedules, refills and administra-

tion), care co-ordination (e.g. helping with managing multiple healthcare providers and treatments) and lifestyle support (e.g. helping with maintaining healthy diets and encouraging physical activity)” (Organisation for Economic Co-operation and Development/European Commission, 2024). EUROCARES, the European Association of carers organizations, defines a carer as “a person who provides – usually – unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework”. They consider personal care, housekeeping, transportation, financial management and emotional support as common tasks of a carer (Eurocarers, 2024).

All these examples do not intend to be exhaustive and are merely intended to highlight the lack of a standardized term and standardized definition of caring outside a formal setting. Therefore, when comparing studies, it is always important to check exactly what is meant by caring.

One disadvantage of the term “informal care” is that it is often associated with negative connotations, especially in the English-speaking world. Because the term “informal” implies something casual and unofficial, it certainly does not fit the hard work involved in taking care of a loved one (Applebaum, 2022). As caring is not only provided by family members, also the term “family care” does not always seem appropriate. Even though the majority of studies refer to care for a family member, sometimes care is provided between non-relatives such as friends or neighbours (De Klerk et al., 2021; Marks et al., 2002). Because caring outside a formal context can involve a form of financial support, also the term “unpaid care” may not always be correct. For example, in Germany there is financial support (“Pflegegeld”) paid to people in need of care living outside a formal setting, which may often be transferred to the carers (Federal Ministry of Health, 2025). For all these reasons, it was decided during the development of this doctoral thesis and in collaboration with other researchers from the EUROCARE project, that the terms “caring” and “carer” seem to be most appropriate. In the following, caring always refers to caring outside a formal setting, unless otherwise specified.

The common element in all definitions is that caring involves activities outside a formal setting for a person with limitations in performing daily tasks because of a physical, cognitive or emotional illness or disability. However, there is a wide range of activities associated with caring ranging from lower level activities such as giving advices or phone contact (Kalmijn, 2007) to much more intensive activities such as personal care, which includes tasks such as bathing and feeding (Quashie et al., 2022). Mostly, carers are individuals the

person in need of care has a social relationship with, usually people from the family such as spouses, parents and children, but sometimes also people who are non-kin.

2.2 Prevalence of caring

In line with these differences in the definition of caring it is not easy to determine the exact number of carers and the proportion of care carried out outside a formal setting. However, policy makers and researchers agree that care outside a formal setting plays a major role in Europe today.

According to estimates of official statistics about 80 % of LTC in Europe is organized and provided by carers outside a formal setting. Thus, far more people rely on care outside a formal setting than on formal care provided by trained care staff. However, it remains difficult to quantify the extent of this care, as in many countries there are no direct financial transfers identifying care outside a formal setting or since this form of caring is not always remunerated on a market (European Commission, 2021; Hoffmann & Rodrigues, 2010).

For example, in Germany it is possible to get closer to the number of people in need of care since the introduction of the “Pflegeversicherung” at the beginning of 1995, a compulsory insurance financed on a pay-as-you-go basis. The aim of the introduction was to improve the situation of people in need of care and their families and to expand the provision of care outside a formal setting instead of formal care. To receive transfers from this insurance, an assessment of the need for LTC is required beforehand. For this, trained staff evaluates the degree of impairment of the person in need of care based on various aspects, such as mobility, self-sufficiency, mental and communication skills. In Germany, an increased level of impairment is associated with a higher care degree (“Pflegegrad”). There are five care degrees and higher degrees are associated with higher financial transfers. This assessment enables us to capture the number of people in need of care and their degree of dependency (Federal Ministry of Health, 2025). In 2023, almost 5.7 million people in Germany were categorized as needing care with 54 % of them aged 80 years or older. Almost 4.9 million people in Germany or 85.9 % of those in need of care are cared for inside their own household. Of these, more than three million people are cared for exclusively by carers outside a formal setting and without any formal support, such as from an outpatient nursing service. In Germany, only 800.000 people or 14 % of all people diagnosed as needing care live in an inpatient care facility (own calculations based on Federal Statistical Office of Germany,

2024). Using Germany as an example, these numbers highlight the importance of carers outside a formal setting. Because these statistics from Germany only include those officially categorised as needing care following a formal application process, the exact number of people in need of care may be even higher.

Furthermore, the decision to provide care is not a random decision. One of the most important determinants of care provision is the presence of a person in need of care, which is closely linked to a second aspect, the absence of other alternatives mostly including a lack of other potential carers or formal alternatives. Next, the willingness to provide care, including personal characteristics of the carer like personality traits and the socio-economic situation, are associated with the individual decision to care or to not. Furthermore, the ability to provide care which refers to the potential carers' own health status or a geographical closeness. Not all, in particular older people have sufficient resources to become a carer, usually because of own impairments (Schmidt & Westphal, 2015). Based on various literature Broese van Groenou and De Boer in 2016 develop a behavioural model, the "Informal care model" (ICM), to describe the multiple and diverse arguments of an individual to take up caring when confronted with someone in need of care. The model states that the decision to provide care is based on the individual characteristics, general attitudes and beliefs of the carer and on the context, for example national LTC policies and support from others (Broese van Groenou & De Boer, 2016; Dujardin et al., 2011).

Most studies to date suggest that women provide more care work than men across Europe (Dahlberg et al., 2007; Doebler et al., 2016; Dujardin et al., 2011; Hansen et al., 2013; McMunn et al., 2009; Tur-Sinai et al., 2020). Much of this care is provided by daughters (in-law), spouses or mothers (Wetzstein et al., 2015). For example, a German study shows that men are less likely to provide care for relatives and friends at the age of sixty than women do. The probability at this age is 20 % for women and 13 % for men (Klaus & Vogel, 2019). A European Study found that daughters provided more support to their parents than sons across all countries. Sporadic support to a parent was given by 26 % of all daughters and 21 % of all sons. Intensive support, defined as almost daily help with household tasks and/or personal care, was provided by 9 % of the daughters and 4 % of sons (Schmid et al., 2012). Findings from a population survey in Norway indicate that women were more likely to give personal care, while men were overrepresented in practical help (Skinner & Sogstad, 2022). Gender differences in the provision of care for men and women vary between countries and are linked to the availability of public care services for older people in need of care. It has

been found that in Southern and Eastern European countries, the relatively low level of public care services was associated with a greater care gap between men and women. In contrast, well-developed public care systems like in the Nordic countries have prevented such a gap from emerging (Da Roit et al., 2015).

Along with the availability of public care services, the total prevalence of caring differs across Europe. The highest share of caring outside the household was found in Belgium (23.1 %), the Netherlands (20.1 %), and Denmark (18.1 %), while the share of caring inside the household was highest in Southern European countries such as Spain and Italy (Kaschowitz & Brandt, 2017). A study combining three European surveys found that the prevalence of carers was 13 % in Portugal and Spain, almost 18 % in Central European countries such as Austria and Germany and in countries with Mediterranean social systems such as Italy and Greece and more than 22 % in Luxembourg, Belgium and Denmark (Tur-Sinai et al., 2020). Also another study with a less specific definition of caring (positive answer to the question whether one spends any time looking after or giving help to family members, friends, neighbors or other because of long-term psychical or mental ill health of disability or problems related to old age) found marked differences between European countries: Caring was more common in Nordic countries than in Central, Eastern, and Southern Europe and the proportion of carers ranged from 43.6 % in Finland to 8.2 % in Hungary. When intensity is considered, a completely different picture emerges. Countries in Central, Eastern, and Southern Europe, in particular Portugal, had a higher proportion of intensive carers, defined as providing at least 11 hours of care per week, than the Nordic countries (Verbakel et al., 2017).

Looking at different birth cohorts (1900-1929, 1930-1934, 1940-1944, 1945-1949, 1950-1954), a study found a decline in the prevalence of care outside the household, defined as personal care or practical household help given to a family member living outside their household, among men from later born cohorts and stable cohort trends for women in Europe. In contrast, the prevalence of care inside the household, defined as helping regularly with personal care in the same household, has increased for all cohorts born later (Rodrigues et al., 2023).

Furthermore, age of the carer is a key factor that should be considered when assessing the prevalence of caring in Europe. Middle-aged people up to around the end of their fifties or mid-sixties are more likely to provide care, mainly because they are more likely than other age groups to have parents in need of care (Dahlberg et al., 2007; De Klerk et al., 2021; McMunn et al., 2009; Tur-Sinai et al., 2020). Next to care for a parent, in course of life

people are more likely to have a spouse or partner who needs help (De Klerk et al., 2021; Mentzakis et al., 2009). As couples mostly age together, spousal care increases with age and in many couples the less impaired partner provides care for the more impaired one (Barbosa et al., 2021; Bertogg & Strauss, 2020). According to a German study, women begin “caring for and supporting others” at the age of 57, which is earlier than men, who begin on average at the age of 61 (Klaus & Vogel, 2019).

Furthermore, socioeconomic differences in the engagement in care are found. For example a study from Germany found that intensive care for more than two hours a day is more common in low and middle education groups (Wetzstein et al., 2015). Further research suggests that individuals with lower incomes and lower levels of education are more likely to provide care inside the household (Mentzakis et al., 2009; Quashie et al., 2022). In contrast, a study with a broader definition of care found lower prevalences for caring among the poorly educated compared to those with higher levels of education (Tur-Sinai et al., 2020).

All these figures show that there is no exact number of carers outside a formal setting in Europe, as each study defines it differently. Thus, at this point it is of great importance to look closely at that is meant by caring when studies are compared or statements are made.

2.3 Caring in the future

Because demographic and societal change will affect the population in Europe, the upcoming part gives a brief insight into current developments regarding ageing of societies, life expectancy, changes in family structures and health and care dependency in later life and role of these developments for caring outside a formal setting.

All statistics are provided by Eurostat, the statistical office of the European Union (EU) based in Luxembourg. Eurostat publishes official, harmonized statistics that provide a comparable, reliable and objective picture of the European society and economy. Eurostat does not collect any data itself, but uses data from the statistical offices of the Member States. The role of Eurostat is to consolidate the data and ensure that data is compiled according to the same methodology. More details on the data collection in Eurostat can be found elsewhere (Eurostat, 2024a). In the following, the average values for the 27 member states of the EU are shown (EU 27) (European Union, 2025).

2.3.1 Need of care in the future

Ageing of societies

One aspect that underscores the European population is ageing and the increasing number of people over time (**Figure 1**). In recent years, the average population aged 65 years and older in the EU 27 has increased from 17.6 % in 2010 to more than 21.3 % in 2023. In addition, the proportion of people aged 80 years or older has increased from under 5 % in 2010 to 6 % in 2023 (Eurostat, 2024e).

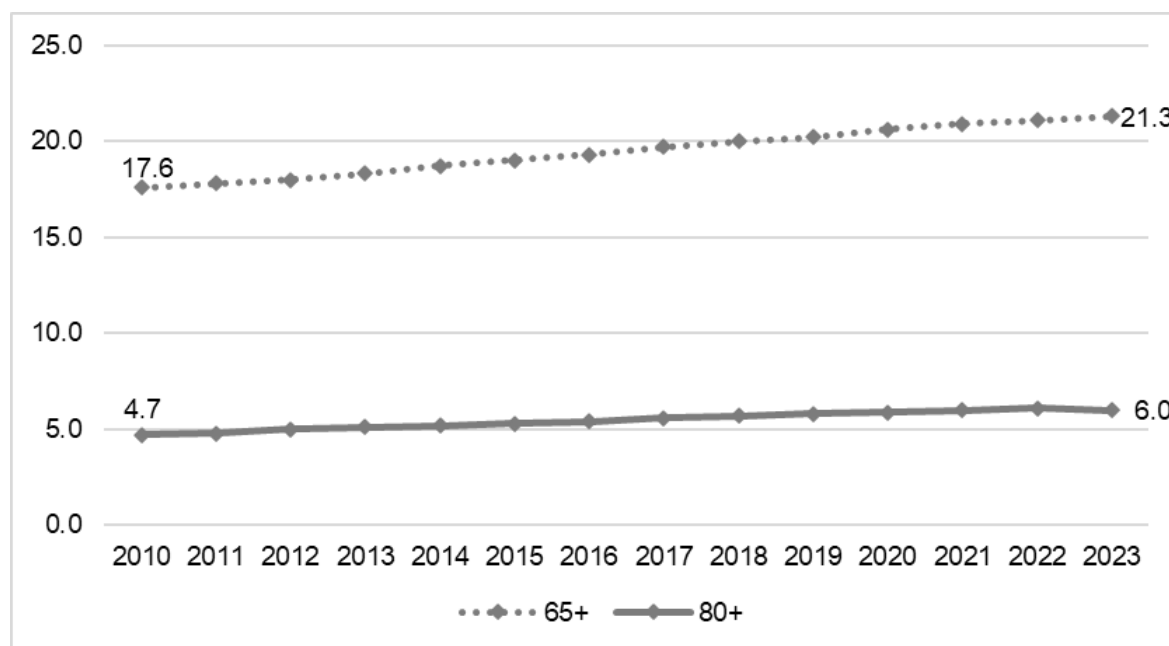


Figure 1: Population 65+ and 80+ in % in EU 27, 2010-2023.

Source: Own representation based on Eurostat (Eurostat, 2024e).

Alongside these changes in the age composition, the median age is rising. From 2010 to 2023, the average age in Europe increased from 41.3 years to 44.5 years. However, the median age in 2023 varies greatly across countries, ranging from 38.4 years in Cyprus to 48.4 years in Italy (Eurostat, 2024e).

Population projections are “what-if scenarios” that show the hypothetical development of population sizes and structures in the future. They are based on assumptions for fertility, mortality and migration based on observed demographic trends the assumption of partial convergence of these trends in a certain country. In addition to this baseline scenario shown below, Eurostat calculates five more alternative scenarios (not shown) that provide information on how different assumptions (lower fertility, lower mortality, zero net migration, lower non-EU immigration and higher non-EU immigration) affect the projected population

(Eurostat, 2024f). More information on different demographic scenarios in the EU can be found elsewhere (Lutz et al., 2019).

According to the baseline scenario, the trend of more people getting older will continue in the future, with people aged 80 years of older representing the fastest-growing age group (**Figure 2**). In 2050, the proportion of people aged 80 and older is expected to be 15.3 %, more than double the number for 2023. The group of people aged between 65 and 79 years is expected to increase from 15.2 % in 2023 to 17.2 % in 2050. In contrast to this increase in older age groups, a decline is predicted in the population under the age of 15 and in particular in the potentially economically active population aged between 15 and below 65 years (Eurostat, 2024d).

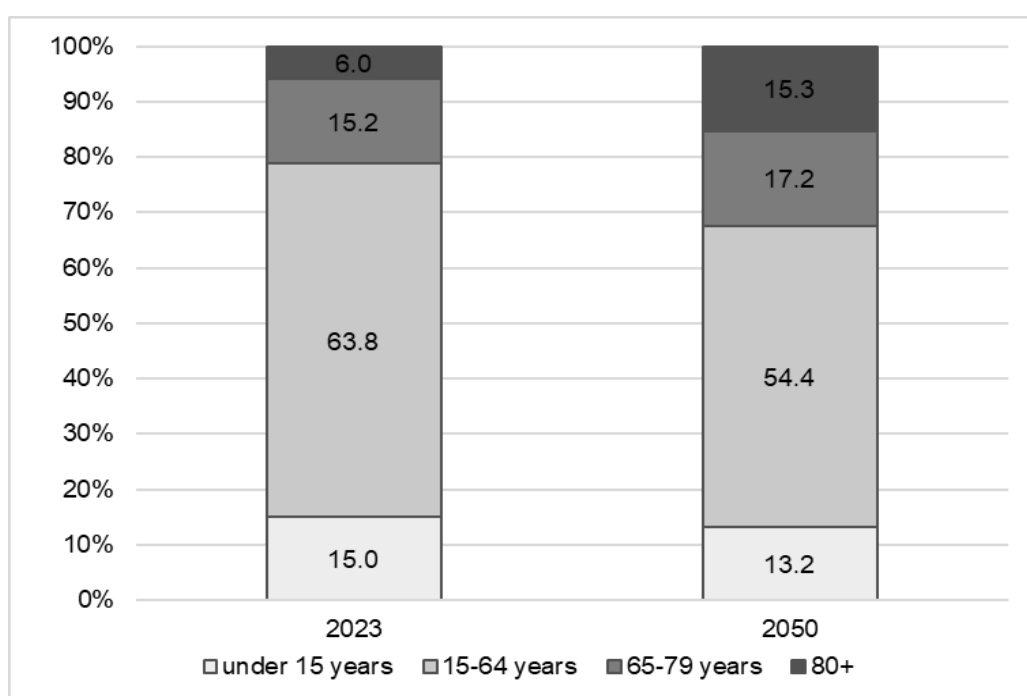


Figure 2: Age composition in % in EU 27, 2023 and 2050.

Source: Own representation based on Eurostat (Eurostat, 2024d).

Life expectancy

Life expectancy at birth indicates the average years of life of a new-born, if mortality pattern remain the same throughout life. The total life expectancy in the EU 27 in 2023 was 81.5 years, almost two years higher than in 2010. Looking at men and women separately, the average life expectancy is 78.9 years for boys and 84.2 years for girls born in 2023 (**Figure 3**). Thus, women live on average more than five years longer than their male counterparts.

Overall, the gender gap in life expectancy in Europe is decreasing over time because in recent years the life expectancy of men has increased faster than the life expectancy of women (Eurostat, 2024c).

These increases in life expectancy are attributed to improved health care prevention and treatment (GBD 2021 Europe Life Expectancy Collaborators, 2025). Furthermore, the successful control of major infectious diseases such as cholera and tuberculosis contributed to the significant increase in life expectancy (Raleigh, 2019).

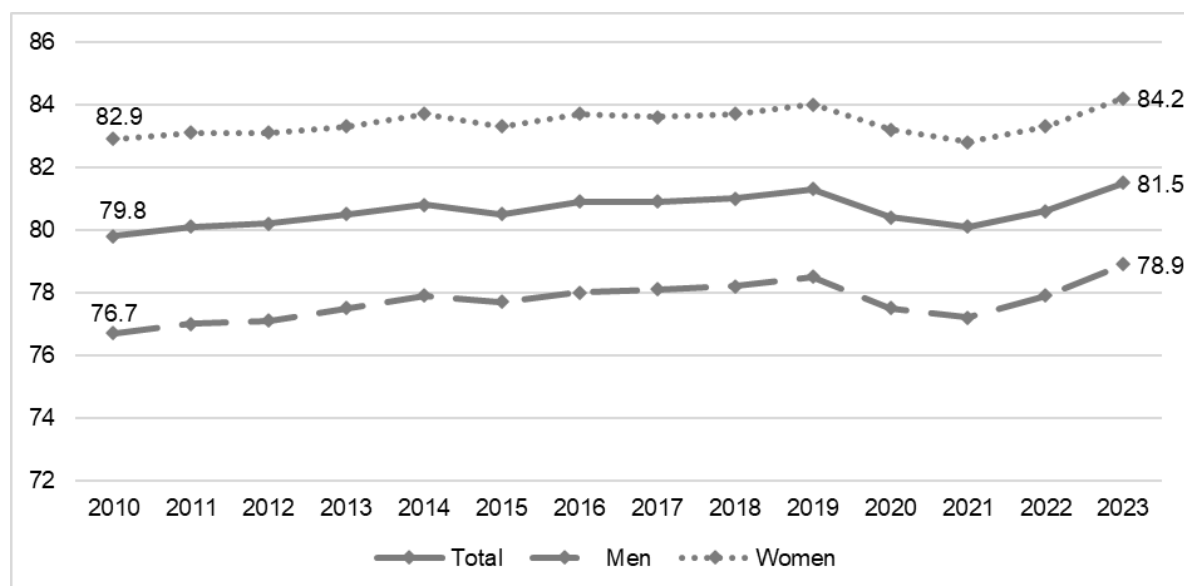


Figure 3: Life expectancy at birth in years in EU 27, 2010-2023.

Source: Own representation based on Eurostat (Eurostat, 2024c).

Diseases

Today, the disease incidence is strongly characterized by non-transmissible, mostly chronic diseases. These include in particular cardiovascular diseases such as stroke, metabolic diseases such as diabetes mellitus, diseases of the musculoskeletal system such as osteoporosis, cancer and dementia (Raleigh, 2019; Santos et al., 2024). One leading cause of dependence and disability in old age is dementia (GBD 2019 Diseases and Injuries Collaborators, 2020). People with dementia are increasingly dependent on the care and support of others, especially in the advanced stage of the disease (Doblhammer et al., 2022). The incidence of dementia increases with age and dementia is most common in people aged 75 years and older (Doblhammer et al., 2022; Wolters et al., 2020). A study including various population based cohort studies from Europe and the United States found an incidence of dementia from 1.6 to 8.6 per 1.000 person-years in the age group “65 to 69 years” to between 42.2 and 97.0 per 1.000 in the age group “85 to 89 years” (Wolters et al., 2020). From 2014 to 2017 dementia

was already the most prevalent disease at time of death among women aged 70 years and older and in fifth place among men in Germany (Doblhammer et al., 2022). In particular in low and medium income countries, the number of people with dementia is expected to increase by 2050 (Alzheimer's Disease International, 2013).

In the late 1970s and early 1980s three alternative scenarios were proposed for the future evolution of health of the aging population (Nielsen et al., 2021). First, Ernest Gruenberg argues that mortality rates are decreasing over time because of better medical care induced by the introduction of sulphonamide and penicillin. People who would have died earlier are not kept alive, but in a less healthy state, which is called “expansion of morbidity” (Gruenberg, 1977). Based on this assumption, the proportion of older people in need of care will increase in future generations. The second scenario by James Fries predicts the opposite consequence, namely a “compression of morbidity”. Within this theoretical framework it is argued that improved health care will postpone the onset of morbidity to an older age. Thus, the time in need of care will be reduced to a shorter period before the end of life (Fries, 1984). A third theory developed by Kenneth Manton is the “concept of dynamic equilibrium”. This theory assumes that the proportion of older people with diseases will increase, while the severity of impairments is decreasing. For example, the high level of medical progress in diabetes mellitus and hypertension enables many patients to live normal lives without major limitations (Manton, 1982).

According to calculations, an expansion of morbidity and increase of people requiring care is most likely. For example, a worldwide study estimates that 48 million people will die experiencing serious health-related suffering by 2060, compared with only 26 million people in 2016. The most rapid increases are expected among people older than 70 years, and those with dementia (Sleeman et al., 2019). Similarly, according to population forecasts by the Federal Statistical Office in Germany, the number of people in need of care in Germany will rise from 5.7 million in 2023 to 6.8 million in 2055 (Federal Statistical Office of Germany, 2023, 2024).

2.3.2 Potential of care in the future

Not only increasing life expectancy and changes in the age composition are affecting our society, but also family and household structures are affected by changes. Because in Europe a large proportion of care is provided by children and spouses, issues like increasing childlessness and increasing geographical distance between children and their parents may affect

caring for parents (in-law) and the decline in lifelong marriages may influence caring for a spouse.

Availability of children

Nowadays, people in Europe generally have fewer children and the proportion of people remaining childless is increasing. While the fertility rate, defined as the average number of children a woman gives birth to in her lifetime during her lifetime, in all European countries was over 2 in 1960, the average in 2022 is only 1.48 (Eurostat, 2024b). A study examining childlessness in Europe over time found a lower rate of childlessness among women born in the years 1945 to 1949 than among those born in the years 1965 to 1969 (Miettinen et al., 2015).

Consequently, these trends of fewer children can be interpreted as fewer potential carers for aging parents. Since women born between 1965 and 1969 are usually not yet at an age where they require care, the consequences of these trends towards fewer children and increasing childlessness will become increasingly apparent in the future (Kinsella & Philipps, 2005; Miettinen et al., 2015). Furthermore, research already revealed that childless older people have functioning social networks, but nevertheless, a care gap is more common among childless older people than among those with children, in particular when they rely on intensive care (Deindl & Brandt, 2017).

Geographical distance

At the same time, there are also changes for people with children and larger geographical distances between children and their parents are more common than in previous generations. For example, a study from the Netherlands found that the average geographical distance between a couple's household and the husband's parents was 25.7 kilometres and the wife's parents 27.5 kilometres (Blaauboer et al., 2010). A European study found that 70 % of adult children live up to 25 kilometres away from their parents. However, they also found large differences between countries and larger geographical distances between adult children and their parents in Northern European countries. In Sweden and Denmark, only about half of children live within 25 kilometres around their parents (Isengard, 2013). These high number of children and parents living far apart may pose a further barrier for caring in the future, especially for tasks such as personal care or practical household that require physical contact and cannot be performed by remote help or mobile solutions (Stuifbergen et al., 2008).

Divorce and separation

Another aspect that can affect caring in later life, especially between spouses, is the declining number of lifelong marriages and the increasing number of “grey divorces”, meaning marital dissolutions after the age of 50, or “silver splits”, meaning all dissolutions after the age of 50 (Alderotti et al., 2022; Brown & Lin, 2022). A study from the United States found that the proportion of males who are married over the age of 50 decreased from 78 % in 1990 to 67.3 % in 2015. Among women of the same age, the proportion of married women stagnated at about 53 % in 1990 and in 2015. Accordingly, the proportion of divorced people over the age of 50 in 2015 is significantly higher than in 1990 (Brown & Wright, 2017). A study from France revealed that in 1996, only 17 % of all divorces involved men aged over 50 and 11 % women aged over 50. In 2016 the proportion had risen to 38 % and 26 % respectively (Solaz, 2021). A study using SHARE data also points to a increasing number of separations, particularly among people without children or grandchildren (Alderotti et al., 2022).

However, not only a separation or divorce in later life, but also the death of a spouse or partner prompts people to ask themselves whether and how they should enter a new relationship. As spouses and partners have historically been an important pillar of care, this decline in the number of older adults in marriage or partnership, whether due to separation or widowhood, raises important questions about caring in the future (Brown & Wright, 2017).

After a divorce, single life, unmarried partnerships and cohabitation are becoming increasingly more common (Brown & Wright, 2017; Silverstein & Giarrusso, 2010). A study from the United States has shown that couples in non-married cohabitation were less likely to receive care than married couples. This was attributed to the fact that couples in cohabitation often have fewer obligations regarding care responsibilities compared to the institution of marriage (Brown & Kawamura, 2010; Noel-Miller, 2011). In line with these findings from the United States, a qualitative study from the United Kingdom found similar arguments among widows. Older women, who lost their husband, often do not want to remarry due to intrinsic factors, as they are not willing to take over the care of a spouse (again). As a result, widows are more likely to live in cohabitation or alone because they do not feel the need to take over the caring responsibilities associated with marriage (again). In contrast, widowers are more often influenced by extrinsic factors such as age and poor health shape when deciding on a new partnership (Davidson, 2001).

Furthermore, a divorce affects not only caring between spouses and partners, but also caring between children and their parents. In this regard, previous research reveals a lack of support for divorced fathers. This is explained by the fact that contact between children and fathers

is less frequent because children more often live with their mother after a divorce (Kalmijn, 2007; Lin, 2008). A study from the Netherlands indicates that in divorces before 1970, half of the children and the father even had no contact at all. In later cohorts, the proportions of those who had no contact became smaller (Van Spijker et al., 2022). Now, however, a generation of divorced parents is getting older first, in which a strong involvement by fathers after a divorce was still untypical. This, in turn, may shape the children's decision to take over care for an absent father. Even if joint physical custody of children is becoming more and more important in Europe (Hakovirta et al., 2023), this pattern may not change until the more distant future. Furthermore, a study from Germany revealed that even after a "grey divorce" and when children already have moved out, the solidarity of children more often tilts in favour of the mother, while fathers are at higher risk of social isolation (Buyukkececi & Leopold, 2024). It can be interpreted that for fathers, the failure of a marriage means not only the loss of a spouse, but also the loss of the kinkeeping role of the wife (Kalmijn, 2007). In summary, based on these results, there may be an increasing number of childless people who may have fewer potential carers available. At the same time, those with children who live more distant may not be able to receive (intensive) care from their children. Due to more divorces in later life and fewer commitments in relationships after divorce or widowhood, caring between spouses and partner may also change.

3 Mental health

In addition to caring, mental health is the second concept of interest of this doctoral thesis. This chapter defines mental health, presents various instruments for assessing mental health and provides a short overview of previous findings on mental health in Europe.

3.1 Definition

In the Constitution of the WHO, which entered into force in 1948, health is defined “as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”. A high health standard is one if the fundamental rights of all humans regardless of religion, race and social or economic position (World Health Organization, 1948). The definition of the WHO illustrates that health encompasses not only one but several dimensions, namely physical, mental and social aspects.

This means, mental health is a fundamental human right and a key component of health, underpinning the individual and collective abilities to make decisions and build relationships. Mental health is a complex concept that is experienced differently by each person, with varying degrees of difficulties and potentially very different social and clinical outcomes. Furthermore, mental health is not a constant state, but rather changes throughout life and fluctuates in response to changing situations and stress factors. Mental health in later life is not only determined by physical, social and environmental conditions, but also by cumulative effects of previous life events and specific age-related stress factors (World Health Organization, 2022).

One strand of research suggests that mental health problems have increased worldwide in recent years and decades, even independently of the outbreak of the COVID-19 pandemic (Andersen et al., 2011; Backhaus et al., 2023; Fu et al., 2013; Ten Have et al., 2023). Some studies, however, conclude that it is not the prevalence of mental health problems itself that has increased, but rather the progress that has been made in diagnosing mental illnesses (Fischer, 2012; Suris et al., 2016). In addition, research findings suggest that the opportunity to talk about this important part of health and help-seeking for mental health problems are important mediating factors (Schomerus & Angermeyer, 2008; Yonemoto & Kawashima, 2023).

At the same time, research shows that these developments are not linear and not observed across all mental diseases. For example, in the case of depression, slightly increasing help-seeking has been observed over time (Angermeyer et al., 2023) and a decrease of the so-

called mental health stigma (MHS), which was identified as a significant barrier to seeking mental health treatment (Clement et al., 2015; Pescosolido et al., 2021; Schomerus et al., 2022; Sickel et al., 2014). In the case of other mental illnesses, such as schizophrenia, an increase in stigmatisation has been observed on recent years (Schomerus et al., 2022). During the COVID-19 pandemic, delays and a decline in help-seeking behaviour have been observed again (Yonemoto & Kawashima, 2023).

One of the predominant mental disorders, especially in older adults, is depression (Blazer, 2003; World Health Organization, 2017). The term “depression” comes from the Latin words “depressare” and “deprimere”, which can be translated as “press down”. Essentially, the term is associated with a feeling of being “pressed down”, which is often described as “sad”, “blue” or “down” (Kanter et al., 2008). The term “depression” is not a precise and technical term but has a variety of meanings and associated symptoms (Hale, 2007; Kanter et al., 2008). With this, it is really important to distinguish between a “normal” feeling of low mood and depression, which refers to a chronic experience of feeling sad or down, with symptoms occurring most of the day and almost every day (Kanter et al., 2008; Mayberg et al., 1999).

In most cases a depression is triggered by stressful life events and many patients initially experience physical symptoms, so-called somatization (Hale, 2007; Kendler et al., 1998). Important somatic symptoms of a depression were found to be the loss of emotional reactivity to normally pleasurable surroundings, activities and events, early waking up, psychomotor retardation or agitation, marked loss of appetite and weight loss (Hale, 2007). Other symptoms include persistently depressed mood, a loss of interest and pleasure (anhedonia), reduced energy and activity, poor concentration and attention, low self-esteem and self-confidence, feelings of guilt and unworthiness, bleak, a pessimistic outlook on the future, and even thoughts or actions of self-harm or suicide (Hale, 2007; Kanter et al., 2008; Kennedy, 2008; Maj et al., 2020).

3.2 Assessment of mental health

Well-known classification systems for a clinical diagnosis of mental disorders are the Eleventh Revision of the International Classification of Diseases and Related Health Problems (ICD-11) of the WHO and the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) of the American Psychiatric Association (American Psychiatric Association, 2022; Stein et al., 2020; World Health Organization, 2024a). In the ICD-11,

mental, behavioural and neurodevelopmental disorders are defined as “syndromes characterized by clinically significant disturbance in an individual’s cognition, emotional regulation or behaviour that reflects a dysfunction in the psychological, biological or developmental processes that underlie mental and behavioural functioning. These disturbances are usually associated with distress or impairment in personal, family, social, educational, occupational or other important areas of functioning” (World Health Organization, 2024a). The definition in DSM-5 is pretty much the same (American Psychiatric Association, 2022).

Next to the ICD-11 and the DSM-5 for clinical diagnoses of depression, one screening instrument for depression frequently used in research is the Patient Health Questionnaire (PHQ), in particular the 9-item scale (PHQ-9). Since its original validation in 2001 (Kroenke et al., 2001), the PHQ-9 has been used in several publications and has been translated into more than 30 languages. Some years later, the 8-item version of the PHQ (PHQ-8) was developed, in which a score of ten or higher is considered as a clinically relevant depression. The PHQ-8 has been shown to be a valid and reliable method for assessing current depression in the general population (Kroenke et al., 2008).

In addition to clinical diagnoses of depression based on specific criteria, research frequently investigates screening tools for depressive symptoms. In some studies, depressive symptoms are measured using the Center for Epidemiologic Studies Depression Scale (CES-D). Here, respondents are asked to indicate how often in the week before the survey they felt or behaved in a certain way, for example “How much of the time during the past week did you enjoy life?”, with answer categories ranging from none or almost none of the time (0) to all or almost all of the time (3). The CES-D was created in 1977 (Radloff, 1977) and revised by Eaton et al. (2004) as a short self-report scale designed to measure depressive symptoms in the general population. Next to original version consisting of 20 items, an 8-item short version (CESD-8) is showing a good reliability and validity (Karim et al., 2014; Missinne et al., 2014). The CES-D also proved to be a valid method for investigating depression in people aged 50 and older (Lewinsohn et al., 1997).

Another measure for detecting depressive symptoms in older people is the European Depression Scale (EURO-D) (Prince et al., 1999). This instrument is used in SHARE and consists of twelve items (depression, pessimism, suicidality, guilt, sleep, interest, irritability, appetite, fatigue, concentration, enjoyment and tearfulness). Each item is categorized as either present (1) or absent (0), resulting in a 12-point scale that classifies respondents from not depressed (0) to very depressed (12). For more information can be found in the chapter “Methods” and Mehrbrodt (2021).

Next to the assessment of depression and depressive symptoms, quality of life (QoL) has become important in the evaluation and improvement of health in older population (van Leeuwen et al., 2019). One well-known QoL scale is the CASP scale. The CASP scale measures the QoL of individuals in later life based on a theory of human need, which was originally developed by Hyde et al. (2003). The CASP scale is based on four ontologically grounded domains of need that form the acronym (control, autonomy, pleasure and self-realization). Each domain includes four to six items (control: six items; autonomy: five items; pleasure: four items and self-realization: four items) resulting in a total of 19 items (CASP-19). Each item can be answered with “often” (1), “sometimes” (2), “rarely” (3) and “never” (4). The developers found that all of the four domains have a good internal homogeneity, inter-domain correlations and high loading on a latent factor (Hyde et al., 2003). A shortened 12-item version of the original was designed specifically for use in SHARE (CASP-12). This shortened version scale also consists of the four original domains (control, autonomy, pleasure and self-realization), with three items per domain. The sum score of the CASP-12 ranges from a minimum of twelve to a maximum of 48, with higher scores corresponding to a higher QoL (Mehrbrodt, 2021; Wiggins et al., 2008).

In addition to depressive symptoms (Brenna & Di Novi, 2015; Chakraborty et al., 2023; Hansen et al., 2013; Litwin et al., 2014) and QoL (Ekwall & Hallberg, 2007; McMunn et al., 2009), which are analysed in this doctoral thesis, there are many other indicators and scales for assessing mental health. Other studies on the association between caring and mental health for example examine burden (Biliunaite et al., 2022; Gallicchio et al., 2002; Swinkels et al., 2019), life satisfaction (Hansen & Slagsvold, 2013; McMunn et al., 2009) or self-rated health (Hiel et al., 2015; Kaschowitz & Brandt, 2017).

All these instruments demonstrate that mental health is complex and cannot be explained by a single factor. Rather mental health is always constituted by various symptoms that persist not just once, but rather over a longer period of time. Overall it is found that CES-D captures a more extreme pool of depressed individuals than EURO-D scale (Courtin et al., 2015) or the PHQ (Amtmann et al., 2014) and that there are less gender differences in QoL. Therefore, it is very important to always consider how depression is measured when comparing studies. An overview of instruments used in previous studies on the association between caring and mental health can be found in **Table A 1** in column “Measurement of dependent variable (mental health)”. Further information on the PHQ-8 (**Table A 2**), the CESD-8 (**Table A 3**), the EURO-D (**Table A 4**) and the CASP-12 (**Table A 5**) are provided in the Appendix.

3.3 Previous findings on mental health in Europe

In order to provide an overview of mental health in Europe in general, a brief summary of findings is provided in the following.

As one of the most common and serious mental health conditions, depressive symptoms vary considerably by gender and country. Previous research reveals that on average depressive symptoms tend to be lower among men than among women (Angst et al., 2002; Huijts et al., 2017; Van de Velde et al., 2010). Although these gender differences are found in most European countries, they vary by country. Van de Velde et al. (2010), for example, present average depression scores (scale: 0-24) based on the CESD-8, which are about one point higher for women (6.34) than for men (5.40). Here, mean depression scores range from 4.17 in Norway (men: 3.98; women: 4.38) to 8.15 in Hungary (men: 7.73; women: 8.47). Overall, greatest gender differences are found in Southern and Eastern European countries, which is explained by the fact that women in these countries are more likely to be in paid work, while at the same time performing the majority of care work, which may result in higher levels of stress (Van de Velde et al., 2010). Huijts et al. (2017) dichotomized the CESD-8 and defined scores below nine as cut-off point for serious depressive symptoms (0-9: No serious depressive symptoms; 10-24: Serious depressive symptoms). In this study, serious depressive symptoms are lower in Northern European countries, in particular Finland and Norway, and higher in Southern, Central and Eastern European countries, in particular Portugal and the Czech Republic. Across countries they found that 10.2 % of men and 18.8 % of women had serious depressive symptoms (Huijts et al., 2017). Another European study found that the prevalence of a current depressive disorder, measured by the PHQ-8, was 6.4 % across all countries (men: 4.5 %; women: 7.7 %). The prevalence varied between countries from 2.6 % in the Czech Republic to 10.3 % in Iceland (Arias-de la Torre et al., 2021).

These gender and country differences are also apparent in SHARE. For example, unweighted results from the latest SHARE wave 9 show that the prevalence for elevated depressive symptoms ranges from 18.8 % in Slovakia to 41.7 % in Lithuania (**Table 1**). Among the EU 27 countries, the prevalence of depressive symptoms above the threshold is lower in men than in women. Particularly in the lower half of the table, where mental health is poorer, major differences between men and women are observed. As in other studies, SHARE data reveal a higher prevalence for elevated depressive symptoms in Southern and Eastern European countries.

Table 1: Prevalence of elevated depressive symptoms based on the EURO-D in EU 27 in SHARE wave 9. Countries. Numbers of persons (50 years and older) with information on EURO-D. Total prevalence (sorted ascending) and prevalence for men and women in percent (%) and gender difference in depressive symptoms between women and men in percentage points (pp).

Country	N	Total (%)	Men (%)	Women (%)	Gender differences (pp)
Slovakia	1.042	18.8	15.0	21.9	6.9
Greece	3.003	18.9	14.8	21.9	7.1
The Netherlands	2.036	19.4	14.9	23.1	8.2
Denmark	2.291	19.6	14.4	24.0	9.6
Cyprus	717	19.9	16.6	22.4	5.8
Hungary	1.776	21.1	17.0	24.2	7.2
Austria	3.247	22.4	16.7	26.4	9.7
Slovenia	4.185	22.6	14.7	28.2	13.5
Sweden	2.337	23.2	17.1	28.3	11.2
Latvia	1.659	23.5	17.5	27.2	9.7
Finland	1.712	25.6	19.7	30.8	11.1
Bulgaria	813	26.2	18.8	31.0	12.2
Croatia	4.398	26.6	19.7	32.0	12.3
Germany	4.338	27.1	20.0	33.2	13.2
Luxembourg	784	27.6	22.3	31.8	9.5
Czech Republic	3.162	27.7	18.6	33.2	14.6
Poland	4.540	30.2	22.7	35.8	13.1
Belgium	4.313	31.4	22.4	38.5	16.1
Italy	3.474	32.1	24.7	37.6	12.9
Spain	1.937	32.5	22.2	40.1	17.9
Romania	1.459	32.7	24.5	38.6	14.1
France	2.782	32.9	24.2	39.6	15.4
Estonia	4.252	35.2	27.6	39.7	12.1
Malta	849	35.5	24.7	44.0	19.3
Portugal	1.431	41.4	26.5	52.7	26.2
Lithuania	1.351	41.7	30.2	48.3	18.1

Source: Own representation based on unweighted data from SHARE wave 9.

No information available for Ireland.

Table 2: Means of QoL based on the CASP in EU 27 in SHARE wave 9. Countries. Numbers of persons (50 years and older) with information on CASP. Total mean (sorted ascending) and means for men and women with associated standard deviations (sd) and gender difference in QoL between women and men in points.

Country	n	Total Mean (sd)	Men Mean (sd)	Women Mean (sd)	Gender difference
Greece	3.022	32.0 (5.2)	32.7 (5.0)	31.6 (5.2)	-1.1
Bulgaria	814	33.0 (6.0)	33.6 (5.8)	32.6 (6.0)	-1.0
Lithuania	1.292	33.8 (6.2)	33.7 (6.3)	33.8 (6.1)	0.1
Romania	1.456	34.3 (6.7)	35.1 (6.6)	33.8 (6.7)	-1.3
Latvia	1.643	34.4 (5.7)	34.7 (5.6)	34.3 (5.8)	-0.4
Portugal	1.367	34.8 (5.8)	35.4 (5.6)	34.3 (5.9)	-1.1
Italy	3.481	34.8 (6.1)	35.5 (6.0)	34.2 (6.1)	-1.3
Cyprus	700	34.9 (6.2)	35.6 (6.1)	34.3 (6.2)	-1.3
Slovakia	1.047	36.2 (6.8)	36.3 (6.8)	36.1 (6.8)	-0.2
Czech Republic	3.076	36.2 (5.5)	36.8 (5.4)	35.9 (5.5)	-0.9
Estonia	4.160	36.7 (6.2)	36.7 (6.3)	36.7 (6.2)	0.0
Spain	1.898	36.8 (6.3)	37.7 (6.1)	36.1 (6.3)	-1.6
Croatia	4.370	36.9 (6.2)	37.5 (6.0)	36.4 (6.3)	-1.1
Poland	4.547	37.3 (6.3)	37.6 (6.3)	37.1 (6.2)	-0.5
Malta	833	37.5 (5.4)	38.0 (5.2)	37.1 (5.5)	-0.9
Hungary	1.765	37.6 (6.6)	37.8 (6.6)	37.4 (6.7)	-0.4
Belgium	4.167	38.5 (5.7)	39.1 (5.4)	38.0 (5.9)	-1.1
Finland	1.687	38.6 (5.2)	38.2 (5.3)	38.9 (5.1)	0.7
France	2.715	38.7 (5.7)	39.3 (5.6)	38.2 (5.7)	-1.1
Germany	4.253	39.0 (5.5)	39.2 (5.5)	38.9 (5.4)	-0.3
Sweden	2.307	39.1 (5.0)	39.2 (5.0)	39.0 (5.1)	-0.2
Slovenia	4.143	39.4 (5.8)	40.0 (5.5)	39.1 (5.8)	-0.9
Luxembourg	749	40.1 (5.4)	40.3 (5.3)	40.0 (5.5)	-0.3
Austria	3.214	40.5 (5.4)	41.0 (5.1)	40.2 (5.6)	-0.8
The Netherlands	1.995	40.9 (4.9)	40.9 (4.8)	40.8 (5.0)	-0.1
Denmark	2.243	41.2 (4.5)	41.1 (4.5)	41.3 (4.5)	0.2

Source: Own representation based on unweighted data from SHARE wave 9.

No information available for Ireland.

Table 2 shows mean values for QoL. SHARE uses the 12-item version (CASP-12) of the original CASP-19 by Hyde et al. (2003). Each of the four original domains (control, autonomy, self-realization and pleasure) is associated with three statements, which should be rated on a four-point Likert scale. The sum score ranges up to 48, with higher values indicating a higher QoL and thus better mental health. More information on CASP can be found in the section “Dependent variables” and Mehrbrodt (2021).

Because a higher QoL is associated with better mental health, the QoL is coded reversed to depressive symptoms. This means, QoL is lower in the countries in the upper half of the table, for example Greece, Bulgaria and Lithuania, than in those countries in the lower half of the table, for example Denmark and the Netherlands. In line with the results for depressive symptoms, SHARE data demonstrate a lower average QoL in Southern and Eastern European countries. Overall, the sum score for QoL ranges from 32.0 in Greece to 41.2 in Denmark. In terms of QoL, the values between men and women are more similar than in the case of depressive symptoms, which suggests that QoL appears to be less gender-sensitive.

Next to gender and country differences, further aspects are of importance for mental health. For example, in general a good socioeconomic position was found to be associated with lower levels of depression for both men and women and across Europe (Van de Velde et al., 2010). Another study found differences in mental health by age. The prevalence of a major depressive disorder (MDD), assessed by the DSM-5 (five or more symptoms), was for men and women highest in the age group “45-54” (men: 8.9 %; women: 16.6 %) and lowest in the age groups “65-74” (men: 6.2 %; women: 14 %) and “75+” (men: 6.5 %; women: 12.2 %) (Angst et al., 2002). However, another study using data from the European Health Interview Survey (EHIS) and measuring depressive symptoms with the PHQ-8 found the highest prevalences for depressive symptoms among people aged 65 and older (Hapke et al., 2019).

The pronounced gender differences in depression are often explained by different coping strategies used by men and women in challenging situations. While men more often reacted with increasing their physical activity and consumption of alcohol, women more often coped with such situations through emotional release like crying and laughing. Furthermore, the same study revealed that depression affects different areas of life to different degrees in men and women. While women are on average more severely affected in their quality of sleep and general health, men are more severely affected in their ability to work (Angst et al., 2002). Other factors contributing to this increased prevalence of depression in women include a greater exposure to stressors and increased reactivity and susceptibility to stressors

(Hammen, 2005), which are driven by hormonal, inflammatory, epigenomic and social-environmental mechanisms (Mengelkoch & Slavich, 2024). At the same time, research indicates that women are more likely than men to communicate their negative feelings and depressive symptoms to family members or friends and to seek for professional help (Addis & Mahalik, 2003; Leimkühler-Müller, 2002; Padesky & Hammen, 1981). These gender differences in non-professional and professional help-seeking may reflect traditional gender stereotypes, which define masculinity as denial of weakness or vulnerability, emotional control, the appearance of strength, rejection of neediness, and physical dominance (Addis & Mahalik, 2003; Courtenay, 2000; Staiger et al., 2020). Thus, the lower prevalence of depression in men can be explained, on the one hand, by gender differences in the coping with stressors as an important predictor for depressive symptoms and, on the other hand, by differences in help-seeking behaviour. Further sociodemographic, socioeconomic and country-specific differences in mental health can, amongst other factors, be attributed to differences in health literacy in terms of mental well-being (“mental health literacy”), regional differences in social structure and cultural differences (Hapke et al., 2019).

4 Caring and carer mental health

The following chapter focuses on the main topic of this work, namely the association between caring and carer mental health, which has been frequently discussed in previous research.

In order to obtain a comprehensive overview of the literature on the association between caring and mental health at the beginning of this research, a structured literature search was conducted. PubMed and Google Scholar served as the primary databases, as they provide broad and interdisciplinary coverage of medical, psychological and social science research. Searches were performed using combinations of keywords including “mental health”, “depressive symptoms”, “caring”, “care”, “caregiving”, “location of care”, “type of care” and “relationship type”. The search process was complemented by the so-called snowball method. Starting point was the knowledge and previous publications of the researchers from the EURO CARE project as well as relevant reviews (Pinquart & Sorensen, 2011; Zygouri et al., 2021). A key advantages of the snowball method is that it starts from relevant research and builds on this as basis for further investigation (Wohlin, 2014).

In total, more than forty quantitative and qualitative studies as well as systematic reviews published in English language between 1983 to 2024 are considered. All identified papers dealt with the health of adults who take on caring outside of a professional context. While most of the identified relevant research papers come from Europe, other relevant articles, for example from the United States, Canada or Singapore, were also taken into account.

An overview of all included research papers with information about the country, the data source and design, the measurement of the independent variable (caring), the measurement of the outcome (mental health) and the main results is provided in **Table A 1**.

4.1 Mechanisms

When people think about care, the first thing that usually comes to their minds is the health of the person in need of care, the recipient of care. But also the health of the carer, the person providing the care, is an important aspect to ensure high-quality care (Zygouri et al., 2021). A literature review by Van Durme et al. (2012) covering more than a hundred studies, has already shown that there are a variety of positive, negative, and neutral outcomes, that are used to assess the association between caring and health of the carer. While some studies focus on positive outcomes such as QoL or well-being or neutral outcomes such as health,

the majority of studies concentrates on negative outcomes such as burden, stress or depressive symptoms (Van Durme et al., 2012).

The largest strand of research on caring outside a formal setting identifies negative associations with mental health (Hiel et al., 2015; Pinquart & Sorensen, 2003; Verbakel et al., 2017). These findings of poorer health of carers have often been interpreted as effects of high strain and burden associated with caring (Roth et al., 2009; Schulz et al., 1997), limited rewards (McMunn et al., 2009) or a lack of reciprocity (Siegrist & Wahrendorf, 2009) and fewer opportunities for other activities besides caring (Rokicka & Zajkowska, 2020).

Other studies focus on positive and negative aspects simultaneously (Beach et al., 2000; Broese van Groenou et al., 2013) or only on positive aspects of caring (Tarlow et al., 2004). Common positive aspects associated with caring include a greater closeness to the person in need of care and the feeling of being needed (Hansen & Slagsvold, 2013; Netto et al., 2009; Tarlow et al., 2004). Furthermore, a positive evaluation of caring is often closely linked with the motivations for providing care. Common motivators for both male and female carers are their affection, the feelings of compassion and the duty to provide care for their beloved ones (Zygouri et al., 2021). Carers who were intrinsically motivated to help were more likely to have positive feelings about caring than people who associate caring with feelings of obligation, responsibility and a lack of choice (Beach et al., 2000; Dombestein et al., 2020; Lyonette & Yardley, 2003). Positive evaluations of care were higher among spouses when they were motivated to prevent their spouse from entering residential care, and among children when they were motivated by strong personal ties to their parents (Broese van Groenou et al., 2013). Another study demonstrates that even in a highly stressful environment, a reciprocal relationship between spouses can have a positive effect on the well-being of the caring partner and can lead to feelings of love and empathy (Poulin et al., 2010). Beyond that, positive associations are linked to a “healthy carer effect”, as healthy people are more likely to become carers (McCann et al. 2004).

As already described several times, there are many ways to define care and numerous studies have highlighted various aspects of the care situation that are relevant to the association between caring and mental health of the carer. Although there is this extensive amount of research conducted in this area, there are still no clear conclusions regarding the direction and strength of the association between caring and carer mental health. In order to clarify these differing findings, central aspects of the care situation and the underlying mechanisms that may be relevant to the association with mental health are analysed in more detail next.

Type of care

In some studies caring is only formulated quite vaguely and is associated with terms such as “help”, “look after” or “support” (Bom & Stöckel, 2021; Doebler et al., 2016; Lacey et al., 2024). While some studies focus solely on one type or activity related to care, for example personal care in Hansen et al. (2013), others combine various activities related to care, for example watching a family member, bathing or providing transportation in Roth et al. (2009).

Following the central ideas of the job demand-control model, which examines the associations between job-related demands and opportunities for control, the type of care may be of great importance. The job demand-control model is one important theoretical approach to investigate the association between work and health and was founded in 1979 by sociologist Robert Karasek (Karasek, 1979). In the model, the two central dimensions, “demand” and “control”, are divided into “high” and “low” resulting in four possible outcomes (“high-strain”, “low-strain”, “active” and “passive jobs”). According to the basic assumptions of the model, working conditions that are characterized by high demands (“job demands” or “psychological demands”) but offer hardly any control or decision-making opportunities (“job decision latitude”) are associated with feelings of overload, anxiety and increased susceptibility to illness (“high strain jobs”). The extent of job decision latitude is further divided into skill discretion and decision autonomy. High-strain jobs include time pressure and repetitive tasks, as is often the case for production workers (Fan et al., 2019; Karasek & Theorell, 1990). In general, the model proposes that work-related mental health could be improved without compromising productivity by increasing this decision-making latitude (Karasek, 1979).

According to the central ideas of Karasek (1979) caring outside a formal setting may sometimes include time pressure and repetitive tasks (“demands”) and lower possibilities for skill discretion and decision autonomy (“control”). A study on this topic has already found initial evidence that central ideas of the job demand-control model are applicable to non-formal “jobs” like caring (Molloy et al., 2005). However, the basic principles of the model indicate that the association with health may vary depending on the exact type of care, as some types include more demands and less control than others.

A longitudinal study by Zwar et al. (2018) examined different types of caring, “helping around the house (e.g. cleaning, shopping, preparing meals)”, “looking after someone (e.g. emotional support, supervision, accompanying to appointment or other organizational tasks)”, “performing nursing care services (e.g. helping with basic needs like eating, bathing

or help with medication)” and their association with cognitive performance among carers aged 65 years and older. Results showed that “looking after someone” was associated with an increase in carer cognitive ability, while findings the other two types remained insignificant (Zwar et al., 2018). Although the study focuses on a different outcome than this doctoral thesis, findings provide evidence that health effects may vary depending on the type of care. Furthermore, a study that distinguishes between different types of social productivity, voluntary work, informal help and caring for a person, found that voluntary work, which is usually associated with a higher degree of autonomy and perceived control, was associated negatively with depressive symptoms. In contrast, caring for a sick or disabled person, as an activity with a generally low degree of autonomy, was positively associated with depressive symptoms and poorer mental health outcomes (Wahrendorf et al., 2008).

These results provide evidence that activities that do not involve time pressure (“low demands”) and offer more autonomy in deciding when and how they are performed (“high control”), such as gardening, may be associated differently with health of the carer than activities that require a high level of intensity and timing (“high demands”) and offer little autonomy (“low control”), such as feeding.

Location of care

In some studies, the location of care is taken into account, meaning whether care is provided inside or outside the household of the carer. Care inside the household is also called (co-) resident care and care outside the household non-resident or extra-resident care.

There are some studies that highlight differences in the association with mental health depending on the location where care takes place. For example, a European study focusing on mental health effects of caring across national contexts indicates that people who begin caring inside the household experience a decline in mental health in all welfare state types, while the impact on caring outside the household is unclear (Kaschowitz & Brandt, 2017). In an older study from Canada, Novak and Guest (1989) reported that persons who care for a spouse in their own home report the highest level of burden. But also more recent research emphasized that carers who resided with the person in need of care described a slightly poorer mental health than carers residing elsewhere (Roth et al., 2009) or found a significant higher burden score for carers living together with the care recipient (Biliunaite et al., 2022). Furthermore, Hansen et al. (2013) find a negative association between caring and mental health only for those children living together with their parents in need of care. This results can be explained by the fact that resident caring compared with non-resident caring generally

involves more hours of care, requires more responsibility for ensuring continuity of care, and has more impact on social life and sleep (Hansen et al., 2013). Additional studies revealed likewise that caring for a resident person in need of care is more often associated with a higher intensity of care (De Koker, 2009; Mentzakis et al., 2009), less time for physical activities, social life and hobbies (Rokicka & Zajkowska, 2020) and fewer social contacts (Roth et al., 2009). In a study from the United Kingdom, for example, 45 % of resident carers provide more than 35 hours of care per week, whereas the majority (93 %) of non-resident carers provide less than 20 hours of care per week.

These results may also underscore the fact that it is difficult to clearly separate caring responsibilities from leisure time when carer and care recipient live in a cohabitation. This phenomenon, known as “blurring of boundaries”, has already been discussed frequently in studies on paid work. The phenomenon describes the overlapping boundaries between paid work and private life that can result from working from home (Eurofound and the International Labour Office, 2017). One problem reported by employees working from home is the lack of balance between work and personal life. Some employees noted a blurring of boundaries between work and leisure and found it difficult to concentrate on work, as they had no way of distracting themselves from household chores (Simenenko & Lentjushenkova, 2021). For caring, this would correspondingly mean that people who provide care in their own household may have similar difficulties in allocating leisure time at home and time for caring.

At the same time, people who live in a different household than the person in need of care may spend more time traveling to visit that person. Previous research on working conditions and commuting during paid work suggests that commuting is associated with more stress, lower satisfaction in leisure time and poorer mental health (Clark et al., 2019; Rissel et al., 2014). Beyond that, it seems that care outside the household more often competes with other time-demanding tasks, such as childcare and paid work (Mentzakis et al., 2009).

Relationship type between carer and care recipient

Many studies have a look at the relationship between carers and care recipients. Often, these studies focus on specific types of relationships, particularly caring between spouses and partners (Hagedoorn et al., 2000; Hansen & Slagsvold, 2013) or between parents and children (Brenna & Di Novi, 2015; Hansen et al., 2013). Another study does not directly differentiate between individual groups, but rather if care is intergenerational, for example care between

children and parents, parents-in-law or the partner's parents, or intragenerational, for example care between spouses or partners (Hajek & König, 2016).

Studies that distinguish between several types of relationship between carer and care recipient, mostly also found differences in the association with mental health depending on the relationship type. A study from Canada shows that spousal carers and in particular, carers who are children, had higher odds of a high burden score compared to other relationship types (Gallicchio et al., 2002). Furthermore, a study found that negative health outcomes were more likely for daughters than for daughters-in-law (Do et al., 2015). Furthermore, Cantor (1983) demonstrated that the closer the kinship bond, the greater the amount of strain. As a result, spouses were the most vulnerable group, followed by children, other relatives, friends and neighbors. Similarly, Marks et al. (2002) found that transitioning into care for a primary kin, such as a child, spouse or a biological parent, was associated with a significant increase in depressive symptoms, while, similar to Do et al. (2015), they found that providing care for parents-in-law was not associated with negative mental health outcomes. However, caring for a non-relative was even associated with beneficial effects, such as increased personal growth for both men and women (Marks et al., 2002). Litwin et al. (2014), who used SHARE data from 16 European countries, showed that co-resident carers of a spouse or adult child reported more depressive symptoms than carers who provided care to a parent or other persons. In addition, they found that relationship closeness moderates negative outcomes, showing that carers who classified the care recipient as a confidant reported fewer depressive symptoms than those who cared for non-confidants. One explanation for this finding was that an emotional bond between carers and the person in need of care may reduce the burden associated with caring for that person. The second possible explanation according to Litwin et al. (2014) was taken from the literature on exchange theory, which states that reciprocal exchange reduces the sense of burden and depressive symptoms, while unbalanced exchange does not. While care recipients often have limited opportunities to directly reciprocate for the care they receive, it can be a decisive factor for a balanced exchange if carers feel that the care recipient is someone with whom they can discuss important matters and from whom they can expect empathy (Litwin et al., 2014). Also, an older qualitative study from the United States picks up on this idea of reciprocity. Here, findings revealed that many carers perceived caring as a moral responsibility to give something back to someone, for example their parents for the care and kindness they had received in the past (Noonan et al., 1996).

Gender

Many studies already differentiate their analyses according to gender and most research shows that even today, women take over more care work and carry out different activities than men. More information can already be found in the section “Prevalence of caring”.

In terms of the association between caring and mental health, most previous research found poorer mental health outcomes in women, for example higher burden, stress or strain (Biliunaite et al., 2022; Broese van Groenou et al., 2013; Cantor, 1983; Gallicchio et al., 2002; Kim, 2017; Lacey et al., 2019; Papastavrou et al., 2007; Swinkels et al., 2019), more prescribed antidepressants (Doebler et al., 2016), higher risks for developing a clinical depression (Hagedoorn et al., 2000), more depressive symptoms (Hansen & Slagsvold, 2013; Hansen et al., 2013), less cognitive well-being (Hajek & König, 2016), lower mental well-being (Verbakel et al., 2017) and worse overall health (Bom & Stöckel, 2021; Li et al., 2013). These gender differences to the disadvantage of women are also found outside Europe in low- and middle-income countries (Bhan et al., 2020).

One reason for this is that women are more likely to be expected to take on caring in line with traditional gender norms (Gallicchio et al., 2002; Jacobson et al., 2025; Zygouri et al., 2021). Furthermore, women tend to use an emotion-focused coping strategy in caring, while men are more likely to be more pragmatic, less emotion-focused and a more task-driven strategy, which in turn was found to buffer males from negative health outcomes (Zygouri et al., 2021). These coping strategies are in turn related to taking over different types of care, with women doing more work that requires emotional closeness, such as personal care, and men less emotional types of care, such as practical household work (Arber & Ginn, 1994; Skinner & Sogstad, 2022). Another study suggests that gender differences in the association between caring and mental health may be based on their different perception of instruments used to measure mental health as “[...] the higher level of burden experienced by female caregivers in this study may be due to a greater amount of perceived burden rather than real burden” (Gallicchio et al., 2002). This implies that men might be less likely to openly report problems, have more trouble expressing their feelings and that they evaluate and perceive their mental health differently than women (Girgus et al., 2017; Martin et al., 2013; Sloan & Sandt, 2006).

Long-term perspective

Most studies to date have examined cross-sectional rather than longitudinal associations between caring and mental health. The main problem with cross-sectional data is that it represents a snapshot at a specific point in time and cannot be used to show a cause-and-effect relationship or analyse behaviour over a period of time.

The few studies that take a longitudinal perspective differ considerably in terms of their focus and the period under investigation and sometimes come up with contradictory findings. For example, a study from the United States, in which carers were examined up to 15 years after onset of dementia, found that higher baseline closeness between care and care recipient predicted a greater worsening in mental health over time (Fauth et al., 2012). A German study looking at intra- and intergenerational care in 2002, 2008 and 2011, found that only intragenerational care, defined as care for a spouse or partner, was associated with lower cognitive well-being in women and poorer mental health in both men and women over time. At the same time, the results for intergenerational care, defined as care for parents or parents-in-law, remained insignificant (Hajek & König, 2016). Hansen et al. (2013) have shown that, among Norwegian women, caring was associated with decreasing happiness and increasing depression five years after measurement of care. A study using SHARE data from ten European countries demonstrated that the provision of personal care was significantly associated with poor mental and physical health over a follow-up period of eight years (Hiel et al., 2015). Furthermore, a study from the United Kingdom showed that negative health effects of caring persist up to four or five years after initial care provision (Stöckel & Bom, 2022). In contrast to these negative longitudinal results, a study focusing only on women found that stress increased the risk of mortality in older women more than caring (alone). In this study, carers with low levels of stress had an even lower risk of mortality after three years than non-carers (Fredman et al., 2010).

Another line of research deals with the question of when possible changes in the health status of carers begin. Research by Lacey et al. demonstrates that caring is already detrimental at the point when it is initiated. Female carers or carers that live in the same household as the person requiring care, experienced a deterioration in their health already at the time when they became carers (Lacey et al., 2019; Lacey et al., 2024). Also another study using SHARE data from 17 European countries has indicated that the transition into care has detrimental effects on health (Uccheddu et al., 2019). These findings from Europe are consistent with findings from the United States. Here, it was shown that the transition into caring for a spouse or parent outside the household was associated with a greater increase in depression among

both men and women compared to non-carers (Marks et al., 2002) and that an increase in depression was observed already at an early stage of caring (McCann et al., 2004). Studies looking at the time of giving up caring found that doing so was associated with an increase in QoL (Siegrist & Wahrendorf, 2009) and better health for women living in Southern European countries (Uccheddu et al., 2019).

Furthermore, a systematic review found that the duration of care was one of the strongest determinants of burden, which becomes heavier the longer caring lasts (Lindt et al., 2020). This finding would support the so-called “wear-and-tear hypothesis”, which comes from the field of biology and states that ageing results from a gradual deterioration of the body's cells and tissues through wear and tear, oxidative stress and other deterioration processes. According to this theory, living organisms “wear out” over time through repeated use and increased stress on the body (Quadagno, 2008). Applied to caring, this means that mental health problems accumulate with increasing duration of care, as physical and mental resources are depleted over time (Stöckel & Bom, 2022; Townsend et al., 1989). In contrast, Lacey et al. (2019) found that psychological distress was higher at the initiation among women carers, but no differences in slopes were observed thereafter. These results suggest that there was a constant level of distress over time, which is not consistent with central idea of the “wear-and-tear hypothesis” (Townsend et al., 1989). These findings from by Lacey et al. (2019) would rather support the “trait hypothesis”, which assumes that the negative impact of caring remains constant over time because the carer’s pre-existing coping skills and resources persist (Stöckel & Bom, 2022; Townsend et al., 1989).

4.2 Research gaps and research questions

The presented evaluation of previous research findings shows that caring outside a formal setting has been subject of numerous studies. There are many aspects that are related to the prevalence of caring and the association between caring and the mental health of the carer. However, it is also striking that care was often understood differently and was associated with different care situations, which led to the fact that many results were not directly comparable or provided mixed results.

Therefore, in this doctoral thesis, I would like to place a clear focus on three characteristics of the caring situation, which will be examined systematically: The location where care takes place, the type of care and the relationship type between caregiver and care recipient. This focus is accompanied by the following research questions, which are addressed in particular

in Paper 1 and 2. In addition, Paper 3 deals with the question of what happens when people start caring, thereby contributing to address the causal question of the direction of the association (**Table 3**). As previous studies have shown that men and women differ in terms of the prevalence of mental health issues and in the prevalence of caring responsibilities, all analyses are conducted separately by gender.

1. Who provides care?

- a. Are there differences by location and type of care (Paper 1)?
- b. Are there differences by relationship type between carer and care recipient (Paper 2)?

2. What is the cross-sectional and longitudinal association between caring and carer mental health?

- a. Are there differences by location and type of care (Paper 1)?
- b. Are there differences by relationship type between carer and care recipient (Paper 2)?

Table 3: Summary of published original research. Paper number, dataset used, independent variables, outcome variables and article reference of each study.

Paper number	Dataset	Independent variables	Outcome variables	Article Reference
1	SHARE	Location (inside and outside the household) and type (personal care, practical household help, help with paperwork) of caring	Depressive symptoms (binary)	Schaps et al. (2025a)
2	SHARE	Relationship type between carer and care recipient (spouse, parent, parent-in-law, child, other relative, other non-relative) in personal care inside and outside the household	Depressive symptoms (continuous), QoL (continuous)	Schaps et al. (2025b)
3	SHARE	Personal care inside the household	Depressive symptoms (continuous) before and after transitioning into care	Wahrendorf et al. (2025)

Source: Own representation.

5 Methods

The methodology chapter provides an overview of the data set as well as the measurement of dependent, independent and other relevant variables in SHARE. In addition, the analytical strategy used in the research papers associated with this doctoral thesis is explained.

5.1 Data source

SHARE is a survey conducted approximately every two years that examines the living, family, economic and health circumstances of people aged 50 years and older and their cohabiting partners regardless of age. The main goal of SHARE is to achieve a better understanding of challenges and opportunities of population aging as one of the social challenges of the 21st century. Persons are excluded if they are imprisoned, hospitalized or have left the country during the survey period or if they do not speak any of the national languages or have moved to an unknown address (Börsch-Supan et al., 2013).

The survey was conducted in all countries by using a “Computer-Assisted Personal Interview” (CAPI), supplemented by a self-completed paper-and-pencil questionnaire (“drop-off questionnaire”). The CAPI forms the largest part of SHARE. On average, interviews took about 80 minutes to complete for a one-person household and about 120 minutes for a two-person household. After completing the CAPI, more sensitive topics such as well-being, health care, religiosity and political attitudes are covered using self-administered paper-and-pencil questions (de Luca & Lipps, 2005).

SHARE applies a concept of ex-ante harmonisation, which means that there is one common questionnaire that is translated into the national language. In some countries the questionnaire is translated into more than one language, for example in Switzerland (German, French and Italian) or Belgium (French and Flemish) (SHARE, 2024).

SHARE started in 2004 with twelve countries: Austria, Belgium, Switzerland, Germany, Denmark, Spain, France, Greece, Italy, Netherlands, Sweden and Israel (Börsch-Supan et al., 2013). Over time, several Eastern European countries have joined SHARE. In the latest wave 9 in 2021 and 2022, a total of 28 countries, including EU 27 (without Ireland), Switzerland and Israel, participated in SHARE (SHARE, 2024).

Some special features of the SHARE data collection should be mentioned at this point: Waves 3 and 7 are so-called SHARELIFE surveys with different sets of questions relating to the life history of the respondents. All respondents in wave 3 answered the special SHARELIFE questionnaire and in wave 7, the SHARELIFE modules were handed out to all

respondents who had not participated in wave 3 (82 % of all respondents). Thus, answers from the regular questionnaire were available for only 18 % of respondents in wave 7. Furthermore, the fieldwork of wave 8 started in fall 2019 and was interrupted by the outbreak of the COVID-19 pandemic in March 2020. At this point, about 70 % of all expected interviews had been conducted. In order to address the pandemic, SHARE developed a special questionnaire (“SHARE Corona Survey”) that covered the same topics as the regular questionnaire but was significantly shorter, with an additional focus on the living conditions during the pandemic. The first SHARE Corona Survey was conducted between June and September 2020 and the second round between June and August 2021.

Eleven countries (Austria, Belgium, Denmark, France, Germany, Greece, Italy, Spain, Sweden, Switzerland and the Netherlands) participated from the beginning and without gaps from wave 1 in 2004 until wave 9 in 2021 and 2022. However, in SHARE waves 6 and 7, the Netherlands conducted a mixed-mode experiment and did not participate in the regular waves. For Portugal there is no information available for wave 8, as the country only participated in the SHARE Corona Survey at that time. More detailed information can be found in SHARE, 2024b.

In the first waves, SHARE was primarily funded by the European Commission. In wave 4, SHARE became an international organisation and moved to a decentralised funding model by its member countries (Börsch-Supan et al., 2013). To protect the respondents, SHARE does not accept funds from commercial companies and does not allow data access for commercial companies. All current and previous national funding sources can be found on the SHARE website (SHARE, 2025).

SHARE is closely modelled on and constantly harmonized with its sister studies, the HRS in the United States and ELSA in the United Kingdom. Several other sister studies, which are spread all over the world, were also established based on this concept (Börsch-Supan et al., 2013). These include, for example the Chinese Health and Retirement Survey (CHARLS), the Brazilian Longitudinal Study of Adult Health (ELSA-Brasil), the Japanese Study of Aging and Retirement (JSTAR), the Korean Longitudinal Study of Aging (KLoSA), the Longitudinal Aging Study in India (LASI), the Mexican Health and Aging Study (MHAS) and the Irish Longitudinal Study on Ageing (TILDA) (Börsch-Supan et al., 2013; Lee et al., 2021).

A key strength of SHARE is that it provides not only cross-sectional but also longitudinal perspectives of the lives of people in Europe. This means that all respondents who were interviewed in one wave, are included in the longitudinal sample. In addition, refreshment

samples are drawn to ensure that younger age cohorts are adequately represented in all new waves and to compensate for reductions in the panel sample size due to attrition, for example through death. Because SHARE focuses on persons aged 50 years and older, natural mortality is a greater issue than in other surveys (Börsch-Supan et al., 2013; SHARE, 2024).

5.2 Data Measurement

Since the measurement of care in SHARE cannot be represented by a single item, the questions used in this doctoral thesis are described in detail below. In addition, this chapter will include a detailed description of the dependent variables and additional measures.

5.2.1 Independent variables

Caring outside a formal setting can include different locations of care, for example care inside or outside the carer's household, types of care, for example personal care, practical household help, transportation or help with paperwork, and relationship types between carers and care recipients, for example spouse, parents and non-kin. As already described before, there are many ways in which care is defined in surveys. For clarification, the measurement of care-related variables in SHARE is presented in tabular form, differentiated into care inside (**Table 4**) and outside the household (**Table 5**).

Location of care

Measurement of care provision inside the household is based on the question “Is there someone living in this household whom you have helped regularly during the last twelve months with personal care, such as washing, getting out of bed, or dressing”. Regularly here means daily or almost daily care for at least three months and not help during short-term sickness. This question is only asked if the respondent has a household with more than one person, so all persons living alone did not get this question.

To measure care outside the household, respondents are asked: “Now I would like to ask you about the help you have given to others. In the last twelve months, have you personally given any kind of help to a family member from outside the household, a friend or neighbour?”. “Help” was divided into three types: 1. Personal care, such as dressing, bathing or showering, eating, getting in or out of bed and using the toilet, 2. Practical household help, such as home repairs, gardening, transportation, shopping and household chores and 3. Help with paperwork, such as filling out forms and setting financial or legal matters.

Types of care

The question for care inside the household only refers to one type of care, which is personal care. This includes tasks such as dressing, bathing, eating, getting up and going to the toilet, which require a close physical proximity between the carer and the care recipient. In contrast, care outside the household allows for three different types of care to be differentiated: Personal care, practical household help and help with paperwork. While personal care involves a close physical contact with the care recipient, practical household help tends to involve physical work to improve the environment of the person in need of care. In contrast, help with paperwork refers to mental work that does not necessarily require a direct a physical contact with the person in need of care.

These two main questions on care inside and outside the household can each be answered with “yes” or “no” and refer to the same time, namely whether care was provided in the twelve months prior to the interview.

Relationship type between carer and care recipient

If the main questions about care inside the household or outside the household are answered with “yes”, a follow-up question asks about who is being cared for. SHARE allows to differentiate between 27 possible relationship types between the carer and the care recipient. These possible relationship types are the same for care inside and outside the household. The only difference is that the follow-up question for care inside the household only allows one answer, for example “spouse”, while outside the household up to three persons, for example “spouse”, “parent” and “parent-in-law”, can be specified. Furthermore, for care outside the household respondents can indicate that they provide different types of care for different people at the same time, for example personal care for a parent and help with paperwork for a parent-in-law.

However, this doctoral thesis does not focus on all relationship types, but only on types of relationships that have been identified as common in the existing literature (Bom et al., 2019; De Klerk et al., 2021). The most common relationship types involve care for a spouse or partner, mother(in-law), father(in-law), child, brother, sister, aunt, uncle, friend or neighbor. To allow calculations with larger subgroups, some of these relationship types are grouped together: Mother and father were grouped together as “parents”, mother-in-law and father-in-law as “parents-in-law”, brother, sister, uncle and aunt as “other relatives” and friends and neighbors as “other non-relatives”. In line with the existing literature, these relationship

types were the most common answers in SHARE, while all other relationship types, for example colleagues, were only mentioned very rarely.

In the case of a spouse or partner this is usually a person of the same age as the carer, which is known as “horizontal care” or “intragenerational care”. In contrast, caring for the own parents or parents-in-law and caring for a child are both forms of so-called multigenerational or intergenerational care, because it includes the transfer of resource between two different generations. There are two directions in multigenerational/intergenerational care: Caring for a parent or parent-in-law is upward care, while caring for a child is downward care (Patterson & Margolis, 2019).

Table 4: Measurement of caring inside the household. Variables with the corresponding questions and answer options for the respondents in SHARE.

Variables	Question	Answer options	
Caring inside the household	Is there someone living in this household whom you have helped regularly during the last twelve months with personal care, such as washing, getting out of bed or dressing?	Yes	No
Relationship type between carer and care recipient	Who is that?	Spouse/partner	Grandparent
		Mother	Aunt
		Father	Uncle
		Mother-in-law	Niece
		Father-in-law	Nephew
		Stepmother	Other relative
		Stepfather	Friend
		Brother	(Ex-)colleague/co-worker
		Sister	
		Child	Neighbor
		Step-child/current	Ex-spouse/partner
		Parent's child	Minister/priest or
		Son-in-law	other clergy
		Daughter-in-law	Therapist or professional helper
		Grandchild	Housekeeper/ Home health provider

Source: Own representation based on SHARE.

Table 5: Measurement of caring outside the household. Variables with the corresponding questions and answer options for the respondents in SHARE.

Variables	Question	Answer options	
Caring outside the household	In the last twelve months, have you personally given any kind of help to a family member from outside the household, a friend or neighbor?	Yes	No
Relationship type between carer and care recipient	Which family member from outside the household, friend or neighbor have you helped in the last twelve months?	Spouse/partner Mother Father Mother-in-law Father-in-law Stepmother Stepfather Brother Sister Child Step-child/current parent's child Son-in-law Daughter-in-law Grandchild	Grandparent Aunt Uncle Niece Nephew Other relative Friend (Ex-)colleague/co-worker Neighbor Ex-spouse/partner Minister/priest or other clergy Therapist or professional helper Housekeeper/ Home health provider
Type of care	Which types of help have you given to this person in the last twelve months?	Personal care (e.g. dressing, bathing or showering, eating, getting in or out of bed, using the toilet) Practical household help (e.g. home repairs, gardening, transportation, shopping, household chores) Help with paperwork (e.g. filling out forms, settling financial or legal matters)	

Source: Own representation based on SHARE.

5.2.2 Dependent variables

In SHARE, poor mental health, as one of the most frequent causes of emotional suffering in later life, is measured by increased depressive symptoms using the EURO-D depression scale (Blazer, 2003). The EURO-D value for each respondent is generated from sixteen questions, which are combined into twelve items in the SHARE mental health module (Mehrbrodt, 2021). EURO-D measures the presence or non-presence of the following symptoms in the month prior to the SHARE interview: “Depressed mood”, “pessimism”, “suicidality”, “guilt”, “sleep quality”, “interest”, “irritability”, “appetite”, “fatigue”, “concentration”, “enjoyment” and “tearfulness”. When the number of all symptoms is added up, the EURO-D depression scale ranges from 0 “not depressed” to 12 “very depressed”. Here, a higher scale score indicates a higher number of depressive symptoms.

This scale score is sometimes converted into a binary indicator that defines the presence of three or more symptoms as elevated depressive symptoms. This threshold value has been validated by standardized psychiatric interviews in older population groups and is closely related to other mental health measures in European-wide studies (Prince et al., 1999).

For sensitivity purposes, the CASP index is used in addition to the binary EURO-D measure and the EURO-D depression scale score. The CASP index measures the QoL of individuals in older age based on a theory of human need, which was originally developed by Hyde et al. (2003). The CASP index is based on four ontologically grounded domains of need, which are control, autonomy, pleasure and self-realization. SHARE uses the revised 12-item version (CASP-12) with three items per domain: Control (“My age prevents me from doing the things I would like to”, “I feel that what happens to me is out of my control”, “I feel left out of things”), autonomy (“I can do the things I want to do” (reverse coded), “Family responsibilities prevent me from doing what I want to do”, “Shortage of money stops me from doing things I want to do”), pleasure (“I look forward to each day” (reverse coded), “I feel that my life has meaning” (reverse coded), “On balance, I look back on my life with a sense of happiness”(reverse coded)) and self-realization (“I feel full of energy these days” (reverse coded), “I feel that life is full of opportunities” (reverse coded), “I feel that the future looks good to me” (reverse coded)). Each item should be rated on a 4-point Likert scale, where the answer “often” is assigned a value of 1, “sometimes” a value of 2, “rarely” a value of 3 and “never” a value of 4. However, some items are reverse coded. This results in a sum score that ranges from a minimum of 12 to a maximum of 48, where higher values are associated with a higher QoL (Mehrbrodt, 2021).

The EURO-D and the CASP-12 are shown in **Table A 4** and **Table A 5**.

5.2.3 Additional measures

In general, SHARE focused on people aged 50 years and older and their potentially younger household members. However, respondents under the age of fifty are excluded from this work in order to focus clearly on care in later life. The data is further limited to people aged between 50 and 90 years, as people of very old age are a rather selective group. In people aged 90 years and older, motor skills, such as speed, and physical performance, such as walking on time, decline with age and show a wide range of abilities (Kawas, 2007). Furthermore, dementia is very common among the oldest-old, affecting about 40 % of people aged 90 years and older (Kawas, 2007; Vargese et al., 2023).

To capture the socioeconomic position of the respondents, information about their level of education is taken into account. Education is measured according to the “International Standard Classification of Educational Degrees (ISCED-97)”. The ISCED-97 categorizes respondents into “low”, meaning pre-primary, primary or lower secondary education, “medium”, meaning secondary or post-secondary education, and “high”, meaning first and second stage of tertiary education, education groups (UNESCO-UIS, 2006). For all countries, country-specific degrees are assigned to the tertiles. To include a second more financial aspect of the socioeconomic position, all analyses also controlled for wealth. As in the case of education, country-specific tertiles (low, medium, high) are created. Wealth is based in the household’s total net worth, which includes financial assets such as savings, net equity values and mutual funds, and housing assets such as the value of the primary residence, consumer durables like a car or other real estates. A decisive advantage of the wealth is that it also captures sources that are not based solely on monetary income from paid work. Especially in older cohorts, this is a more accurate approach, as many people are already retired and do not longer receive a direct income from paid work anymore (Galobardes et al., 2006). Since a certain level of physical health is a necessary precondition to care for others, this is included as a possible confounder. Commonly used concepts include the need for ADL, meaning life-sustaining self-care activities such as feeding, bathing, and ambulation, or IADL, meaning activities such as using the telephone, preparing meals and managing finances (Lawton & Brody, 1969). Since IADL are more complex and include tasks that are necessary for an independent living, this measure is considered in the papers related to this doctoral thesis.

Paper 3 additionally includes three policy indicators based on Verbakel et al. (2023). The first, “carer support”, captures the types of support available for care through and within the family, such as counselling, financial allowance or care leave options. Furthermore, financial support for care recipients and the number of beds for LTC per 1.000 people in the population aged 65 years and older in a country are taken into consideration.

5.3 Analytical strategy

In Paper 1, Poisson regression models with robust variance are used to investigate the association between several characteristics of the caring situation, such as the type and location of care and relationship type between carer and care recipient, and mental health. Poisson regressions are an alternative to logistic regression that enable the estimation of measures that are easier to interpret than Odds Ratios, in particular, when the outcomes of interest are common (Zou, 2004). Furthermore, average marginal effects (AME) additionally enable the quantification of predicted differences in proportions between different groups. For example, how the adjusted prediction for carers differs from the adjusted predictions for non-carers (Williams, 2012).

Paper 2 estimates a series of multilevel linear regression models with individuals nested in countries. Here, a cross-sectional analysis assesses differences in level of the outcomes, depressive symptoms and QoL, at baseline in relation to the exposure, which is caring. Longitudinal analysis used follow-up measures of depressive symptoms and QoL as the outcome, which are adjusted for the corresponding baseline value.

Paper 3 applies propensity score matching (PSM), which was first introduced by Rosenbaum and Rubin in 1983 (Rosenbaum & Rubin, 1983). PSM matches observed treatments in the data with controls that have similar profiles (Kane et al., 2020). In Paper 3, PSM is used to compare the mental health trajectories of people who became carers, which are called the “treatments”, with people who remained non-carers, which are called the “controls”.

All models are adjusted for the previously described covariates and are calculated separately for men and women. This makes it possible to examine gender-specific differences in the engagement in care and the association between caring and carer mental health. All calculations and figures in the papers are created in Stata (Version 18.0). All estimates are presented together with confidence intervals (CI 95 %) in the “Results” section of each paper and further methodological details can be found in the “Methods” section of each paper.

6 Results (Published Original Articles)

- 6.1 Schaps, V., Hansen, T., Nes, R. B., & Wahrendorf, M. (2025). How are location and type of caring associated with the carer's mental health? Cross-sectional and longitudinal findings from SHARE. *European Journal of Ageing*, 22(5), 1-15. <https://doi.org/10.1007/s10433-025-00843-3>**

This paper investigates the prevalence of different care situations as well as the cross-sectional and longitudinal associations between these different care situations and depressive symptoms. Information come from SHARE wave 6 and 8 and depressive symptoms are measured by a binary indicator from the EURO-D depression scale. In doing so, the location of care (inside and outside the household) and type of care (personal care, practical household help, help with paperwork) are taken into account.

Overall, women, people in the oldest age group and lowest socioeconomic groups are more likely to provide personal care inside the household, while the opposite was true for caring outside the household, regardless of type. Furthermore, findings indicate that for men and women personal care inside the household is associated with an increased risk of reporting and developing depressive symptoms. Also personal care and help with paperwork outside the household is associated with an increased risk of reporting depressive symptoms, while no significant results are found for practical household help.

- 6.2 Schaps, V., McMunn, A., Deindl, C., & Wahrendorf, M. (2025). Carer mental health in Europe. Does it matter who you care for? Cross-sectional and longitudinal findings from SHARE. *Aging Ment Health*, 1-13. <https://doi.org/10.1080/13607863.2025.2558889>**

This paper investigates the prevalence of different relationship types between carer and the person in need of care inside and outside the household as well as the cross-sectional and longitudinal associations between these care situations and depressive symptoms. Information come from SHARE waves 1, 2, 6, 7, 8 and 9 and depressive symptoms are measured by the continuous EURO-D depression scale score. A special focus was placed on whether personal care was provided to a spouse, parent, parent-in-law, child, an other relative or an other non-relative.

Overall, personal care inside the household is mostly provided for spouses, while personal care outside the household is mostly provided for parents. Both inside and in particular care outside the household, especially for a parent, an other relative or an other non-relative. is more common among women. Caring for primary relatives like spouses, own parents and children is associated with an increased number of depressive symptoms. Most results are slightly more pronounced for women and for caring inside the household. For men and women, providing care for a spouse inside the household is associated with an increased number of depressive symptoms, even in the long term.

- 6.3 Wahrendorf, M., McMunn, A., Xue, B., Schaps, V., Deindl, C., Di Gessa, G., & Lacey, R. E. (2025). Mental health trajectories of men and women who start providing personal care: European findings from SHARE using propensity score matching. *J Gerontol B Psychol Sci Soc Sci*, 80(6), gbaf053. <https://doi.org/10.1093/geronb/gbaf053>**

This paper compares mental health trajectories of respondents transitioning into personal care inside the household with those of matched non-carers from the same country. Information come from nine SHARE waves and depressive symptoms are measured by the continuous EURO-D depression scale score.

Men and women have a slight increase before the transition and a clear increase in depressive symptoms during their transition into personal care inside the household. This worsening of mental health during the transition into personal care is slightly more pronounced for women and those in poorer individual socioeconomic circumstances. At the macro level, no systematic differences in terms of LTC policy indicators are found.

7 Discussion

7.1 Summary of findings

Prevalence of caring

Overall, descriptive findings demonstrate that caring is an issue in the life of many people aged 50 years and older. About 7 % of men and 9.5 % of women provide personal care, which includes tasks such as dressing, bathing or showering, eating, getting in or out of bed and using the toilet, for someone living inside their own household. About 27 % provide any type of care, either personal care, practical household help or help with paperwork, for someone outside the household (men: 27.2 %; women: 27.4 %). Looking more closely at these different types of care outside the household, the prevalence of care types varies a lot: 23.2 % of men and 22.2 % of women help with practical household tasks, including tasks such as home repairs, gardening, transportation, shopping and household chores, and 7.9 % of men and 9.6 % of women help with paperwork, including tasks such as filling out forms and setting financial or legal matters. Furthermore, 2.7 % of men and 7.9 % of women provide personal care for someone living outside their own household. Consequently, the prevalence of personal care outside the household (men: 2.7 %; women: 7.9 %) is considerably lower than for care inside the household (men: 7 %; women: 9.5 %). In line with traditional gender roles, women more often focus on personal care for those in need of care, while men more often focus on practical work that does not require physical proximity (Paper 1, Table 1). All these findings enable a very detailed analysis of where men and women provide care and what types of care they perform. The key finding, that women engage in personal care much more often than men is consistent with the results from other studies (Skinner & Sogstad, 2022).

Furthermore, caring can be addressed to different people. While personal care inside the household is usually for the spouse or partner, outside the household it is usually a parent who needs care. 5.7 % of men and 6.5 % of women care for a spouse inside the own household, while care for a spouse outside the household is rare (men: 0.7 %; women: 1.0 %). Here, there are clear differences by gender, particularly in terms of care outside the household. While among carers inside the household, the proportion of women caring for a parent (1.5 %) is only slightly higher than among men (0.7 %), differences between genders are more pronounced for personal care outside the household (men: 1.2 %; women: 3.2 %). These gender differences also apply to all the other relationship types, in particular caring

for an other relative (men: 0.5 %; women: 1.8 %) or non-relative (men: 0.6 %; women: 1.8 %) outside the household, which is rarely done by men.

These results highlight that caring still differs a lot according to gender of the carer. Differences are largest for personal care, with women providing significantly more personal care than men (Paper 2, Table 2). The presented gender differences are in line with previous studies (Tur-Sinai et al., 2020; Wetzstein et al., 2015). However, De Klerk et al. (2021) and Broese van Groenou et al. (2013) found a higher prevalence among men in terms of caring for a spouse, but without further differentiating the type of care provided.

Burdensome caring situations

Findings indicate that personal care, both inside and outside the household, is associated with a significantly higher level of depressive symptoms than other types of care. Furthermore, men and women without increased depressive symptoms have an increased risk of developing elevated depressive symptoms four years after personal care was reported. But also help with paperwork outside the household is stronger associated with elevated depressive symptoms than practical household help (Paper 1, Table 4).

These results may be explained by the fact that personal care tasks are very time-dependent and need to take place regularly and usually at specific times. For example, feeding someone or helping someone to get up are tasks that naturally have a specific time frame and cannot be postponed. Also help with paperwork, such as filling out forms and dealing with financial or legal matters, may involve issues that sometimes cannot wait and can have legal or financial consequences if they are delayed. Therefore, it may be plausible that personal care and help with paperwork cannot be coordinated as flexible with other activities of the carer as practical household help. Furthermore, it is conceivable that personal care and help with paperwork involve more stressful tasks, for example physically demanding tasks in the case of personal care or intellectually challenging tasks in the case of help with paperwork. In contrast, practical household help in general include tasks such as shopping, gardening or repairs, which can probably be carried out more flexibly in terms of time. In addition, these tasks are mostly not needed as regularly as for example personal care, which is generally needed daily.

Furthermore, caring in several relationship types between carer and care recipient inside and outside the household are associated with poorer mental health outcomes. Caring for a spouse (both genders), parent (both genders), child (both genders), parent-in-law (only for women), other relative (only for women) or non-relative (both genders only outside the

household) is associated with an increased number of depressive symptoms. In accordance with previous research work (Gallicchio et al., 2002; Marks et al., 2002), the strongest associations were found for caring of primary relatives like spouses, parents and children. In addition, differences between parents and parents-in-law are found among men. While men who cared for their own parents either inside or outside the own household had significantly higher scores for depressive symptoms than non-carers, this pattern is not found in care for parents-in-law (Paper 2, Table 3). Respondents providing care to their cohabiting spouse (both genders) or child (only for women) experienced an increase in depressive symptoms even in the long run (Paper 2, Table 3).

Only in terms of personal care results for caring inside or outside the household can be directly compared. In general, personal care both inside and outside the household is associated with an increased prevalence of depressive symptoms, although there is a stronger association for personal care inside the household. The prevalence of elevated depressive symptoms in personal care inside the household is 6.4 percentage points (female: 10.7 percentage points) and in personal care outside the household 5.8 percentage points (women: 7.2 percentage points) higher for male carers compared with their non-caring counterparts (Paper 1, Table 4). These findings are in line with explanations from other studies, stating that caring outside the own household has a less direct impact on sleep and social life than caring inside the household (Hansen et al., 2013). Moreover, the findings are consistent with research on the phenomenon of “blurring of boundaries”, which has been frequently explored in studies on paid work (Eurofound and the International Labour Office, 2017). In this context, employees working from home more often reported an imbalance between work and leisure time (Simenenko & Lentjushenkova, 2021). Applied to caring, the cross-sectional findings provide evidence that also caring “from home”, meaning care inside the household, was slightly more often associated with an increased risk of reporting depressive symptoms than care outside the household. Thus, many carers may also perceive this imbalance between care work and leisure time.

However, when taking the relationship type between carer and care recipient into consideration, there are hardly any differences whether care for parents takes place inside or outside the household of the carer. For example, men who care for a parent inside the household had a 0.417-point (women: 0.473) and outside the household a 0.433-point (women: 0.471) higher score of depressive symptoms compared with non-carers (Paper 2, Table 3). These results in turn also provide evidence, in line with research on working conditions and commuting in paid work for example from Clark et al. (2019), that commuting and more time

spent on travelling to visit the person in need of care is perceived as burdensome. In addition, these results may reflect the fact that in particular care for parents, which usually takes place outside the household of the carer, often competes with other time intensive activities because carers are potentially younger and still in paid work or may have other duties such as childcare.

Lastly, caring for a spouse seems to be even more demanding when it takes place outside the household. Here, women who care for a spouse inside the household had a 0.690 (men: 0.420) and outside the household an even 0.865-point (men: 0.715) higher score of depressive symptoms compared with non-carers (Paper 2, Table 3). At this point, it should be noted that it is rather rare that spousal care takes place outside the own household. This situation may only apply when the spouse lives in a formal long term care setting, a situation which is perceived as particularly burdensome.

Long-term perspective

For personal care, the longitudinal analyses reveal an increased risk of developing elevated depressive symptoms after four years for men and women inside the household and only for women outside the household (Paper 1, Table 4). In addition, an increase in depressive symptoms even in the long run is found for male and female respondents who provide personal care for their cohabiting spouse and women who provide personal care for a cohabiting child (Paper 2, Table 4). These findings of lasting long-term effects of caring are in line with previous studies, for example from Stöckel and Bom (2022).

As part of sensitivity analyses, longitudinal models are recalculated to account for possible changes between two waves in SHARE. This includes four possible outcomes, which are caring at both waves, giving up caring, starting caring and no caring at both waves. In particular, long-term personal care, defined as caring in two waves in SHARE, is associated with worse mental health outcomes. The prevalence of elevated depressive symptoms is 5.1 percentage points higher for women providing personal care inside and even 6.9 percentage points higher for women providing personal care outside the household in both waves compared with women not caring at both waves. Among men providing personal care in both waves, the prevalence of elevated depressive symptoms inside the household is 5.1 percentage points and outside the household 4.0 percentage points higher compared to non-carers. These results demonstrate that personal care provided over a longer period, is associated with a lasting negative mental health effect. Personal care outside the household over a longer period seems to be particularly stressful for women (Paper 1, Supplementary Table

S2). In line with findings from Lindt et al. (2020), these findings also tend to support the central ideas of the “wear-and-tear hypothesis”, which states that mental health deteriorates with increasing duration of caring as resources are depleted over time.

Furthermore, a closer look at mental health trajectories reveals that both men and women experience a clear increase in depressive symptoms when they start providing personal care inside the household. This increase is more pronounced among women and people in disadvantaged socioeconomic circumstances and it begins even before the transition. This may be explained by the fact that the person in need of care already experienced health issues that placed a burden on the participants prior to their active involvement in care (Paper 3, Figure 2 and Figure 3). In line with previous findings for example from Lacey et al. (2019) and Lacey et al. (2024), these findings provide support for the causal direction of the association between caring and mental health by showing that starting personal care inside the household is accompanied with an increase in depressive symptoms.

Further results

As part of further sensitivity analyses, some of the analyses were rerun using a positive outcome variable closely related to mental health, the CASP index. In general, the results of the CASP index as a measure for QoL are like those for depressive symptoms. For both mental health indicators, the cross-sectional results revealed that caring for a close relative like a spouse, parent or child was associated with poorer mental health, while no notable differences between carers and non-carers were observed for other relationship types (Paper 2, Table 3). As depressive symptoms and QoL and their association with caring have not been considered alongside each other in previous research, this doctoral thesis presents new insights around this topic.

Further new insights are gained from an analysis that differentiates between three subscales of the EURO-D scale in order to whether the associations exist across subscales or are determined by a specific scale. The first subscale, “affective suffering”, covers symptoms such as depressive mood, wishing death and tearfulness, and a second subscale, “motivation”, covers symptoms such as loss of interest, poor concentration and lack of enjoyment (Prince et al. 1999; Guerra et al. 2015). A third subscale covers somatic factors, such as insomnia, loss of appetite and fatigue. When estimating each subdimension of the EURO-D scale separately, the results were similar, with slightly stronger associations in the “affective suffering” subscale (Paper 1, Supplementary Table S3).

When considering mental health also independent of caring, this work found that the overall magnitude of increased depressive symptoms was higher in women. In the overall sample of people aged 50 years and older, women have higher prevalence of increased depressive symptoms than men. 31.9 % of women and only 18.1 % of men have elevated depressive symptoms (Paper 1, Table 1). Continuous measurement of depressive symptoms indicates that women have a considerably higher average of depressive symptoms on a 12-point scale than men (women: 2.8; men: 2.0) (Paper 2, Table 1). These gender differences are in line with previous research, such as a literature review revealed, that in 82 % of all studies, results showed gender differences in depression to the disadvantage of women (Girgus et al., 2017). Furthermore, using information from SHARE, this work found differences in the prevalence of increased depressive symptoms across countries with a tendency for less pronounced elevated depressive symptoms in Northern European countries, for example Sweden and Denmark, than in Southern European countries, for example Portugal and Italy, or Eastern European countries, for example Poland (Paper 1, Figure 3). Even though previous literature does not provide a clear picture of which countries are particularly affected, the pattern that mental health outcomes differ across countries has already been demonstrated in several studies before (Arias-de la Torre et al., 2021; Hapke et al., 2019; Van de Velde et al., 2010). While, for example, Hapke et al. (2019) and Arias-de la Torre et al. (2021) found highest prevalence of depressive symptoms, both using PHQ-8, in Portugal, Luxembourg and Germany, Van de Velde et al. (2010) found highest mean depression scores, assessed by the 8-item version of the CES-D, in Eastern European countries like Hungary, Ukraine and Bulgaria.

Furthermore, the results of this doctoral thesis suggest that the national context may influence the likelihood to become a carer as LTC indicators, like carer support, cash benefits to the care recipient and LTC beds per 1.000 in the population of people aged 65 years and older, vary a lot by country (Paper 3, Table 2). At the same time no systematic differences are found in mental health trajectories by the level of these supportive LTC indicators. This suggests that personal care inside the household has a negative impact that cannot be mitigated by policy interventions (Paper 3, Figure 4), a finding also demonstrated by Kaschowitz and Brandt (2017).

7.2 Strengths and limitations

A major strength of the papers in this doctoral thesis is that they include not only a cross-sectional perspective but also a longitudinal perspective, allowing for the analysis of the development of depressive symptoms over time. Another strength lies in the fact that great attention is paid to what is meant by care including the location and type of care and the relationship type between carer and care recipient. In addition, the papers make a distinction between men and women in order to investigate gender-specific prevalences of certain care situations and its association with mental health, which may differ between men and women. The main mental health outcome under investigation, which is depressive symptoms, may involve some potential limitations. The instrument used to assess depressive symptoms in people aged 50 years and older, the EURO-D scale, has a potential gender bias. Many aspects covered in the scale refer to symptoms that are more frequent in women, such as depressed mood, appetite and sleep disturbances. So-called typically male symptoms, such as risk-taking behaviour, alcohol or drug use, are not included in EURO-D (Cavanagh et al., 2017; Martin et al., 2013). As a result, the prevalence of depressive symptoms in men may be underestimated.

Furthermore, this work has a look at differences between countries but not at possible cultural differences within countries. However, norms are not exclusively set at the country level, but also people living in the same country may differ a lot, for example in their attitudes toward socio-cultural norms. For example, a study from the United States showed that African Americans and Hispanics are more likely than white people to see caring as their duty (Falzarano et al., 2022).

A strength of the data source of this work, SHARE, is that it includes information from several European countries, enabling separate analyses by country. However, due to the already complex nature of the research questions, country differences are only a minor focus in this work. To address this limitation, for personal care inside the household an exemplary country-specific analysis was included (Paper 1, Figure 2). In line with findings from other studies (Huijts et al., 2017; Van de Velde et al., 2010), the figure demonstrates that the prevalence of elevated depressive symptoms varies across countries, which generally better mental health outcomes in Northern European countries. Furthermore, in all countries people who provided personal care inside the household had higher risks of reporting elevated depressive symptoms than non-carers. Therefore, there is good reason to assume that despite differences in the general prevalence of depressive symptoms across Europe, the association

between personal care inside the household and carer mental health appears to be similar across countries.

SHARE allows to control over a wide range of potential confounders, thereby strengthening the causal claim. In addition to the aspects controlled for in this work, further important aspects are the intensity of care, for example if caring is needed daily or less often, the quality of the relationship between carer and care recipient and ethnicity. For example, previous research found most severe mental health effects for intensive carers, who provide many hours of care per week (Bom & Stöckel, 2021; Broese van Groenou et al., 2013; Chakraborty et al., 2023; Kolodziej et al., 2022; Roth et al., 2009; Stöckel & Bom, 2022; Verbakel et al., 2017; Zygouri et al., 2021). In their study for Britain and Belgium, Dujardin et al. (2011) showed that intensive care in both countries was associated with poorer health than less intensive care. They even found that for women who care less 20 hours per week, a slightly reduced risk of reporting poor health. Gender-separated analysis by Swinkels et al. (2019) indicate that more hours of care were associated with greater burden only for men, but not for women. However, there also seems to be no universally valid definition of “intensive care”. Sometimes it is defined as more than eleven hours of care per week (Verbakel et al., 2017), more than 40 hours per week (Chakraborty et al., 2023) or most commonly as 20 hours of care per week (Bom & Stöckel, 2021; Dujardin et al., 2011; Roth et al., 2009) or 80 hours per month (Kolodziej et al., 2022). Furthermore, there is a lot of research on the quality of the relationship between carer and care recipient. Cantor (1983) found that the closer the personal bond between carer and care recipient, the greater the amount of strain. In Litwin et al. (2014) the closeness of the relationship was ascertained by distinguishing whether the carer viewed the care recipient as a confidant or not. In contrast to Cantor (1983), Litwin et al. (2014) reported that carers who had a confidant relationship with the person in need of care reported fewer depressive symptoms. In contrast, they reported that carers who had a confidant relationship with the person in need of care reported fewer depressive symptoms. who had a confidant relationship with the person in need of care reported fewer depressive symptoms. In a study from the United States, Fauth et al. (2012) showed that greater baseline closeness, assessed by a 6-item instrument including statements such as “My relative always understands what I value in life” and “My relative always makes me feel like a special person”, predicted lower levels of baseline depression, but also greater worsening in mental health over time. In addition, previous studies reveal that intensity of care and the relationship quality are not independent of each other. For example, Kolodziej et al. (2022) demonstrates that intensive cares, defined as those provides at least 20 hours of care per week or

80 hours per month, were less likely to report a high relationship quality than less intensive carers. In addition, Roth et al. (2009) points to interesting findings on ethnicity. They reveal that in the United States White carers are more likely than Afro American carers to report mental and emotional strain as a results of caring, even though African American carers reported more hours and higher rates of co-residence care (Roth et al., 2009). Also a study from the United Kingdom revealed differences in caring profiles and intensity of caring among Bangladeshi, Pakistani and White individuals (Wells et al., 2025).

7.3 Theoretical recommendations

This work has demonstrated that there are many ways to define caring outside a formal setting and even when a similar term is used, it does not always refer to the same. As shown, different aspects of the care situation, such as the location of care, the type of care and the relationship type between the carer and the care recipient, are of great importance, which should always be considered in upcoming research.

Moreover, this work showed that fundamental theories primarily focusing on paid work, can also be applied to caring outside a formal setting. According to the central ideas of the job demand-control model, it was demonstrated that care situations involving high demands and low autonomy, for example personal care, can be categorised as “high strain jobs” because they are more likely to be perceived as burdensome than other types of care. In addition, it is evident that caring inside the own household is challenging. This may be due to carers being unable to exit the situation, resulting in an experience of “blurring of boundaries”, similar to the experience of people working from home.

In addition, the findings highlight that there are still large differences between men and women, in particular in the prevalence of different care situations. To avoid inaccurate conclusions, findings should always be differentiated by gender.

To strengthen existing evidence on the cause-and-effect relationship and long-term association between caring and mental health, a special focus in the future should be placed on longitudinal analyses.

7.4 Policy recommendations

This work was able to show, that caring outside a formal setting plays a key role in caring in later life. Considering demographic changes and ageing of societies, future generations will probably be faced with even more people requiring care. Consequently, further societal and

governmental support is needed to ensure dignified aging for all in the future. In this, three strands should be focussed. At first, care situations identified as particularly burdensome should be reduced. Second, it is necessary to create better conditions for carers. Third, a special focus should be placed on the improvement of general health to reduce the general need for care.

Reduction of burdensome care situations

This work was able to show that certain care situations are more likely to be associated with poorer mental health than others. These more demanding care situations include personal care inside the household, in particular for a primary relative. These situations are more likely to be associated with increased depressive symptoms than practical household help outside the household of care for a more distant relative.

Supportive LTC policies may play a significant role here, especially when they are able to reduce the general extent of which those care situations that are more often experienced as burdensome are needed. For example, Quashie et al. (2022) found that social spending at a national level reduced the amount of personal care inside the household. Likewise, Verbakel (2018) found that a more generous formal LTC provision, for example more LTC beds in institutions and hospitals, more LTC workers and a higher public expenditure on LTC, crowded out intensive and in turn more burdensome care situations.

Create better conditions for carers

In many countries, there are already a variety of approaches that involve financial, psychological and personal support and opportunities for carers to relieve from care. For example, in Germany financial support (“Pflegegeld”) is provided for those in need of care, who live outside a nursing home. The amount of financial support is based on the level of care needed. In 2025 financial support in Germany ranges between 347 Euro (for “Pflegegrad 2”) and 990 Euro (for “Pflegegrad 5”) each month (Federal Ministry of Health, 2025). Like in Germany, financial support in other European countries is either paid to the person requiring care (“care allowance”) or to the carers (“attendance allowance”) (Courtin et al., 2014).

Above this, to compensate for lost wages in the event of a short-term inability to work due to care responsibilities, employees in Germany can get further financial support (“Pflegeunterstützungsgeld”) for up to ten working days per calendar year, which corresponds to 90 % of the lost net wages. Furthermore, employees in companies with more than 15 employees in Germany have a legally defined entitlement to care leave (“Pflegezeit”), which involves full or partial unpaid exemption from work for up to six months. Also, there are

short-term relief options with a total annual amount of up to 3.539 Euro per year. This is helpful if people in need of care are temporarily dependent on full inpatient care, for example after a fall (“Kurzeitpflege”) or if carers take time off or go on vacation (“Verhinderungspflege”) (Federal Ministry of Health, 2025).

Other European countries also offer various options for paid and/or unpaid leave. In many countries, pension points are introduced as part of pension reform. These are usually credited in form of a certain amount of time added to the carer’s working hours. However, in most cases, pension points are granted to a much greater extent for childcare than for care in later life (Courtin et al., 2014).

In addition to these opportunities for financial support and time relief, carers may benefit from behaviour-oriented approaches. For example, a systematic review by Wiegelmann et al. (2021) had a look at different interventions for carers of persons with dementia. In this, the most positive effects in the reduction of depressive symptoms have been found for cognitive behavioural approaches. This was explained by three possible mechanisms: Carers learn to use cognitive restructuring or reappraisal techniques and benefit from focusing on positive thoughts, carers learn to focus on self-care practices, relaxation and communicating their own needs and carers gain more competence in caring for others. In addition, the review found that interventions in the areas of leisure and physical activity as well as psychoeducational programs, have been associated with a reduction in burden (Wiegelmann et al., 2021). A qualitative study with data from seven European countries identified that health professionals who have regular contact with carers, develop action plans to meet their needs and identify appropriate support services could play an important role in addressing adverse health effects for carers outside a formal setting (Ambugo et al., 2021). A study on carers of people with dementia revealed that counselling, family discussions and support groups have been experienced as helpful (Zarit & Zarit, 1982) .

Since people aged 50 years and older are often in paid work alongside caring responsibilities, a special focus should also be placed on this area of life. According to analysis of my doctoral thesis, for example, 30.2 % of men and almost 32.3 % of women engaged in paid work and practical household help outside the household. About 5 % of men and 6.1 % of women engaged in paid work and personal care inside the household at the same time (Paper 1, Table 2). Here, employers are required to create good conditions not only for childcare, but also for care in later life, allowing a good balance of caring responsibilities and paid work. For example, paid and unpaid leave options, flexible work hours, vacation and overtime arrangements or working from home or from the household of the person in need of care

could help to promote mental health of carers (Pavalko & Henderson, 2006; Wiecezorek et al., 2022). A report from the United States emphasizes that employers more often focus on support for newborns, but pay much less attention to other form of care, which may be also true for Europe (Fuller & Raman, 2019). Therefore, there is untapped potential on the employer side that should be addressed in the future.

In addition, previous findings suggest that effectiveness of approaches depends on various factors such as the national context and the value of carers in a country, work organisation, family structures and the level of care-dependency (Potočnik & Hlebec, 2025; Revenson et al., 2016). Therefore, it is appropriate to examine more closely which approaches are suitable for which group of carers (Revenson et al., 2016).

Improve general health

The third aspect of political engagement should involve a focus on medical process and prevention. More tailored medical research and the development of better screening programs on common diseases, such as cancer or dementia, which occur frequently in old age and are often linked to care dependency, are important aspects to focus on. Additionally, increased efforts in health promotion and disease prevention could reduce behavioural risk factors such as smoking, alcohol consumption, poor nutrition and lack of exercise, which are causes of many chronic diseases (Fries et al., 1998; Gmeinder et al., 2017). For example, a recent study from Germany reveals that, 36 % of all dementia cases can be attributed to modifiable risk factors such as physical inactivity, smoking and alcohol consumption, which could be prevented by more targeted prevention (Blotenberg & Thyrian, 2025).

Further aspects

As the results of this work and further research have already shown, gender differences in the prevalence of caring still exist today and women are more often engaged in burdensome care situations than men. Thus, changing role expectations between men and women could result in men becoming more involved in caring, thereby promoting a more balanced division of care work between genders.

In addition, the whole society could benefit from a greater focus on mental health awareness and mental health literacy. When mental health of carers becomes a topic of broad societal attention, carers can be empowered to better and possibly earlier address mental health issues.

7.5 Conclusion

Caring outside a formal setting is an important public health challenge today as it is the most important form of care in later life. There are indications that more people will require care in the future, while at the same time fewer potential carers are available, for example due to larger geographical distances between parents and their children, increasing childlessness and a decrease in lifelong marriages. Therefore, addressing the mental health of carers is essential to sustain this fundamental pillar of care in our society.

There is not one universally accepted definition of caring. Rather, caring can include various locations of care, for example care inside or outside the household, types of care, for example personal care, practical household help and help with paperwork, and relationship types between carers and care recipients, for example spouses, parents, parents-in-law, children, other relatives or non-relatives. Because these aspects are important for health-related consequences for the caring person they need to be considered to identify conditions under which caring is detrimental to health and to provide tailored support for the unique challenges carers face in different situations. According to this work, the most vulnerable groups are those providing personal care, care inside the household and care for a primary relative.

8 References

- Addis, M. E., & Mahalik, J. R. (2003). Men, masculinity, and the contexts of help seeking. *Am Psychol*, 58(1), 5-14. <https://doi.org/10.1037/0003-066x.58.1.5>
- Alderotti, G., Tomassini, C., & Vignoli, D. (2022). ‘Silver splits’ in Europe: The role of grandchildren and other correlates. *Demographic Research*, 46(21), 619-652. <https://doi.org/10.4054/DemRes.2022.46.21>
- Almeida-Meza, P., Di Gessa, G., Lacey, R., Xue, B., & McMunn, A. (2025). Gender inequalities in care across long-term care public spending systems in Europe: evidence from the European Health Interview Survey. *International Journal of Care and Caring*, 9(3), 490-503. <https://doi.org/10.1332/23978821Y2025D000000133>
- Alzheimer's Disease International. (2013). *Policy Brief for Heads of Government. The Global Impact of Dementia 2013-2050* Retrieved 07/12/2025 from <https://www.alzint.org/resource/policy-brief-the-global-impact-of-dementia-2013-2050/>
- Ambugo, E. A., de Bruin, S. R., Masana, L., MacInnes, J., Mateu, N. C., Hagen, T. P., & Arrue, B. (2021). A Cross-European Study of Informal Carers’ Needs in the Context of Caring for Older People, and their Experiences with Professionals Working in Integrated Care Settings. *International Journal of Integrated Care*, 21(3), 1-11. <https://doi.org/10.5334/ijic.5547>
- American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (Vol. Fifth Edition). American Psychiatric Association.
- Amtmann, D., Kim, J., Chung, H., Bamer, A. M., Askew, R. L., Wu, S., Cook, K. F., & Johnson, K. L. (2014). Comparing CESD-10, PHQ-9, and PROMIS depression instruments in individuals with multiple sclerosis. *Rehabilitation Psychology*, 59(2), 220-229. <https://doi.org/10.1037/a0035919>
- Andersen, I., Thielen, K., Bech, P., Nygaard, E., & Diderichsen, F. (2011). Increasing prevalence of depression from 2000 to 2006. *Scand J Public Health*, 39(8), 857-863. <https://doi.org/10.1177/1403494811424611>

- Angermeyer, M. C., Schindler, S., Matschinger, H., Baumann, E., & Schomerus, G. (2023). The rise in acceptance of mental health professionals: help-seeking recommendations of the German public 1990-2020. *Epidemiol Psychiatr Sci*, 32, e11. <https://doi.org/10.1017/S204579602300001X>
- Angst, J., Gamma, A., Gastpar, M., Lepine, J. P., Mendlewicz, J., Tylee, A., & Depression Research in European Society, S. (2002). Gender differences in depression. Epidemiological findings from the European DEPRES I and II studies. *Eur Arch Psychiatry Clin Neurosci*, 252(5), 201-209. <https://doi.org/10.1007/s00406-002-0381-6>
- Applebaum, A. J. (2022). There is nothing informal about caregiving. *Palliat Support Care*, 20(5), 621-622. <https://doi.org/10.1017/S1478951522001092>
- Arber, S., & Ginn, J. (1994). Gender differences in informal caring. *Health & Social Care in the Community*, 3(1), 19-31. <https://doi.org/10.1111/j.1365-2524.1995.tb00003.x>
- Arias-de la Torre, J., Vilagut, G., Ronaldson, A., Serrano-Blanco, A., Martin, V., Peters, M., Valderas, J. M., Dregan, A., & Alonso, J. (2021). Prevalence and variability of current depressive disorder in 27 European countries: a population-based study. *Lancet Public Health*, 6(10), e729-e738. [https://doi.org/10.1016/S2468-2667\(21\)00047-5](https://doi.org/10.1016/S2468-2667(21)00047-5)
- Backhaus, I., Gero, K., Dragano, N., & Bambra, C. (2023). *Health inequalities related to psychosocial working conditions in Europe*. ETUI. Retrieved 28/12/2025 from <https://www.etui.org/publications/health-inequalities-related-psychosocial-working-conditions-europe>
- Bamicha, E., & Verropoulou, G. (2023). Assessment of the CASP-12 Scale Among People Aged 50+ in Europe: An Analysis Using SHARE Data. In C. H. Skiadas & C. Skiadas (Eds.), *Quantitative Demography and Health Estimates* (pp. 53-60). Springer. <https://doi.org/10.1007/978-3-031-28697-1>
- Barbosa, F., Delerue Matos, A., Voss, G., & Costa, P. (2021). Spousal Care and Pain Among the Population Aged 65 Years and Older: A European Analysis. *Front Med*, 8, 602276. <https://doi.org/10.3389/fmed.2021.602276>

- Barker, J. C. (2002). Neighbors, Friends, and Other Nonkin Caregivers of Community-Living Dependent Elders. *Journal of Gerontology: SOCIAL SCIENCES*, 57B(3), 158–167. <https://doi.org/10.1093/geronb/57.3.s158>
- Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and Positive Health Effects of Caring for a Disabled Spouse: Longitudinal Findings From the Caregiver Health Effects Study. *Psychology and Aging*, 15(2), 259-271. <https://doi.org/10.1037//08S2-7974.15.2.259>
- Belmonte, M., & Nedee, A. (2024). *Demographic projections of long-term care needs in the EU up to 2070*. <https://publications.jrc.ec.europa.eu/repository/handle/JRC136608>
- Bertogg, A., & Strauss, S. (2020). Spousal care-giving arrangements in Europe. The role of gender, socio-economic status and the welfare state. *Ageing and Society*, 40(4), 735-758. <https://doi.org/10.1017/s0144686x18001320>
- Bhan, N., Rao, N., & Raj, A. (2020). Gender Differences in the Associations Between Informal Caregiving and Wellbeing in Low- and Middle-Income Countries. *J Womens Health (Larchmt)*, 29(10), 1328–1338. <https://doi.org/10.1089/jwh.2019.7769>
- Bieber, A., Bartoszek, G., Stephan, A., Broda, A., & Meyer, G. (2018). Formelle und informelle Unterstützung der häuslichen Pflege bei Demenz: Eine Mixed-Method Studie im Rahmen des Actifcare Projekts. *Z Evid Fortbild Qual Gesundhwes*, 139, 17-27. <https://doi.org/10.1016/j.zefq.2018.11.004>
- Biliunaite, I., Kazlauskas, E., Sanderman, R., & Andersson, G. (2022). Informal caregiver support needs and burdens: a survey in Lithuania. *BMJ Open*, 12(1), e054607. <https://doi.org/10.1136/bmjopen-2021-054607>
- Blaauboer, M., Mulder, C. H., & Zorlu, A. (2010). Distances between couples and the man's and woman's parents. *Population, Space and Place*, 17(5), 597-610. <https://doi.org/10.1002/psp.648>

- Blazer, D. G. (2003). Depression in late life. Review and Commentary. *Journal of Gerontology: Medical Sciences*, 58A(3), 249–265.
<https://doi.org/10.1093/gerona/58.3.m249>
- Blotenberg, I., & Thyrian, J. R. (2025). Toward targeted dementia prevention: Population attributable fractions and risk profiles in Germany. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 17(4), e70225.
<https://doi.org/10.1002/dad2.70225>
- Bom, J., Bakx, P., Schut, F., & van Doorslaer, E. (2019). The Impact of Informal Caregiving for Older Adults on the Health of Various Types of Caregivers: A Systematic Review. *Gerontologist*, 59(5), e629-e642.
<https://doi.org/10.1093/geront/gny137>
- Bom, J., & Stöckel, J. (2021). Is the grass greener on the other side? The health impact of providing informal care in the UK and the Netherlands. *Soc Sci Med*, 269, 113562.
<https://doi.org/10.1016/j.socscimed.2020.113562>
- Börsch-Supan, A., Brandt, M., Hunkler, C., Kneip, T., Korbmacher, J., Malter, F., Schaan, B., Stuck, S., Zuber, S., & Team, S. C. C. (2013). Data Resource Profile: the Survey of Health, Ageing and Retirement in Europe (SHARE). *Int J Epidemiol*, 42(4), 992-1001. <https://doi.org/10.1093/ije/dyt088>
- Brenna, E., & Di Novi, C. (2015). Is caring for older parents detrimental to women's mental health? The role of the European North–South gradient. *Review of Economics of the Household*, 14(4), 745-778. <https://doi.org/10.1007/s11150-015-9296-7>
- Broese van Groenou, M. I., & De Boer, A. (2016). Providing informal care in a changing society. *Eur J Ageing*, 13(3), 271-279. <https://doi.org/10.1007/s10433-016-0370-7>
- Broese van Groenou, M. I., de Boer, A., & Iedema, J. (2013). Positive and negative evaluation of caregiving among three different types of informal care relationships. *Eur J Ageing*, 10(4), 301-311. <https://doi.org/10.1007/s10433-013-0276-6>

- Brown, S. L., & Kawamura, S. (2010). Relationship quality among cohabitators and marrieds in older adulthood. *Soc Sci Res*, 39(5), 777-786.
<https://doi.org/10.1016/j.ssresearch.2010.04.010>
- Brown, S. L., & Lin, I. F. (2022). The Graying of Divorce: A Half Century of Change. *J Gerontol B Psychol Sci Soc Sci*, 77(9), 1710-1720.
<https://doi.org/10.1093/geronb/gbac057>
- Brown, S. L., & Wright, M. R. (2017). Marriage, Cohabitation, and Divorce in Later Life. *Innov Aging*, 1(2), igx015. <https://doi.org/10.1093/geroni/igx015>
- Burns, C. M., Abernethy, A. P., Leblanc, T. W., & Currow, D. C. (2011). What is the role of friends when contributing care at the end of life? Findings from an Australian population study. *Psychooncology*, 20(2), 203-212.
<https://doi.org/10.1002/pon.1725>
- Buyukkececi, Z., & Leopold, T. (2024). Parent–Child Relationships Following Gray Divorce: Stronger Ties With Mothers, Weaker Ties With Fathers. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 79(5), 1-9.
<https://doi.org/10.1093/geronb/gbac004>
- Cantor, M. H. (1983). Strain Among Caregivers: A Study of Experience in the United States. *The Gerontologist*, 23(6), 597-604. <https://doi.org/10.1093/geront/23.6.597>
- Cavanagh, A., Wilson, C. J., Kavanagh, D. J., & Caputi, P. (2017). Differences in the Expression of Symptoms in Men Versus Women with Depression: A Systematic Review and Meta-analysis. *Harv Rev Psychiatry*, 25(1), 29-38.
<https://doi.org/10.1097/HRP.0000000000000128>
- Chakraborty, R., Jana, A., & Vibhute, V. M. (2023). Caregiving: a risk factor of poor health and depression among informal caregivers in India - A comparative analysis. *BMC Public Health*, 23(1), 42. <https://doi.org/10.1186/s12889-022-14880-5>
- Clark, B., Chatterjee, K., Martin, A., & Davis, A. (2019). How commuting affects subjective wellbeing. *Transportation*, 47(6), 2777-2805.
<https://doi.org/10.1007/s11116-019-09983-9>

- Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., Morgan, C., Rüsch, N., Brown, J. S. L., & Thornicroft, G. (2015). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychological Medicine*, 45, 11-27.
<https://doi.org/10.1017/S0033291714000129>
- Courtenay, W. H. (2000). Constructions of masculinity and their influence on men's well-being. *Social Science & Medicine*, 50, 1385-1401.
- Courtin, E., Jemai, N., & Mossialos, E. (2014). Mapping support policies for informal carers across the European Union. *Health Policy*, 118(1), 84–94.
<https://doi.org/10.1016/j.healthpol.2014.07.013>
- Courtin, E., Knapp, M., Grundy, E., & Avendano-Pabon, M. (2015). Are different measures of depressive symptoms in old age comparable? An analysis of the CES-D and Euro-D scales in 13 countries. *Int J Methods Psychiatr Res*, 24(4), 287-304.
<https://doi.org/10.1002/mpr.1489>
- Da Roit, B., Hoogenboom, M., & Weicht, B. (2015). The Gender Informal Care Gap. *European Societies*, 17(2), 199-218.
<https://doi.org/10.1080/14616696.2015.1007153>
- Dahlberg, L., Demack, S., & Bambra, C. (2007). Age and gender of informal carers a population-based study in the UK. *Health and Social Care in the Community*, 15(5). <https://doi.org/10.1111/j.1365-2524.2007.00702.x>
- Davidson, K. (2001). Late life widowhood, selfishness and new partnership choices: a gendered perspective. *Ageing and Society*, 21(3), 297-317.
<https://doi.org/10.1017/s0144686x01008169>
- De Klerk, M., De Boer, A., & Plaisier, I. (2021). Determinants of informal care-giving in various social relationships in the Netherlands. *Health Soc Care Community*, 29(6), 1779-1788. <https://doi.org/10.1111/hsc.13286>
- De Koker, B. (2009). Socio-demographic determinants of informal caregiving: co-resident versus extra-resident care. *Eur J Ageing*, 6(1), 3-15.
<https://doi.org/10.1007/s10433-008-0103-7>

- de Luca, G., & Lipps, O. (2005). Fieldwork and Survey Management in SHARE. In A. Börsch-Supan & H. Jürges (Eds.), *The Survey of Health, Aging, and Retirement in Europe – Methodology*. Mannheim Research Institute for the Economics of Aging.
- Deindl, C., & Brandt, M. (2017). Support networks of childless older people: informal and formal support in Europe. *Ageing and Society*, 37(8), 1543-1567.
<https://doi.org/10.1017/s0144686x16000416>
- Do, Y. K., Norton, E. C., Stearns, S. C., & Van Houtven, C. H. (2015). Informal care and caregiver's health. *Health Econ*, 24(2), 224-237. <https://doi.org/10.1002/hec.3012>
- Doblhammer, G., Fritze, T., Reinke, C., & Fink, A. (2022). Can dementia become the most prevalent disease at the time of death in Germany? Projections up to the year 2060 for the five most important diseases at the time of death. *Journal of Population Ageing*, 15(2), 523-540. <https://doi.org/10.1007/s12062-022-09365-7>
- Doebler, S., Ryan, A., Shortall, S., & Maguire, A. (2016). Informal care-giving and mental ill-health – differential relationships by workload, gender, age and area-remoteness in a UK region. *Health and Social Care in the Community*, 25(3), 987-999.
<https://doi.org/10.1111/hsc.12395>
- Dombestein, H., Norheim, A., & Lunde Husebø, A. M. (2020). Understanding informal caregivers' motivation from the perspective of self-determination theory: an integrative review. *Scand J Caring Sci*, 34(2), 267–279.
<https://doi.org/10.1111/scs.12735>
- Dujardin, C., Farfan-Portet, M. I., Mitchell, R., Popham, F., Thomas, I., & Lorant, V. (2011). Does country influence the health burden of informal care? An international comparison between Belgium and Great Britain. *Soc Sci Med*, 73(8), 1123-1132.
<https://doi.org/10.1016/j.socscimed.2011.07.016>
- Eaton, W. W., Smith, C., Ybarra, M., Muntaner, C., & Tien, A. (2004). Center for Epidemiologic Depression Scale: Review and Revision (CESD and CESD-R). In M. E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcomes assessment. Instruments for adults* (3rd ed., pp. 363-377). Routledge.

- Ekwall, A., Sivberg, B., & Hallberg, I. R. (2004). Dimensions of informal care and quality of life among elderly family caregivers. *Scand J Caring Sci*, 18(3), 239-248.
<https://doi.org/10.1111/j.1471-6712.2004.00283.x>
- Ekwall, A. K., & Hallberg, I. R. (2007). The association between caregiving satisfaction, difficulties and coping among older family caregivers. *J Clin Nurs*, 16(5), 832-844.
<https://doi.org/10.1111/j.1365-2702.2006.01382.x>
- EUROCARE-Project. (2025). *EUROCARE: Inequalities in informal caregiving over the adult life course in Europe*. Retrieved 18/10/2025 from
<https://www.ucl.ac.uk/population-health-sciences/epidemiology-health-care/research/ucl-research-department-epidemiology-public-health/research/eurocare-inequalities-informal-caregiving-over-adult-life-course-europe>
- Eurocarers. (2024). *About carers*. Retrieved 16/03/2025 from <https://eurocarers.org/about-carers/>
- Eurofound and the International Labour Office. (2017). *Working anytime, anywhere. The effects on the world of work* Retrieved 07/12/2025 from
<https://www.eurofound.europa.eu/en/publications/all/working-anytime-anywhere-effects-world-work>
- European Commission. (2021). *Study on exploring the incidence and costs of informal long-term care in the EU*. Publications Office of the European Union. Retrieved 07/12/2025 from <https://data.europa.eu/doi/10.2767/06382>
- European Union. (2018). *Informal care in Europe. Exploring Formalisation, Availability and Quality*. Retrieved 07/12/2025 from
<https://ec.europa.eu/social/BlobServlet?docId=19681&langId=en#:~:text=We%20take%20informal%20care%20to,living%20with%20mental%20health%20problems.>
- European Union. (2025). *EU countries*. Retrieved 07/12/2025 from https://european-union.europa.eu/principles-countries-history/eu-countries_en

- Eurostat. (2024a). *Data collection*. Retrieved 04/01/2025 from <https://ec.europa.eu/eurostat/web/population-demography/demography-population-stock-balance/information-data#expandable-example-content>
- Eurostat. (2024b). *Fertility indicators*. Retrieved 04/01/2025 from https://ec.europa.eu/eurostat/databrowser/view/demo_find__custom_14856515/default/table?lang=en
- Eurostat. (2024c). *Life expectancy by age and sex*. Retrieved 04/01/2025 from [https://ec.europa.eu/eurostat/databrowser/view/demo_mlexpec\\$DV_292/default/table](https://ec.europa.eu/eurostat/databrowser/view/demo_mlexpec$DV_292/default/table)
- Eurostat. (2024d). *Population on 1st January by age, sex and type of projection*. Retrieved 04/01/2025 from https://ec.europa.eu/eurostat/databrowser/view/proj_23np__custom_14854548/default/table?lang=en&page=time:2100
- Eurostat. (2024e). *Population structure indicators at national level*. Retrieved 04/01/2025 from https://ec.europa.eu/eurostat/databrowser/view/demo_pjanind__custom_14853895/default/table?lang=en
- Eurostat. (2024f). *Statistics Explained. Population projections in the EU - methodology*. Retrieved 04/01/2025 from <https://ec.europa.eu/eurostat/statistics-explained/SEPDF/cache/115485.pdf>
- Falzarano, F., Moxley, J., Pillemer, K., & Czaja, S. J. (2022). Family Matters: Cross-Cultural Differences in Familism and Caregiving Outcomes. *J Gerontol B Psychol Sci Soc Sci*, 77(7), 1269-1279. <https://doi.org/10.1093/geronb/gbab160>
- Fan, W., Moen, P., Kelly, E. L., Hammer, L. B., & Berkman, L. F. (2019). Job Strain, Time Strain, and Well-Being: A Longitudinal, Person-Centered Approach in Two Industries. *J Vocat Behav*, 110(PT A), 102-116. <https://doi.org/10.1016/j.jvb.2018.10.017>
- Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., Lyketsos, C., & Tschanz, J. (2012). Caregivers' relationship closeness with the person with

dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging Ment Health*, 16(6), 699-711.
<https://doi.org/10.1080/13607863.2012.678482>

Federal Ministry of Health. (2025). *Ratgeber Pflege. Alles, was Sie zum Thema Pflege wissen sollte*. Retrieved 07/12/2025 from <https://www.publikationen-bundesregierung.de/pp-en/search-for-publications/ratgeber-pflege-2341498>

Federal Statistical Office of Germany. (2023). *Long-term care projection: 1.8 million more people in need of long-term care expected until 2055*.
https://www.destatis.de/EN/Press/2023/03/PE23_124_12.html

Federal Statistical Office of Germany. (2024). *Pflegestatistik - Pflege im Rahmen der Pflegeversicherung 2023*. Retrieved 07/12/2025 from
<https://www.destatis.de/DE/Themen/Gesellschaft-Umwelt/Gesundheit/Pflege/Publikationen/Downloads-Pflege/statistischer-bericht-pflege-deutschlandergebnisse-5224001239005.html>

Fischer, B. A. (2012). A review of American psychiatry through its diagnoses: the history and development of the Diagnostic and Statistical Manual of Mental Disorders. *J Nerv Ment Dis*, 200(12), 1022-1030.
<https://doi.org/10.1097/NMD.0b013e318275cf19>

Fredman, L., Cauley, J. A., Hochberg, M., Ensrud, K. E., Doros, G., & Study of Osteoporotic Fractures. (2010). Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: results of caregiver-study of osteoporotic fractures. *J Am Geriatr Soc*, 58(5), 937-943.
<https://doi.org/10.1111/j.1532-5415.2010.02808.x>

Fries, J. F. (1984). The Compression of Morbidity. In *Aging and Technological Advances* (pp. 169-187). https://doi.org/10.1007/978-1-4613-2401-0_16

Fries, J. F., Koop, C. E., Sokolov, J., Beadle, C. E., & Wright, D. (1998). Beyond health promotion: reducing need and demand for medical care. *Health Aff (Millwood)*, 17(2), 70-84. <https://doi.org/10.1377/hlthaff.17.2.70>

- Fu, T. S.-T., Lee, C.-S., Gunnell, D., Lee, W.-C., & Cheng, A. T.-A. (2013). Changing trends in the prevalence of common mental disorders in Taiwan: a 20-year repeated cross-sectional survey. *Lancet*, 381(9862), 235-241. [https://doi.org/10.1016/S0140-6736\(12\)61264-1](https://doi.org/10.1016/S0140-6736(12)61264-1)
- Fuller, J. B., & Raman, M. (2019). *The Caring Company. How employers can help employees manage their caregiving responsibilities—while reducing costs and increasing productivity*. <https://www.hbs.edu/faculty/Pages/item.aspx?num=55558>
- Gallicchio, L., Siddiqi, N., Langenberg, P., & Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *Int J Geriatr Psychiatry*, 17(2), 154-163. <https://doi.org/10.1002/gps.538>
- Galobardes, B., Shaw, M., Lawlor, D. A., Lynch, J. W., & Davey Smith, G. (2006). Indicators of socioeconomic position (part 2). *J Epidemiol Community Health*, 60(2), 95-101. <https://doi.org/10.1136/jech.2004.028092>
- GBD 2019 Diseases and Injuries Collaborators. (2020). Global burden of 369 diseases and injuries in 204 countries and territories, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet*, 396(10258), 1204-1222. [https://doi.org/10.1016/S0140-6736\(20\)30925-9](https://doi.org/10.1016/S0140-6736(20)30925-9)
- GBD 2021 Europe Life Expectancy Collaborators. (2025). Changing life expectancy in European countries 1990–2021: a subanalysis of causes and risk factors from the Global Burden of Disease Study 2021. *Lancet Public Health* 10, e172–188. [https://doi.org/10.1016/S2468-2667\(25\)00009-X](https://doi.org/10.1016/S2468-2667(25)00009-X)
- Girgus, J. S., Yang, K., & Ferri, C. V. (2017). The Gender Difference in Depression: Are Elderly Women at Greater Risk for Depression Than Elderly Men? *Geriatrics (Basel)*, 2(4). <https://doi.org/10.3390/geriatrics2040035>
- Gmeinder, M., Morgan, D., & Müller, M. (2017). How much do OECD countries spend on prevention? *OECD Health Working Papers*, 101. <https://doi.org/10.1787/f19e803c-en>

- Gruenberg, E. M. (1977). The Failures of Success. *The Milbank Quartely*, 55(1), 3-24.
<https://doi.org/10.1111/j.1468-0009.2005.00400.x>
- Haberkern, K., Schmid, T., & Szydlik, M. (2013). Gender differences in intergenerational care in European welfare states. *Ageing and Society*, 35(2), 298-320.
<https://doi.org/10.1017/s0144686x13000639>
- Hagedoorn, M., Buunk, B. P., Kuijer, R. G., Wobbes, T., & Sanderman, R. (2000). Couples dealing with cancer. Role and gender differences regarding psychological distress and quality of life. *Psycho-Oncology*, 9(3), 232-242.
[https://doi.org/10.1002/1099-1611\(200005/06\)9:3<232::AID-PON458>3.0.CO;2-J](https://doi.org/10.1002/1099-1611(200005/06)9:3<232::AID-PON458>3.0.CO;2-J)
- Hajek, A., & König, H.-H. (2016). The Effect of Intra- and Intergenerational Caregiving on Subjective Well-Being – Evidence of a Population Based Longitudinal Study among Older Adults in Germany. *PLoS ONE* 11(2), e0148916.
<https://doi.org/10.1371/journal.pone.0148916>
- Hakovirta, M., Meyer, D. R., Salin, M., Lindroos, E., & Haapanen, M. (2023). Joint physical custody of children in Europe: A growing phenomenon. *Demographic Research*, 49, 479-492. <https://doi.org/10.4054/DemRes.2023.49.18>
- Hale, A. S. (2007). ABC of mental health. Depression. *BMJ*, 317(7099), 43-46.
<https://doi.org/10.1136/bmj.315.7099.43>
- Hammen, C. (2005). Stress and depression. *Annu Rev Clin Psychol*, 1, 293-319.
<https://doi.org/10.1146/annurev.clinpsy.1.102803.143938>
- Hansen, T., & Slagsvold, B. (2013). The psychological effects of providing personal care to a partner: a multidimensional perspective. *Health Psychology Research*, 1(2), e25. <https://doi.org/10.4082/hpr.2013.e25>
- Hansen, T., Slagsvold, B., & Ingebretsen, R. (2013). The Strains and Gains of Caregiving: An Examination of the Effects of Providing Personal Care to a Parent on a Range of Indicators of Psychological Well-Being. *Social Indicators Research*, 114(2), 323-343. <https://doi.org/10.1007/s11205-012-0148-z>

- Hapke, U., Cohrdes, C., & Nübel, J. (2019). Depressive symptoms in a European comparison - Results from the European Health Interview Survey (EHIS) 2. *Journal of Health Monitoring*, 4(4), 57-65. <https://doi.org/10.25646/6227>
- Hiel, L., Beenackers, M. A., Renders, C. M., Robroek, S. J., Burdorf, A., & Croezen, S. (2015). Providing personal informal care to older European adults: should we care about the caregivers' health? *Prev Med*, 70, 64-68. <https://doi.org/10.1016/j.ypmed.2014.10.028>
- Hoffmann, F., & Rodrigues, R. (2010). *Informal carers. Who takes care of them?* Retrieved 07/12/2025 from <https://www.euro.centre.org/downloads/detail/1256>
- Huijts, T., Stornes, P., Eikemo, T. A., Bambra, C., & HiNews, C. (2017). Prevalence of physical and mental non-communicable diseases in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. *Eur J Public Health*, 27(suppl_1), 8-13. <https://doi.org/10.1093/eurpub/ckw232>
- Hyde, M., Wiggins, R. D., Higgs, P., & Blane, D. B. (2003). A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP-19). *Aging Ment Health*, 7(3), 186-194. <https://doi.org/10.1080/1360786031000101157>
- Isengard, B. (2013). Der Apfel lebt nicht weit vom Stamm. Wohnentfernungen zwischen Eltern und ihren erwachsenen Kindern in Europa. *Comparative Population Studies*, 38(2), 263-290. <https://doi.org/10.4232/10.CPoS-2013-09de>
- Jacobson, D., Parker, T., Cadel, L., Mansfield, E., & Kuluski, K. (2025). The Intersection of Gender, Culture and Society for Caregivers of Older Adults Ageing in Place in Ontario, Canada. *Health Expectations*, 28(2), e70259. <https://doi.org/10.1111/hex.70259>
- Kalmijn, M. (2007). Gender Differences in the Effects of Divorce, Widowhood and Remarriage on Intergenerational Support: Does Marriage Protect Fathers? *Social Forces*, 85(3), 1079-1104. <https://doi.org/10.1353/sof.2007.0043>
- Kane, L. T., Fang, T., Galetta, M. S., Goyal, D. K. C., Nicholson, K. J., Kepler, C. K., Vaccaro, A. R., & Schroeder, G. D. (2020). Propensity Score Matching. A

- Statistical Method. *Clinical Spine Surgery*, 33(3).
<https://doi.org/10.1097/BSD.0000000000000932>
- Kanter, J. W., Busch, A. M., Weeks, C. E., & Landes, S. J. (2008). The Nature of Clinical Depression: Symptoms, Syndromes, and Behavior Analysis. *The Behavior Analyst*, 31(1), 1-21. <https://doi.org/10.1007/BF03392158>
- Karasek, R. A. (1979). Job Demands, Job Decision Latitude, and Mental Strain: Implications for Job Redesign. *Administrative Science Quarterly*, 24(2), 285-308. <https://doi.org/10.2307/2392498>
- Karasek, R. A., & Theorell, T. (1990). *Healthy Work. Stress, Productivity and the Reconstruction of Working Life*. Basic Books.
- Karim, J., Weisz, R., Bibi, Z., & ur Rehman, S. (2014). Validation of the Eight-Item Center for Epidemiologic Studies Depression Scale (CES-D) Among Older Adults. *Current Psychology*, 34(4), 681-692. <https://doi.org/10.1007/s12144-014-9281-y>
- Kaschowitz, J., & Brandt, M. (2017). Health effects of informal caregiving across Europe: A longitudinal approach. *Soc Sci Med*, 173, 72-80. <https://doi.org/10.1016/j.socscimed.2016.11.036>
- Kawas, C. H. (2007). The oldest old and the 90+ Study. *Alzheimers Dement*, 4, S56-S59. <https://doi.org/10.1016/j.jalz.2007.11.007>
- Kendler, K. S., M., K. L., & Prescott, C. (1998). Stressful Life Events and Major Depression: Risk Period, Long-Term Contextual Threat, and Diagnostic Specificity. *The Journal of Nervous & Mental Disease*, 186(11), 661-669.
- Kennedy, S. H. (2008). Core symptoms of major depressive disorder: relevance to diagnosis and treatment. *Dialogues in Clinical Neuroscience*, 10(3), 271-277. <https://doi.org/10.31887/DCNS.2008.10.3/shkennedy>
- Kim, D. (2017). Relationships between Caregiving Stress, Depression, and Self-Esteem in Family Caregivers of Adults with a Disability. *Occup Ther Int*, 2017, 1686143. <https://doi.org/10.1155/2017/1686143>

- Kinsella, K., & Philipps, D. R. (2005). Global Aging. The Challenge of success. *Population Bulletin*, 60(1), 3-40.
- Klaus, D., & Vogel, C. (2019). Unbezahlte Sorgetätigkeiten von Frauen und Männern im Verlauf der zweiten Lebenshälfte. In C. Vogel, M. Wettstein, & C. Tesch-Römer (Eds.), *Frauen und Männer in der zweiten Lebenshälfte: älterwerden im sozialen Wandel* (pp. 91-112). Springer VS. https://doi.org/10.1007/978-3-658-25079-9_6
- Klenk, J., Keil, U., Jaensch, A., C., C. M., & Nagel, G. (2016). Changes in life expectancy 1950–2010: contributions from age- and diseasespecific mortality in selected countries. *Popul Health Metrics*, 14(20), 1-11. <https://doi.org/10.1186/s12963-016-0089-x>
- Kolodziej, I. W. K., Coe, N. B., & Van Houtven, C. H. (2022). The Impact of Care Intensity and Work on the Mental Health of Family Caregivers: Losses and Gains. *J Gerontol B Psychol Sci Soc Sci*, 77(Suppl_1), S98-S111. <https://doi.org/10.1093/geronb/gbac031>
- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9 Validity of a Brief Depression Severity Measure. *Journal of General Internal Medicine*, 16(9), 606-613. <https://doi.org/10.1046/j1525-14972001016009606x>
- Kroenke, K., Strine, T. W., Spitzer, R. L., Williams, J. B., Berry, J. T., & Mokdad, A. H. (2008). The PHQ-8 as a measure of current depression in the general population. *J Affect Disord*, 114(1-3), 163-173. <https://doi.org/10.1016/j.jad.2008.06.026>
- Lacey, R. E., McMunn, A., & Webb, E. (2019). Informal caregiving patterns and trajectories of psychological distress in the UK Household Longitudinal Study. *Psychol Med*, 49(10), 1652-1660. <https://doi.org/10.1017/S0033291718002222>
- Lacey, R. E., Xue, B., Di Gessa, G., Lu, W., & McMunn, A. (2024). Mental and physical health changes around transitions into unpaid caregiving in the UK: a longitudinal, propensity score analysis. *Lancet Public Health*, 9(1), e16-e25. [https://doi.org/10.1016/S2468-2667\(23\)00206-2](https://doi.org/10.1016/S2468-2667(23)00206-2)

- Lawton, M. P., & Brody, E. M. (1969). Assessment of Older People. Self maintaining and instrumental activities of daily living. *The Gerontologist*, 9(3), 179-186.
https://doi.org/10.1093/geront/9.3_Part_1.179
- Lee, J., Phillips, D., & Wilkens, J. (2021). Gateway to Global Aging Data. In D. Gu & M. E. Dupre (Eds.), *Encyclopedia of Gerontology and Population Aging* (1 ed.). Cham: Springer.
- Leimkühler-Müller, A. M. (2002). Barriers to help-seeking by men. A review of sociocultural and clinical literature with particular reference to depression. *Journal of Affective Disorders*, 71(1-3), 1-9. [https://doi.org/10.1016/s0165-0327\(01\)00379-2](https://doi.org/10.1016/s0165-0327(01)00379-2)
- Lewinsohn, P. M., Seeley, J. R., Roberts, R. E., & Allen, N. B. (1997). Center for Epidemiologic Studies Depression Scale (CES-D) as a screening instrument for depression among community-residing older adults. *Psychology and Aging*, 12(2), 277-287. <https://doi.org/10.1037/0882-7974.12.2.277>
- Li, J., & Song, Y. (2019). Formal and Informal Care. In D. Gu & M. Dupre (Eds.), *Encyclopedia of Gerontology and Population Aging*. Springer.
https://doi.org/https://doi.org/10.1007/978-3-319-69892-2_847-1
- Li, Q. P., Mak, Y. W., & Loke, A. Y. (2013). Spouses' experience of caregiving for cancer patients: a literature review. *International Nursing Review*, 60(2), 178–187.
<https://doi.org/10.1111/inr.12000>
- Lin, I. F. (2008). Consequences of Parental Divorce for Adult Children's Support of Their Frail Parents. *Journal of Marriage and Family*, 70(1), 113-128.
<https://doi.org/10.1111/j.1741-3737.2007.00465.x>
- Lindt, N., van Berkel, J., & Mulder, B. C. (2020). Determinants of overburdening among informal carers: a systematic review. *BMC Geriatr*, 20(1), 304.
<https://doi.org/10.1186/s12877-020-01708-3>
- Litwin, H., Stoeckel, K. J., & Roll, A. (2014). Relationship status and depressive symptoms among older co-resident caregivers. *Aging Ment Health*, 18(2), 225-231.
<https://doi.org/10.1080/13607863.2013.837148>

- Lutz, W., Amran, G., Bélanger, A., Conte, A., Gailey, N., Ghio, D., Grapsa, E., K., J., Loichinger, E., Marois, G., Muttarak, R., Potančoková, M., Sabourin, P., & Stonawski, M. (2019). *Demographic Scenarios for the EU - Migration, Population and Education*. Retrieved 07/02/2026 from https://publications.jrc.ec.europa.eu/repository/bitstream/JRC116398/demographic_online_20190527.pdf
- Lyonette, C., & Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Ageing and Society*, 23(4), 487–506. <https://doi.org/10.1017/S0144686X03001284>
- Mackenzie, A., & Greenwood, N. (2012). Positive experiences of caregiving in stroke: a systematic review. *Disability and Rehabilitation*, 34(17), 1413-1422. <https://doi.org/10.3109/09638288.2011.650307>
- Maj, M., Stein, D. J., Parker, G., Zimmerman, M., Fava, G. A., De Hert, M., Demyttenaere, K., McIntyre, R. S., Widiger, T., & Wittchen, H.-U. (2020). The clinical characterization of the adult patient with depression aimed at personalization of management. *World Psychiatry* 19(3), 269-293. <https://doi.org/10.1002/wps.20771>
- Manton, K. G. (1982). Changing Concepts of Morbidity and Mortality in the Elderly Population. *The Milbank Memorial Fund Quarterly*, 60(2), 183-244. <https://doi.org/10.2307/3349767>
- Marks, N. F., Lambert, J. D., & Choi, H. (2002). Transitions to Caregiving, Gender, and Psychological Well-Being: A Prospective U.S. National Study. *Journal of Marriage and Family*, 64(3), 657-667. <https://doi.org/10.1111/j.1741-3737.2002.00657.x>
- Martin, L. A., Neighbors, H. W., & Griffith, D. M. (2013). The Experience of Symptoms of Depression in Men vs Women. Analysis of the National Comorbidity Survey Replication. *JAMA Psychiatry*, 70(10), 1100-1108. <https://doi.org/10.1001/jamapsychiatry.2013.1985>
- Mayberg, H. S., Liotti, M., Brannan, S. K., McGinnis, S., Mahurin, R. K., Jerabek, P. A., Silva, J. A., Tekell, J. L., Martin, C. C., Lancaster, J. L., & Fox, P. T. (1999).

- Reciprocal Limbic-Cortical Function and Negative Mood: Converging PET Findings in Depression and Normal Sadness. *The American Journal of Psychiatry*, 156(5), 675-682. <https://doi.org/10.1176/ajp.156.5.675>
- McCann, J. J., Hebert, L. E., Bienias, J. L., Morris, M. C., & Evans, D. A. (2004). Predictors of Beginning and Ending Caregiving During a 3-Year Period in a Biracial Community Population of Older Adults. *American Journal of Public Health*, 94(10), 1800–1806. <https://doi.org/10.2105/ajph.94.10.1800>
- McMunn, A., Nazroo, J., Wahrendorf, M., Breeze, E., & Zaninotto, P. (2009). Participation in socially-productive activities, reciprocity and wellbeing in later life: baseline results in England. *Ageing and Society*, 29(5), 765-782. <https://doi.org/10.1017/s0144686x08008350>
- Mehrbrodt, T. G., S.; Wagner, M. (2021). *Scales and Multi-Item Indicators*. Retrieved 28/12/2025 from https://share-eric.eu/fileadmin/user_upload/Other_Publications/ScalesManual_rel.8-0-0.pdf
- Mengelkoch, S., & Slavich, G. M. (2024). Sex Differences in Stress Susceptibility as a Key Mechanism Underlying Depression Risk. *Current Psychiatry Reports*, 26(4), 157-165. <https://doi.org/10.1007/s11920-024-01490-8>
- Mentzakis, E., McNamee, P., & Ryan, M. (2009). Who cares and how much: exploring the determinants of co-residential informal care. *Review of Economics of the Household*, 7(3), 283-303. <https://doi.org/10.1007/s11150-008-9047-0>
- Miettinen, A., Rotkirch, A., Szalma, I., Donno, A., & Tanturri, A.-L. (2015). Increasing childlessness in Europe. *Families and Societies*, 33.
- Missinne, S., Vandeviver, C., Van de Velde, S., & Bracke, P. (2014). Measurement equivalence of the CES-D 8 Depression-Scale among the ageing population in eleven European countries. *Social Science Research*, 46, 38-47. <https://doi.org/10.1016/j.ssresearch.2014.02.006>
- Molloy, G. J., Johnston, D. W., Johnston, M., Morrison, V., Pollard, B., Bonetti, D., Joice, S., & MacWalter, R. (2005). Extending the demand-control model to informal

- caregiving. *J Psychosom Res*, 58(3), 243-251.
<https://doi.org/10.1016/j.jpsychores.2004.08.009>
- Netto, N. R., Jenny, G. Y. N., & Philip, Y. L. K. (2009). Growing and gaining through caring for a loved one with dementia. *Dementia*, 8(2), 245-261.
<https://doi.org/10.1177/1471301209103269>
- Nielsen, C. R., Ahrenfeldt, L. J., Jeune, B., Christensen, K., & Lindahl-Jacobsen, R. (2021). Healthy life expectancy by frailty state in Europe from 2004 to 2015: findings from SHARE. *Eur J Public Health*, 31(3), 554-560.
<https://doi.org/10.1093/eurpub/ckab012>
- Noel-Miller, C. M. (2011). Partner caregiving in older cohabiting couples. *J Gerontol B Psychol Sci Soc Sci*, 66(3), 341-353. <https://doi.org/10.1093/geronb/gbr027>
- Noonan, A. E., Tennstedt, S. L., & Rebelsky, F. G. (1996). MAKING THE BEST OF IT: Themes of Meaning among Informal Caregivers to the Elderly. *Journal of Aging Studies*, 10(4), 313-327. [https://doi.org/10.1016/S0890-4065\(96\)90004-3](https://doi.org/10.1016/S0890-4065(96)90004-3)
- Novak, M., & Guest, C. (1989). Application of a Multidimensional Caregiver Burden Inventory. *The Gerontologist*, 29(6). <https://doi.org/10.1093/geront/29.6.798>.
- Oliva-Moreno, J., Pena-Longobardo, L. M., & Vilaplana-Prieto, C. (2015). An estimation of the value of informal care provided to dependent people in Spain. *Appl Health Econ Health Policy*, 13(2), 223-231. <https://doi.org/10.1007/s40258-015-0161-x>
- Ophir, A., & Polos, J. (2022). Care Life Expectancy: Gender and Unpaid Work in the Context of Population Aging. *Popul Res Policy Rev*, 41(1), 197-227.
<https://doi.org/10.1007/s11113-021-09640-z>
- Organisation for Economic Co-operation and Development/European Commission. (2024). *Health at a Glance: Europe 2024: State of Health in the EU Cycle*. Retrieved 07/12/2025 from https://www.oecd.org/en/publications/health-at-a-glance-europe-2024_b3704e14-en.html
- Padesky, C. A., & Hammen, C. L. (1981). Sex differences in depressive symptoms expression and help-seeking among college students *Sex Roles*, 7(3).

- Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: family caregiver burden. *J Adv Nurs*, 58(5), 446-457. <https://doi.org/10.1111/j.1365-2648.2007.04250.x>
- Patterson, S. E., & Margolis, R. (2019). The Demography of Multigenerational Caregiving: A Critical Aspect of the Gendered Life Course. *Socius: Sociological Research for a Dynamic World*, 5. <https://doi.org/10.1177/2378023119862737>
- Pavalko, E. K., & Henderson, K. A. (2006). Combining Care Work and Paid Work. Do Workplace Policies Make a Difference? *Research on Aging*, 28(3). <https://doi.org/10.1177/0164027505285848>
- Pavolini, E., & Ranci, C. (2008). Restructuring the welfare state: reforms in long-term care in Western European countries. *Journal of European Social Policy*, 18(3), 246-259. <https://doi.org/10.1177/0958928708091058>
- Pescosolido, B. A., Halpern-Manners, A., Luo, L., & Perry, B. (2021). Trends in Public Stigma of Mental Illness in the US, 1996-2018. *JAMA Netw Open*, 4(12), e2140202. <https://doi.org/10.1001/jamanetworkopen.2021.40202>
- Pinquart, M., & Sorensen, S. (2003). Differences Between Caregivers and Noncaregivers in Psychological Health and Physical health: A Meta-Analysis. *Psychol Aging*, 18(2), 250-267. <https://doi.org/10.1037/0882-7974.18.2.250>
- Pinquart, M., & Sorensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: a meta-analytic comparison. *Psychol Aging*, 26(1), 1-14. <https://doi.org/10.1037/a0021863>
- Potočnik, T., & Hlebec, V. (2025). Work–Care Reconciliation Strategies for a Variety of Informal Carers: What Works and What Does Not? *Healthcare*, 13(16). <https://doi.org/10.3390/healthcare13161961>
- Poulin, M. J., Brown, S. L., Ubel, P. A., Smith, D. M., Jankovic, A., & Langa, K. M. (2010). Does a helping hand mean a heavy heart? Helping behavior and well-being among spouse caregivers. *Psychol Aging*, 25(1), 108-117. <https://doi.org/10.1037/a0018064>

- Prince, M. J., Reischies, F., Beekman, A. T., Fuhrer, R., Jonker, C., Kivela, S. L., Lawlor, B. A., Lobo, A., Magnusson, H., Fichter, M., van Oyen, H., Roelands, M., Skoog, I., Turrina, C., & Copeland, J. R. (1999). Development of the EURO-D scale--a European, Union initiative to compare symptoms of depression in 14 European centres. *Br J Psychiatry*, *174*, 330-338. <https://doi.org/10.1192/bjp.174.4.330>
- Quadagno, J. (2008). *Aging and The Life Course: An Introduction to Social Gerontology* (Fourth Edition ed.). McGraw-Hill Humanities, Social Sciences & World Languages.
- Quashie, N. T., Wagner, M., Verbakel, E., & Deindl, C. (2022). Socioeconomic differences in informal caregiving in Europe. *Eur J Ageing*, *19*(3), 621-632. <https://doi.org/10.1007/s10433-021-00666-y>
- Radloff, L. S. (1977). The CES-D Scale: A Self-Report Depression Scale for Research in the General Population. *Applied Psychological Measurement*, *1*, 385-401.
- Raleigh, V. (2019). Trends in life expectancy in EU and other OECD countries : Why are improvements slowing? *OECD Health Working Papers*, *108*.
- Revenson, T. A., Griva, K., Luszczynska, A., Morrison, V., Panagopoulou, E., Vilchinsky, N., & Hagedoorn, M. (2016). *Caregiving in the Illness Context*. Palgrave Pivot. <https://doi.org/10.1057/9781137558985>
- Rissel, C., Petrunoff, N., Wen, L. M., & Crane, M. (2014). Travel to work and self-reported stress: Findings from a workplace survey in south west Sydney, Australia. *Journal of Transport & Health*, *1*(1), 50-53. <https://doi.org/10.1016/j.jth.2013.09.001>
- Rodrigues, R., Rehnberg, J., Simmons, C., Ilinca, S., Zólyomi, E., Vafaei, A., Jull, J., Phillips, S. P., & Fors, S. (2023). Cohort Trajectories by Age and Gender for Informal Caregiving in Europe Adjusted for Sociodemographic Changes, 2004 and 2015. *Gerontol B Psychol Sci Soc Sci*, *78*(8), 1412–1422. <https://doi.org/10.1093/geronb/gbad011>

- Rokicka, M., & Zajkowska, O. (2020). Informal Elderly Caregiving and Time Spent on Leisure: Evidence from Time Use Survey. *Ageing International*, 45(4), 393-410. <https://doi.org/10.1007/s12126-020-09396-5>
- Rosenbaum, P. R., & Rubin, D. B. (1983). The Central Role of the Propensity Score in Observational Studies for Causal Effects. *Biometrika*, 70(1), 41-55. <https://doi.org/10.2307/2335942>
- Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain: associations with quality of life in a large national sample of middle-aged and older adults. *Qual Life Res*, 18(6), 679-688. <https://doi.org/10.1007/s11136-009-9482-2>
- Santos, J. V., Padron-Monedero, A., Bikbov, B., Grad, D., Alecsandra, Plass, D., Mechili, E. A., & Gazzelloni, F. (2024). The state of health in the European Union (EU-27) in 2019: a systematic analysis for the Global Burden of Disease study 2019. *BMC Public Health* 24. <https://doi.org/10.1186/s12889-024-18529-3>
- Schaps, V., Hansen, T., Nes, R. B., & Wahrendorf, M. (2025a). How are location and type of caring associated with the carer's mental health? Cross-sectional and longitudinal findings from SHARE. *European Journal of Ageing*, 22(5), 1-15. <https://doi.org/10.1007/s10433-025-00843-3>
- Schaps, V., McMunn, A., Deindl, C., & Wahrendorf, M. (2025b). Carer mental health in Europe. Does it matter who you care for? Cross-sectional and longitudinal findings from SHARE. *Aging Ment Health*, 1-13. <https://doi.org/10.1080/13607863.2025.2558889>
- Schmid, T., Brandt, M., & Haberkern, K. (2012). Gendered support to older parents: do welfare states matter? *Eur J Ageing*, 9, 39-50. <https://doi.org/10.1007/s10433-011-0197-1>
- Schmidt, H., & Westphal, M. (2015). Short- and medium term effects of informal care provision on health. *Journal of Health Economics*, 42, 174-185. <https://doi.org/10.1016/j.jhealeco.2015.03.002>

- Schomerus, G., & Angermeyer, M. C. (2008). Stigma and its impact on help-seeking for mental disorders: what do we know? *Epidemiol Psychiatr Soc*, 17(1), 31-37.
<https://doi.org/10.1017/s1121189x00002669>
- Schomerus, G., Schindler, S., Sander, C., Baumann, E., & Angermeyer, M. C. (2022). Changes in mental illness stigma over 30 years - Improvement, persistence, or deterioration? *Eur Psychiatry*, 65(1), e78.
<https://doi.org/10.1192/j.eurpsy.2022.2337>
- Schulz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C., & Jackson, S. (1997). Health effects of caregiving: the caregiver health effects study: an ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine*, 19(2), 110-116.
<https://doi.org/10.1007/BF02883327>. PMID: 9603685.
- SHARE. (2024). *Release Guide 9.0.0*. Retrieved 07/12/2025 from <https://share-eric.eu/data/data-documentation/release-guides>
- SHARE. (2025). *Funding*. Retrieved 07/12/2025 from <https://share-eric.eu/infrastructure/funding>
- Sickel, A. E., Seacat, J. D., & Nabors, N. A. (2014). Mental health stigma update. A review of consequences. *Advances in Mental Health*, 12(3), 202-215.
<https://doi.org/10.1080/18374905.2014.11081898>
- Siegrist, J., & Wahrendorf, M. (2009). Participation in socially productive activities and quality of life in early old age: findings from SHARE. *Journal of European Social Policy*, 19(4), 317-326. <https://doi.org/10.1177/1350506809341513>
- Silverstein, M., & Giarrusso, R. (2010). Aging and Family Life: A Decade Review. *J Marriage Fam*, 72(5), 1039-1058. <https://doi.org/10.1111/j.1741-3737.2010.00749.x>
- Simenenko, O., & Lentjushenkova, O. (2021). *Advantages and disadvantages of distance working* 18th International Conference at Brno University of Technology, Faculty of Business and Management, Brno.
- Skinner, M., & Sogstad, M. (2022). Social and Gender Differences in Informal

- Caregiving for Sick, Disabled, or Elderly Persons: A Cross-Sectional Study. *Sage Open Nursing*, 8, 1-11. <https://doi.org/10.1177/23779608221130585>
- Sleeman, K. E., de Brito, M., Etkind, S., Nkhoma, K., Guo, P., Higginson, I. J., Gomes, G., & Harding, R. (2019). The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *The Lancet Global Health*, 7(7), e883-e892. [https://doi.org/10.1016/S2214-109X\(19\)30172-X](https://doi.org/10.1016/S2214-109X(19)30172-X)
- Sloan, D. M., & Sandt, A. R. (2006). Gender differences in depression. *Women's Health*, 2(3), 425-434. <https://doi.org/10.2217/17455057.2.3.425>
- Solaz, A. (2021). More frequent separation and repartnering among people aged 50 and over. *Population & Societies*, 586(2), 1-4.
- Staiger, T., Stiawa, M., Mueller-Stierlin, A. S., Kilian, R., Beschoner, P., Gundel, H., Becker, T., Frasch, K., Panzirsch, M., Schmauss, M., & Krumm, S. (2020). Masculinity and Help-Seeking Among Men With Depression: A Qualitative Study. *Front Psychiatry*, 11, 599039. <https://doi.org/10.3389/fpsyt.2020.599039>
- Stein, D. J., Szatmari, P., Gaebel, W., Berk, M., Vieta, E., Maj, M., de Vries, Y. A., Roest, A. M., de Jonge, P., Maercker, A., Brewin, C. R., Pike, K. M., Grilo, C. M., Fineberg, N. A., Briken, P., Cohen-Kettenis, P. T., & Reed, G. M. (2020). Mental, behavioral and neurodevelopmental disorders in the ICD11: an international perspective on key changes and controversies. *BMC Medicine*, 18(21). <https://doi.org/10.1186/s12916-020-1495-2>
- Stöckel, J., & Bom, J. (2022). Revisiting longer-term health effects of informal caregiving: Evidence from the UK. *The Journal of the Economics of Ageing*, 21. <https://doi.org/10.1016/j.jeoa.2021.100343>
- Stratmann, M., Forsell, Y., Moller, J., & Liang, Y. (2021). Informal care and the impact on depression and anxiety among Swedish adults: a population-based cohort study. *BMC Public Health*, 21(1), 1263. <https://doi.org/10.1186/s12889-021-11246-1>

- Stuifbergen, M. C., Van Delden, J. J. M., & Dykstra, P. A. (2008). The implications of today's family structures for support giving to older parents. *Ageing and Society*, 28(3), 413-434. <https://doi.org/10.1017/s0144686x07006666>
- Suh, J. (2016). Measuring the "Sandwich": Care for Children and Adults in the American Time Use Survey 2003-2012. *J Fam Econ Issues*, 37, 197-211. <https://doi.org/10.1007/s10834-016-9483-6>
- Suris, A., Holliday, R., & North, C. S. (2016). The Evolution of the Classification of Psychiatric Disorders. *Behav Sci (Basel)*, 6(1). <https://doi.org/10.3390/bs6010005>
- Swinkels, J., Tilburg, T. V., Verbakel, E., & Broese van Groenou, M. (2019). Explaining the Gender Gap in the Caregiving Burden of Partner Caregivers. *J Gerontol B Psychol Sci Soc Sci*, 74(2), 309-317. <https://doi.org/10.1093/geronb/gbx036>
- Swinkels, J. C., van Tilburg, T. G., & Broese van Groenou, M. (2022). Why do spouses provide personal care? A study among care-receiving Dutch community-dwelling older adults. *Health Soc Care Community*, 30(4), e953-e961. <https://doi.org/10.1111/hsc.13497>
- Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive Aspects of Caregiving. *Research on Aging*, 26(4), 429-453. <https://doi.org/10.1177/0164027504264493>
- Ten Have, M., Tuithof, M., van Dorsselaer, S., Schouten, F., Luik, A. I., & de Graaf, R. (2023). Prevalence and trends of common mental disorders from 2007-2009 to 2019-2022: results from the Netherlands Mental Health Survey and Incidence Studies (NEMESIS), including comparison of prevalence rates before vs. during the COVID-19 pandemic. *World Psychiatry*, 22(2), 275-285. <https://doi.org/10.1002/wps.21087>
- Townsend, A., Noelker, L., Deimling, G., & Bass, D. (1989). Longitudinal Impact of Interhousehold Caregiving on Adult Children's Mental Health. *Psychology and Aging*, 4(4), 393-401. <https://doi.org/10.1037//0882-7974.4.4.393>
- Triantafyllou, J., Naiditch, M., Repkova, K., Stiehr, K., Carretero, S., Emilsson, T., Di Santo, P., Bednarik, R., Brichtova, L., Ceruzzi, F., Cordero, L., Mastroiannakis,

- T., Ferrando, M., Mingot, K., Ritter, J., & Vlantoni, D. (2010). *Informal care in the long-term care system. European Overview Paper*. Retrieved 28/12/2025 from <https://www.euro.centre.org/downloads/detail/768>
- Tur-Sinai, A., Teti, A., Rommel, A., Hlebec, V., & Lamura, G. (2020). How Many Older Informal Caregivers Are There in Europe? Comparison of Estimates of Their Prevalence from Three European Surveys. *Int J Environ Res Public Health*, 17(24). <https://doi.org/10.3390/ijerph17249531>
- Uccheddu, D., Gauthier, A. H., Steverink, N., & Emery, T. (2019). The pains and reliefs of the transitions into and out of spousal caregiving. A cross-national comparison of the health consequences of caregiving by gender. *Soc Sci Med*, 240, 112517. <https://doi.org/10.1016/j.socscimed.2019.112517>
- UNESCO-UIS. (2006). *International standard classification of education. ISCED 1997*. Retrieved 07/12/2025 from <https://unesdoc.unesco.org/ark:/48223/pf0000111387>
- United Nations. (2017). *Expert Group Meeting on Care and Older Persons: Links to Decent Work, Migration and Gender* United Nations Department of Economic and Social Affairs,. Retrieved 07/12/2025 from <https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2018/03/17-EGM-Care-Report-7-March-2018.pdf>
- Van de Velde, S., Bracke, P., & Levecque, K. (2010). Gender differences in depression in 23 European countries. Cross-national variation in the gender gap in depression. *Soc Sci Med*, 71(2), 305-313. <https://doi.org/10.1016/j.socscimed.2010.03.035>
- Van de Velde, S. L., K.; Bracke, P. (2009). Measurement equivalence of the CES-D 8 in the general population in Belgium: a gender perspective. *Arch Public Health*, 67(1), 15-29. <https://doi.org/10.1186/0778-7367-67-1-15>
- Van Durme, T., Macq, J., Jeanmart, C., & Gobert, M. (2012). Tools for measuring the impact of informal caregiving of the elderly: a literature review. *Int J Nurs Stud*, 49(4), 490-504. <https://doi.org/10.1016/j.ijnurstu.2011.10.011>
- van Leeuwen, K. M., van Loon, M. S., van Nes, F. A., Bosmans, J. E., de Vet, H. C. W., Ket, J. C. F., Widdershoven, G. A. M., & Ostelo, R. W. J. G. (2019). What does

- quality of life mean to older adults? A thematic synthesis. *PLoS One*, 14(3).
<https://doi.org/10.1371/journal.pone.0213263>
- Van Spijker, F., Kalmijn, M., & van Gaalen, R. (2022). The long-term improvement in father–child relationships after divorce: Descriptive findings from the Netherlands. *Demographic Research*, 46, 441-452. <https://doi.org/10.4054/DemRes.2022.46.15>
- Vargese, S. S., Jylhä, M., Raitanen, J., Enroth, L., Halonen, P., & Aaltonen, M. (2023). Dementia-related disability in the population aged 90 years and over: differences over time and the role of comorbidity in the vitality 90 + study. *BMC Geriatrics*, 23(276). <https://doi.org/10.1186/s12877-023-03980-5>
- Verbakel, E. (2018). How to understand informal caregiving patterns in Europe? The role of formal long-term care provisions and family care norms. *Scand J Public Health*, 46(4), 436-447. <https://doi.org/10.1177/1403494817726197>
- Verbakel, E., Glaser, K., Amzour, Y., Brandt, M., & Broese van Groenou, M. (2023). Indicators of familialism and defamilialization in long-term care: A theoretical overview and introduction of macro-level indicators. *Journal of European Social Policy*, 33(1), 34-51. <https://doi.org/10.1177/09589287221115>
- Verbakel, E., Tamlagsrønning, S., Winstone, L., Fjaer, E. L., & Eikemo, T. A. (2017). Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. *Eur J Public Health*, 27(suppl_1), 90-95. <https://doi.org/10.1093/eurpub/ckw229>
- Wahrendorf, M., McMunn, A., Xue, B., Schaps, V., Deindl, C., Di Gessa, G., & Lacey, R. E. (2025). Mental health trajectories of men and women who start providing personal care: European findings from SHARE using propensity score matching. *J Gerontol B Psychol Sci Soc Sci*, 80(6), gbaf053.
<https://doi.org/10.1093/geronb/gbaf053>
- Wahrendorf, M., Ribet, C., Zins, M., & Siegrist, J. (2008). Social productivity and depressive symptoms in early old age-results from the GAZEL study. *Aging Ment Health*, 12(3), 310-316. <https://doi.org/10.1080/13607860802120805>

- Wells, W., Xue, B., Lacey, R., & A., M. (2025). Differences by ethnicity in the association between unpaid caring and health trajectories over 10 years in the UK Household Longitudinal Study. *Journal of Epidemiology and Community Health*, 79(2), 94-101. <https://doi.org/10.1136/jech-2024-222633>
- Wetzstein, M., Rommel, A., & Lange, C. (2015). Informal caregivers. Germanys largest nursing service. *GBE kompakt*, 6(3). <https://doi.org/10.17886/RKI-GBE-2016-002>
- Wieczorek, E., Evers, S., Kocot, E., Sowada, C., & Pavlova, M. (2022). Assessing Policy Challenges and Strategies Supporting Informal Caregivers in the European Union. *Journal of Aging & Social Policy*, 34(1). <https://doi.org/10.1080/08959420.2021.1935144>
- Wiegelmann, H., Speller, S., Verhaert, L. M., Schirra-Weirich, L., & Wolf-Ostermann, K. (2021). Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia - a systematic literature review. *BMC Geriatr*, 21(1), 94. <https://doi.org/10.1186/s12877-021-02020-4>
- Wiggins, R. D., Netuveli, G., Hyde, M., Higgs, P., & Blane, D. (2008). The evaluation of a self-enumerated Scale of Quality of Life (CASP-19) in the context of research on ageing: A combination of exploratory and confirmatory approaches. *Social Indicators Research*, 89(1), 61-77. <https://doi.org/10.1007/s11205-007-9220-5>
- Williams, R. (2012). Using the Margins Command to Estimate and Interpret Adjusted Predictions and Marginal Effects. *The Stata Journal*, 12(2), 308-331. <https://doi.org/10.1177/1536867X1201200209>
- Wohlin, C. (2014). Guidelines for Snowballing in Systematic Literature Studies and a Replication in Software Engineering. *EASE '14: Proceedings of the 18th International Conference on Evaluation and Assessment in Software Engineerin*, 38, 1-10. <https://doi.org/10.1145/2601248.2601268>
- Wolters, F. J., Chibnik, L. B., Waziry, R., Anderson, R., Berr, C., Beiser, A., Bis, J. C., Blacker, D., Bos, D., Brayne, C., Dartigues, J. F., Darweesh, S. K. L., Davis-Plourde, K. L., de Wolf, F., Debette, S., Dufouil, C., Fornage, M., Goudsmit, J., Grasset, L., . . . Hofman, A. (2020). Twenty-seven-year time trends in dementia

- incidence in Europe and the United States: The Alzheimer Cohorts Consortium. *Neurology*, 95(5), e519-e531. <https://doi.org/10.1212/WNL.00000000000010022>
- World Health Organization. (1948). *Constitution of the World Health Organization*. Retrieved 07/12/2025 from <https://www.who.int/about/governance/constitution>
- World Health Organization. (2017). *Depression and Other Common Mental Disorders. Global Health Estimates*. Retrieved 07/12/2025 from <https://www.who.int/publications/i/item/depression-global-health-estimates>
- World Health Organization. (2022). *World Mental Health Report. Transforming Mental Health for all*. Retrieved 07/12/2025 from <https://www.who.int/publications/i/item/9789240049338>
- World Health Organization. (2024a). *Clinical descriptions and diagnostic requirements for ICD-11 mental, behavioural and neurodevelopmental disorders*. Retrieved 07/12/2025 from <https://www.who.int/publications/i/item/9789240077263>
- World Health Organization. (2024b). *Long-term care financing: lessons for low- and middle-income settings. Brief 10. Supporting informal long-term caregivers*. Retrieved 07/12/2025 from <https://iris.who.int/handle/10665/379077>
- Yonemoto, N., & Kawashima, Y. (2023). Help-seeking behaviors for mental health problems during the COVID-19 pandemic: A systematic review. *J Affect Disord*, 323, 85-100. <https://doi.org/10.1016/j.jad.2022.11.043>
- Zarit, S. H., & Zarit, J., M. (1982). Families under stress. Interventions for caregivers of senile dementia patients. *Psychotherapy: Theory, Research and Practice*, 19(4), 461-471. <https://doi.org/10.1037/h0088459>
- Zou, G. (2004). A modified poisson regression approach to prospective studies with binary data. *Am J Epidemiol*, 159(7), 702-706. <https://doi.org/10.1093/aje/kwh090>
- Zwar, L., Konig, H. H., & Hajek, A. (2018). The impact of different types of informal caregiving on cognitive functioning of older caregivers: Evidence from a longitudinal, population-based study in Germany. *Soc Sci Med*, 214, 12-19. <https://doi.org/10.1016/j.socscimed.2018.07.048>

Zygouri, I., Cowdell, F., Ploumis, A., Gouva, M., & Mantzoukas, S. (2021). Gendered experiences of providing informal care for older people: a systematic review and thematic synthesis. *BMC Health Serv Res*, 21(1), 730.
<https://doi.org/10.1186/s12913-021-06736-2>

9 Appendix

Table A 1: Previous studies on the association between caring and mental health. Study name, country, data source, measurement of the independent and the dependent variable and main results. Wording in studies is used.

Study name	Country	Data source and design	Measurement of caring	Measurement of dependent variable (mental health)	Main results
Negative and Positive Health Effects of Caring for a Disabled Spouse: Longitudinal Findings From the Caregiver Health Effects Study (Beach et al., 2000)	United States (North Carolina, California, Maryland, Pennsylvania)	• Caregiver Health Effects Study, 1993-1995 • Longitudinal (n=680) • Respondents aged 65 years and older	• Potential caregivers were defined as individuals whose spouse had difficulty with at least one ADL or IADL due to physical or health problems or problems with confusion	• Perceived health (5-point scale from poor to excellent) • Health risk behaviours (e.g. eating less than three meals a day, not having enough time to exercise) • Anxiety and depressive symptoms (20 anxiety related items, e.g. restless, irritable and 21 depression-related symptoms, e.g. loss of appetite, trouble falling asleep)	• Increases in help provided was related to decreases in anxiety and depression • Increases in spouse impairment and caregiver strain were related to poorer outcomes over time: poorer perceived health and increased health-risk behaviour, anxiety and depression
Informal caregiver support needs and burden: A survey in Lithuania (Biliunaite et al., 2022)	Lithuania	• Online survey of informal caregivers • Cross-sectional (n=226) • Respondents aged 18 years or older	• Informal caregivers are defined as individuals who provide care without training or experience for significant others such as partners, children, siblings, parents or friends • Participants being informal caregivers or having informal caregiving related experience	• Caregiving knowledge and support needs (e.g. “What are the main caregiving related challenges that you experience?”) • Caregiver burden (24-item Caregivers Burden Inventory) • Well-being and support during COVID-19 (e.g. own well-being, well-being)	• 50 % of the caregivers reported no specific knowledge about the disorder of the care recipient • Women scored significantly higher on burden • Physical and psychological health complaints, poorer self-rated well-being, residing with the care recipient and caring for longer and with higher intensity were associated with increased burden scores • Informal caregivers who started caregiving because there were no other family members

				of the care recipient, availability of support)	available to help were found to be more burdened than individuals who took up caregiving on their own initiative • Most participants indicated no changes in their well-being during COVID-19
Is the grass greener on the other side? The health impact of providing informal care in the UK and the Netherlands (Bom & Stöckel, 2021)	United Kingdom, the Netherlands	• Dutch Study on Transitions in Employment, Ability and Motivation (n=8.129) • United Kingdom Household Longitudinal Study (UKHLS) (n=7.186) • Longitudinal • Respondents between 45 and 65 years • Focus on starting care provision between 2011 and 2013	• The Netherlands: “Did you in the past 12 months spend part of your time on any of the following activities?” • United Kingdom: “Is there anyone living with you who is sick, disabled or elderly whom you look after or give special help to (for example a sick, disabled or elderly relative/husband/wife/friend etc.)?” and “Do you provide regular service or help for any sick, disabled or elderly person not living with you?” • Respondents divided into low (>10 hours per week), medium (10-20 hours) and high intensity (<20 hours)	• Self-reported questions related to health in the past four weeks from the 12-item Short Form Health Survey (SF-12)	• Negative health effects of providing informal care in both countries • The impact of care provision differs by the amount of care provided: Individuals who provide more than 20 hours of care per week and those who face a double burden of care and full-time employment experience the most severe negative mental health effects • Negative mental health effects were found to be larger for females • Health effects are mediated by the context (LTC policies)
Is caring for older parents detrimental to women’s mental health? The role of the European North–South gradient	11 European countries	• SHARE, wave 1 and 2 • Cross-sectional • Female Respondents between 50 and 75 years	• Providing assistance to a parent, step-parent or parent-in-law • Assistance is defined as personal care (e.g. dressing, bathing, eating),	• EURO-D	• The provision of informal care has a negative impact on daughters’ mental health in Mediterranean countries, in countries where the resources allocated to LTC are minimal • In Northern European countries the states are by law responsible for elderly’s care and here

(Brenna & Di Novi, 2015)		Northern (n=1.159), Central (n=1.498) and Southern European (n=1.773) subsamples built on their GDP spending on LTC	practical household help (e.g. home repairs) and help with paperwork (e.g. filling out forms) - Providing assistance on at least a weekly basis - Included assistance inside and outside the same household together		the daughter's choice to assist her parents does not represent a stressful experience
Positive and negative evaluation of care-giving among three different types of informal care relationships (Broese van Groenou et al., 2013)	The Netherlands	- Sample of Dutch informal caregivers - Cross-sectional (n=1.685) - Respondents between 19 and 85 years - Subsamples of spousal, child and other type of care-giving relationships	- Providing care in the last twelve months for (1) a family member who was severely ill or needed assistance, (2) to someone longer than 2 weeks because of an illness, accident or hospital admission, (3) to someone who was chronically ill or impaired and/or (4) to someone because of other reasons - Including physical and behavioural problems of the care recipient, hours of caregiving and number of tasks	- Positive evaluation of care-giving (eight items based on qualitative interviews: e.g. 'Looking after my care receiver gave me a good feeling') - Caregiver burden (Self-perceived pressure form Informal Care Scale) with 14 statements on time and emotional pressure (e.g. 'Generally speaking I felt very pressured because of the situation of my care recipient')	- Majority provided care to their parents or parent-in-law - Spouses were more often male (59 %) and older and less educated than other types of caregivers - Children are more likely to share care - Dual nature of caregiving (positive evaluation and caregiver burden) was found among spouses and children and less among other caregivers - Burden was higher for women, for those who provided many care tasks and many hours of care - Positive evaluation was higher among children who were motivated by a strong personal bond with the parent and a stronger preference of informal care
Strain Among Caregivers: A Study of Experience in the United States (Cantor, 1983)	United States	Study "The Impact of the Entry of the Formal Organization on the Informal Support System of Older Americans"	Elderly people were asked who helped them with tasks of daily living and whom they regarded as their primary source of help (primary caregivers)	- Quality of relationship (seven items) - Strain arising from caring role (emotional, physical, financial) - Impact on life of caregivers (eight items)	- Four types of caregivers: 33 % spouses, 36 % children, 19 % other relatives, and 12 % friends/neighbors 70 % felt very close to the care-recipient - High degree of emotional strain found in spouses, children and other relatives, more

		• Cross-sectional (n=111) • Low-income older persons and their caregivers who were served by a homemaker service (12 hours service for 12 weeks) between June 1979 and March 1980			physical and financial strain in spouses, least amount of strain for friends/neighbours • The closer the bond, the greater the amount of strain; spouses were the group at greatest risk, followed by children, other relatives, and friends and neighbours • Quality of the interpersonal relationship was a further contributor to strain • More impact in daily live for spouses who lived in the same house • Most severe impact in areas such as free time, opportunities to socialize with friends, take vacations, have leisure time pursuits, run one's own house
Caregiving: a risk factor of poor health and depression among informal caregivers in India - A comparative analysis (Chakraborty et al., 2023)	India	• LASI, wave 1 in 2017-2018 • Cross-sectional (n=67,749) • Respondents aged 45 years and older	• Hours spent in caregiving: "How often do you take care of the family member/outside the family?" and "For how many hours do you provide care in the last week?" • Type of activities: ADL, IADL, medical care (e.g. medications, changing bandages), social care (e.g. spending time), financial support • Relationship: spouse/partner, parents, parents-in-law, brother/sisters, children, other relatives, not related	• Depressive symptoms (CES-D, ten items) • Self-rated health (very good, good, fair, poor, very poor)	• 29 % of caregivers reported depressive symptoms and 11 % a poor self-rated health • Caregivers were at higher risk of having a depression and poor health than non-caregivers irrespective of socio-economic characteristics • Caregivers providing 40 hours of care and spousal care reported to have a higher risk of depression and poor self-rated health • Male caregivers show 1.26 times (female: 1.51) higher odds of having depressive symptoms than male non-caregivers; male caregivers report 1.72 times higher odds (female: 1.48) of reporting poor self-rated health than male non-caregivers

Informal care and caregiver's health (Do et al., 2015)	South Korea	• KLoSA, three waves in 2006, 2008 and 2010 • Cross-sectional • Respondents aged 45 years and older • Restricted to women with living parents-in-law (n=2.528) and living parents (n=4.108)	Binary indicator variable of any informal care provided to parents-in-law (daughter-in-law sample) or a binary variable of any informal care provided to parents (daughter sample).	• Pain affecting daily activities • Fair to poor self-rated health	• The magnitude of the estimated effects was greater in the daughter than in the daughter-in-law sample, which may reflect greater negative health consequences among daughters
Informal care-giving and mental ill-health – differential relationships by workload, gender, age and area-remoteness in a UK region (Doebler et al., 2016)	Northern Ireland	• Northern Ireland Longitudinal Study (NILS) • The Northern Ireland Enhanced Prescribing Database (EPD) • Proximity to Service Index • Cross-sectional (n=378.365) • Respondents aged 16 years and older	“Do you look after, or give any help or support to family members, friends, neighbours or other because of either: long-term physical or mental ill-health/disability/problems related to old age?”	• Subjective mental ill-health: “Do you have any of these conditions which have lasted, or are expected to last at least 12 months? – an emotional, psychological or mental health condition?” • Prescribed antidepressants (yes/no)	• 15 % were informal caregivers, majority (59 %) were women • People who provided highly intensive (50+) caregiving were more likely to report a mental health condition • Across all intensities women were twice as likely as men to have been prescribed antidepressants • Caregivers in remote areas with only limited access to shops and services had a significantly increased risk for prescribed antidepressants
Does country influence the health burden of informal care? An international comparison between Belgium and Great Britain (Dujardin et al., 2011)	Belgium, Great Britain	• 2001 census data for Belgium (n=4.368.637) and Britain (England, Scotland, Wales, n=1.361.222) • Cross-sectional	• Two questions: if the individual provided care or not, and the time spent caring (no care, less than 20 hours, more than 20 hours) • It was clearly stated that answers on informal care	• Self-rated health: three items (good, fairly good, not good) in Britain; five items (very good, good, average, bad, very bad) in Belgium	• Caring was more prevalent among women and in Britain: 11.3 % of men and 16.3 % women are informal caregivers in Britain and 7.5 % of men and 11.7 % of women in Belgium • Providing informal care was generally associated with poorer health • Negative impacts on health increased with the amount of care provided for men

		• Respondents aged 25 to 59 years	should include only activities not related to paid employment and those due to other individuals' health problems (therefore excluding caring for healthy children)	• Individuals who reported "not good" health in Britain and "(very) bad" health in Belgium as having poor health	• Women providing less than 20 hours a week slightly reduced the risk of reporting poor health, while providing more than 20 hours increased their health risks • The health burden associated with heavy caregiving is lower in Britain than it is in Belgium
Dimension of informal care and quality of life among elderly family caregivers (Ekwall et al., 2004)	Sweden	• Postal survey • Cross-sectional (n=4,278) • Respondents aged 75 years and older	• Helping a person because of impaired health • Seven alternatives of help: adaption own activities, keeping in touch at least once a week, helping with hospital contacts, cleaning or cooking, personal care, medical care and improving physical functions	• QoL (SF-12)	• Care starts before help with personal hygiene, feeding and getting dressed (PADL) is needed • Low economic situation and own need for help with IADL correlated with QoL • Women did more often preventive care (preventing illness, injury and physical and mental deterioration) in helping with PADL than men
Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being (Fauth et al., 2012)	United States (Cache County, Utah)	• Cache County Dementia Progression Study (DPS) • Cross-sectional and longitudinal • 234 care dyads: 49 % spouses and 51 % adult children • Caregivers enrolled in DPS between 2002 and 2009 • Cross-sectional and longitudinal • No age exclusion (average caregiver age: ~70 years)	Relationship Closeness Scale (six items): "My relative always understands what I value in life." (b) "My relationship with my relative has always been close." (c) "My relative always makes me feel that whatever I do for him/her is not enough (reverse coded)." (d) "My relative always makes me feel like a special person." (e) "My relative is often critical of me (reverse coded).", and (f) "My relative and I can	• Affects Balance Scale (ABS, ten items) including five negative and five positive emotions experienced in the past week • Back Depression Inventory II (BDI, 21-items) • Physical and mental health (SF-12 Physical Component and SF-12 Mental Component)	• Caregivers were female children (42 %), female spouse (34 %), male children (9 %) or male spouses (15 %) • Higher closeness at baseline measurement predicted higher baseline mental health and lower depression and a greater worsening over time

			always discuss things together.”		
Mortality Associated with Caregiving, General Stress, and Caregiving-Related Stress in Elderly Women: Results of Caregiver Study of Osteoporotic Fractures (Fredman et al., 2010)	United States (Maryland, Minnesota, Oregon, Pennsylvania)	• Study of Osteoporotic Fractures, 1999-2007 • Longitudinal (n=1.069) • Respondents aged 65 years and older • Focus on females only	Currently helping a relative or friend with each of seven IADL (use the telephone, get to places out of walking distance, shop, prepare meals, manage medications, manage finances, do heavy housework) and seven ADL (walk across a room, groom, transfer from bed to chair, eat, dress, bath, use the toilet)	• All-cause mortality as of December 31, 2007	• Caregivers were more stressed than noncaregivers • Mortality was lower in caregivers than noncaregivers • High-stress respondents had a higher mortality risk than low-stress respondents in the first three years of follow-up • Low-stress caregivers had significantly lower mortality than noncaregivers
Gender differences in burden and depression among informal caregivers of demented elders in the community (Gallicchio et al., 2002)	Canada	• Canadian Study of Health and Aging (CSHA) • Cross-sectional (n=327) • Respondents aged 65 years and older	Informal primary caregivers who identified themselves as being the most responsible for the day-to-day decision-making and provision of care to the patient with dementia	• Burden interview (22-items) • Depressive symptoms (CES-D, 20-items) • Self-rated physical health (“How would you rate your health is?”) • Some outcomes related to the care recipient (e.g. behaviour disturbance)	• Female caregivers were more likely to live with the patient than male caregivers and spent more time with the patient • A higher level of behaviour disturbance of the care recipient was associated with burden and depression • Caregivers with worse perceived health had higher odds of a high burden • Spouses and children had higher odds of depression than other caregivers • Females had higher odds than male of having a high burden, but not for depression
Couples dealing with cancer: Role and gender differences regarding psychological distress and quality of life (Hagedoorn et al., 2000)	The Netherlands	• Two samples of patients with cancer and their spouses • Cross-sectional (n=173) • No age exclusion	• Couples facing various forms of cancer	• Psychological distress (CES-D) • QoL (from 0 “worst imaginable life” to 10 “best imaginable life”) • Physical limitation (RAND Health Survey, 36-items)	• Female patients and female partners of patients experienced more psychological distress and lower QoL than women in healthy couples • 27 % of female and 22 % of male patients were at risk of developing clinical depression • For partners the percentages were almost 35 % for women and only 12 % for men

The Effect of Intra- and Intergenerational Caregiving on Subjective Well-Being – Evidence of a Population Based Longitudinal Study among Older Adults in Germany (Hajek & König, 2016)	Germany	• German Ageing Survey (DEAD), waves in 2002, 2008 and 2011 • Longitudinal (n=10.434) • Respondents aged 40 years and older	• “Are there people you look after or care for regularly due to their poor state of health, either on a private or volunteer basis?” • Focus on intergenerational (e.g. for a mother, father) and intragenerational care (e.g. for a spouse/partner)	• Cognitive well-being (Satisfaction with Life Scale, five items) • Positive and negative affect (Positive and Negative Affect Schedule, five items) • Mental health (CES-D, 15 items) • Functional health (SF-36, 36 items) • All together defined as subjective well-being	• Intergenerational informal care did not affect the various subjective well-being outcome measures • Intragenerational caregiving was associated with less cognitive well-being (women) and worse mental health (total sample and men) compared with non-caregivers
The Strains and Gains of Caregiving: An Examination of the Effects of Providing Personal Care to a Parent on a Range of Indicators of Psychological Well-Being (Hansen et al., 2013)	Norway	• Norwegian Life-Course, Generation and Gender Study (LOGG), 2007/2008 • Cross-sectional (n=15.109) • Respondents aged 18-84 years • Norwegian Life Course, Ageing and Generation Study (NorLAG), 2002/2003 • Longitudinal (n=3.792) • Respondents aged 40-79 years	• “Have you during the past year given regular help with personal care to someone you (do not) live with. Help with, for example, eating, getting out of bed, dressing, or using the bathroom?” • Focus on care for a parent and parent-in-law	• Life satisfaction (Satisfaction with Life Scale, five items) • Partnership satisfaction (five items) • Self-esteem (Rosenberg Self-Esteem Scale, ten items) • Mastery (Pearlin and Schooler Mastery Scale, seven items) • Happiness (“I feel happy”) • Positive and negative affect (Positive and Negative Affect Schedule, twelve items) • Depression (CES-D, 20 items) • Loneliness (Loneliness Scale, three items)	• 2.6 % of men and 4.7 % of females provide care to a non-resident parent, 0.7 % of men and 1.2 % of women provide care to a resident parent (LOGG) • 5.0 % of men and 9.9 % of women provide regular help with personal care to a non-resident parent, and 1.6 % of men and 1.8 % of women provide such help to a resident parent (NorLAG) • Caregiving is largely unrelated to well-being • For women caring for a resident parent is associated with lower happiness and more negative affect, more depressive symptoms and more loneliness (cross-sectional results) • For women caring is associated with decreasing happiness and increasing depression and caring for a non-resident parent is associated with a positive change in the sense of mastery (longitudinal results)

The psychological effects of providing personal care to a partner: A multidimensional perspective (Hansen & Slagsvold, 2013)	Norway	• LOGG, 2007/2008 • Cross-sectional (n=6.734) • Respondents aged 40-79 years • NorLAG, 2002/2003 and 2007/2008 • Longitudinal (n=2.553) • Respondents aged 40-79 years	• Having a disabled partner and providing regular help to a partner with personal care	• Life satisfaction (Satisfaction With Life Scale) • Self-esteem (Rosenberg 10-item Self-Esteem Scale) • Mastery (Pearlin and Schooler's 7-item Mastery Scale) • Happiness ("I feel happy") • Depression (20-item CES-D)	• Caregiving is associated with marked reduction in life satisfaction, self-esteem (only among men), mastery, happiness (only among men) and depressive symptoms (only among women) • Pathways between caregiving and well-being are complex, depending on combinations of a wide array of personal and situational factors
Providing personal informal care to older European adults: Should we care about the caregivers' health? (Hiel et al., 2015)	10 European countries	• SHARE wave 1, 2 and 4, 2004/2005, 2006/2007 and 2010/2011 • Longitudinal (n=7.858) • Respondents aged 50 years or older	Provision of personal care, e.g. dressing, bathing or showering, eating, getting in or out of bed and using the toilet either inside or outside the household in the past 12 months	• Self-rated health (5-point scale from "excellent" to "poor") • Mental health (EURO-D) • Physical health (appearance of health conditions e.g. pain in back in the past six months)	• Personal care was significantly associated with poor mental and physical health over a follow-up period of eight years • Older and retired caregivers experienced more detrimental consequences of providing care
Health effects of informal caregiving across Europe: A longitudinal approach (Kaschowitz & Brandt, 2017)	10 European countries and England	• SHARE wave 1, 2, 3 and 5 • ELSA waves 2-5 • Cross-sectional and longitudinal • Respondents aged 50 years and older	• ELSA: "Did you look after anyone in the past week [...]?" By 'look after' we mean the active provision of care." And "[Does_.person] you care for live with you?" • SHARE: "Is there someone living in this household whom you have helped regularly during the last twelve months with personal care, such	• Self-perceived health ("poor" (1) to "excellent" (5)) • Depression (ELSA: "very depressed" (0) to "not depressed" (9); SHARE: "very depressed" (0) to "not depressed" (12))	• 9 % gave care inside and 16 % care outside the household • The share of caregivers varied by country: highest in Belgium, the Netherlands and Denmark for outside care and higher in southern countries for inside care • Across Europe caregivers inside the household report worse (self-perceived and mental) health than non-caregivers and in most countries • Caregivers who started caregiving inside the household experienced a decline in mental health

			as washing, getting out of bed, or dressing?“ and “In the last twelve months, have you personally given any kind of help to a family member from outside the household, a friend or neighbor?”: two types of care (inside and outside the household) including daily of almost daily support with personal care or practical help		• People providing care outside the household reported better health than non-caregivers • These differences are explained by the selection into caregiving: People in worse health took up care inside the household while people in better health took up care outside the household
Relationships between Caregiving Stress, Depression, and Self-Esteem in Family Caregivers of Adults with Disability (Kim, 2017)	Korea	• Family members of adult persons with a disability who visited rehabilitation centres, 2016 • Cross-sectional (n=108) • Respondents aged 30 years and older	Visiting hospital rehabilitation centres	• Caregiving-Related Stress (Caregiver Burden Interview) • Depression (Korean Depression Scale) • Self-Esteem (Rosenbergs Self-Esteem Scale)	• Caregiving stress had a positive correlation with depression • Financial and psychological stress had a negative correlation with self-esteem • Caregiver stress was stronger among caregivers who were female, older and the spouse of the care recipient and had no occupation • Depression level was higher in females and those with lower income
The Impact of Care Intensity and Work on the Mental Health of Family Caregivers: Losses and Gains (Kolodziej et al., 2022)	United States	• National Study of Caregiving (NSOC) in 2011, 2015 and 2017 • National Health and Aging Trends Study (NHATS), waves 1, 5 and 7 (for information about the care recipient)	• Intensive caregiving defined as providing at least 80 hours of care per month or 20 hours a week in the past month (reference: less intensive caregiving) • Average hours of care and personal care (defined as eating, showering, dressing, or using the	• Depression (PHQ-4) • Major depression (PHQ-2) • Generative anxiety disorders (GAD-2) • Positive well-being as caregiver self-actualization (life purpose and growth) and positive direct experiences from helping (increased closeness of the re-	• 18 % provide intensive care and do not work, 14 % do both, 41 % work and do not provide intensive care and 27 % do not work and do not provide intensive care • Caregivers provide on average 84 hours of care per month, 39 hours are for personal care • Providing 80 or more hours of care per month to a parent compared to less intensive care increases the PHQ-4 scale score for anxiety and depression disorders

		• Cross-sectional (n=3.309) • Respondents aged between 30 and 80 years	• toilet) are shown descriptively • Limited to adult children	• lationship with care recipient and satisfaction from helping)	• No evidence that working affects mental health • Intensive caregivers are less likely to report a high relationship quality and satisfaction from caregiving than less intensive caregivers
Informal caregiving patterns and trajectories of psychological distress in the UK Household Longitudinal Study (Lacey et al., 2019)	United Kingdom	• UKHLS, wave 1-7 • Longitudinal (n=9.368)	• “Is there anyone living with you who is sick, disabled or elderly whom you look after or give special help to (for example, a sick, disabled or elderly relative/husband/wife/friend etc.)?” • “Do you provide some regular service or help for any sick, disabled or elderly person not living with you?”	• General Health Questionnaire-12 (GHQ-12)	• Informal caregiving was not associated with psychological distress for men • Women, who engaged in long-term (three years or longer) or intermittent caregiving had higher levels of psychological distress at the point of initiation than women who were not caregivers throughout the study period
Mental and physical health changes around transitions into unpaid caregiving in the UK: a longitudinal, propensity score analysis (Lacey et al., 2024)	United Kingdom	• UKHLS, 2009-2020 • Longitudinal (n=3.025 to 5.785) • Respondents aged 16 years and older	• Provision of some regular service or help for any sick, disabled, or elderly person not living with them • Equivalent question whether they do so for someone living with them • Numbers of hours of care per week	• GHQ-12 • SF-12	• Mental health worsened around the time of becoming a caregiver • In particular for those younger than 64 years, providing 20 hours or more care per week and for someone living inside the household • Physical health functioning did not change, but there are lower levels of functioning before caregiving • Not gender differences regarding changes in mental and physical health upon transition to caregiving
Spouses’ experience of caregiving for cancer patients: A literature review (Li et al., 2013)		• Systematic search in Medline, CINAHL, Science Citation Index Expanded, Scopus, PsychINFO and China Academic Journal • Search terms: Cancer/oncology/carcinoma AND caregiver/caregiving/carer AND spouse/couple/partner			• Female caregivers performed more care tasks than male caregivers throughout the process of caring for their spouses

		• Inclusion criteria: Study population are couples coping with cancer, quantitative studies have to include both male and female spousal caregivers in the same study, qualitative studies do not have to meet this criterion • Studies written in English or Chinese from January 2000 to March 2012 • n=20 quantitative studies and n=5 qualitative studies			• Female caregivers perceived the caregiving process more negatively compared with male caregivers of spouses with cancer such as lower mental and physical health, health-related QoL, life satisfaction and marital adjustment • Male caregivers exercised avoidance and found it difficult to express their emotional reaction to caregiving, providing less tangible and emotional support
Relationship status and depressive symptoms among older co-resident caregivers (Litwin et al., 2014)	16 European countries	• SHARE wave 4 • Cross-sectional (n=3.280)	• Care was defined as personal care provided to another person or persons in the household for a period of at least three months during the previous twelve months • Personal care was defined as assistance with self-care tasks such as personal hygiene, dressing, eating, mobility and taking medications	• Depressive symptoms (EURO-D)	• 60 % cared for a spouse or partner • Caregivers of a spouse or an adult child reported more depressive symptoms than those who gave care to parents or others • Caregivers who had a confidant relationship with the care recipient reported fewer depressive symptoms
Transitions to Caregiving, Gender, and Psychological Well-Being: A Prospective U.S. National Study (Marks et al., 2002)	United States	• National Survey of Families and Households, 1987-1988 and 1992-1993 • Longitudinal (n=8.286) • Respondents aged between 19 and 95 years	• “Sometimes because of a physical or mental condition, illness, or disability, people require the assistance of friends or relatives. During the last 12 months have you, yourself, given anyone not living with you at the time any help or assistance because of their	• Depressive symptoms (CES-D, twelve items) • Hostility/irritability (e.g. “On how many days during the past week did you feel irritable, likely to fight or argue?”, three items) • Global happiness (one item) • Personal mastery (five items)	• Women and men who reported becoming a new caregiver for a child with a disability reported a significantly greater increase in depressive symptoms than women and men who did not begin such care • Men and women transitioning into spouse care experienced a greater increase in depression and a greater decline in happiness than non-caregiving peers

			health problem or disability?” • „During the last 12 months have you, yourself, given anyone who was living with you at the time any help with personal care because of their long-term physical or mental condition, illness, or disability?” • Additional questions about the person, who was given most help (e.g. spouse, child, parents, in-laws, other non-kin)	• Positive psychological wellness-scale by Ryff (five items: autonomy, personal growth, positive relations with others, purpose in life, self-acceptance)	• The transition to parent care out-of-household was associated with a significantly greater increase in depression for both men and women than remaining a noncaregiver • Women who provided care for other kin reported a higher level of hostility and greater decline in happiness, but also more autonomy • Men who began caregiving for other kin reported a greater increase in depression and lower levels of personal growth • Transitions into other types of kin was more problematic for men than women • Nonkin care was associated with beneficial effects on several dimensions of psychological wellness: more autonomy, personal growth, purpose in life, and self-acceptance for women and more personal growth for men
Predictors of Beginning and Ending Caregiving During a 3-Year Period in a Biracial Community Population of Older Adults (McCann et al., 2004)	United States	• Chicago Health and Aging Project • Longitudinal (n=4.245) • Respondents aged 65 years and older	• Currently providing unpaid assistance to people of any age owing to health problems, illness or disability at baseline with a three-year follow-up	• Disability (modified Katz Activities of Daily Living Scale; Roscow-Breslau Functional Health Scale; Nagi Scale) • Depressive symptoms (10-item CES-D) • Self-rated physical and mental health (4-item Health-Related QoL measure) • Overall health (4-point scale from poor to excellent; number of days in month that physical/mental health was not good)	• Physically healthier individuals were more likely to become caregivers and to continue caregiving • Physical health is an important caregiver selection factor • Mental health had little influence on beginning caregiving, but declining mental health was associated with continuing caregiving

				• Blood pressure (protocol of the Hypertension Detection and Follow-Up Program)	
Participation in socially-productive activities, reciprocity and wellbeing in later life: Baseline results in England (McMunn et al., 2009)	England	• ELSA wave 2, 2004 • Cross-sectional (n=5.384) • Female respondents aged 60 and male respondents aged 65 years and older (based on the British state pension age)	• Social productive activities (caring for someone, voluntary work and paid work)	• QoL (19-item CASP) • Life satisfaction (Satisfaction with Life Scale) • Depression (8-item CES-D)	• Carers who did not feel appreciated for their caring had significantly worse QoL and life satisfaction compared with non-carers • Carers who felt appreciated were less likely to be depressed than non-carers • Volunteers who felt appreciated for their volunteering had higher QoL and life satisfaction than non-volunteers • Reciprocity in caring emerged as significantly related to wellbeing in later life
Growing and gaining through caring for a loved one with dementia (Netto et al., 2009)	Singapore	• Face-to-face interviews with main caregivers of a person with clinician diagnosed dementia • Cross-sectional (n=12) • No age exclusion	• Primary caregivers of dementia patients	• Caregiver gains (any positive affective or practical return of a reciprocal nature that is experienced as a direct result of becoming a caregiver)	• All respondents have reported that they have gained from caregiving • The most common gain was personal growth, which included becoming more patient, more understanding, stronger and more resilient, having increased self-awareness and being more knowledgeable
MAKING THE BEST OF IT: Themes of Meaning among Informal Caregivers to the Elderly (Noonan et al., 1996)	United States	• Random sample from the Massachusetts Elder Health Project with baseline interview 1984-1985 and follow-up 1988-1995 • 48 interviews	• Caregivers of community-resident older people • 40 % children, 26,2 % spouses, 26,2 % other relatives, 7,6 % non-relatives	• Positive aspects of caregiving	• Predominant themes among caregivers included gratification and satisfaction with the caregiving role, a sense of family responsibility, reciprocity, friendship and company and a commitment to “doing what needs to be done”

Caring for a relative with dementia: family caregiver burden (Papastavrou et al., 2007)	Cyprus	• Descriptive study with 172 patient-primary caregiver dyads, 2004-2005 • Cross-sectional • No age exclusion of caregivers	• Caregivers (partners, daughter, son or other relatives) who had the most frequent contact with the patient with a probable Alzheimer disease assessed using the Memory and Behaviour Problem Checklist from 1990 (MBPC, 21 items)	• Caregiver burden (Burden Interview, 22 items in four dimensions: personal strain, role strain, relational deprivation, management of care) • Depression (CES-D, 20 items) • Ways of coping (38 items, e.g. seeking support, wishful thinking)	• Most caregivers were daughter (48.3 %), spouses (41.3 %), sons (5.8 %) or others (4.1 %) • Majority of caregivers experience a high level of burden and higher risks for depression • Positive correlation between burden and the frequency of the patients' problems • No difference in burden when the patient resided in the community or care institution • Women had a higher burden score than men • Caregivers with higher education and better remuneration had lower levels of burden • Positive coping had a negative and emotional coping had a positive correlation with burden
Differences Between Caregivers and Non-caregivers in Psychological Health and Physical Health: A Meta Analyses (Pinquart & Sorensen, 2003)		• Systematic search in PsychINFO, Medline, Psynex • Search terms: Caregiving/caregiver/carer/support provider AND non-caregivers AND elderly/old age • Inclusion criteria: Samples of informal caregivers of older adults are compared with samples of noncaregivers regarding perceived stress, depression, general subjective well-being, physical health or self-efficacy • Studies written in English, French, German or Russian from 1987 to summer 2002 • n=84 studies			• Caregivers had lower levels of subjective well-being, physical health and self-efficacy and higher levels of stress and depression than noncaregivers • Older samples reported higher levels of depression and lower levels of self-efficacy than younger samples • Younger caregivers reported increased stress than older caregivers • Differences between caregivers and noncaregivers were greater for stress, self-efficacy, depression and subjective well-being than for physical health
Informal Elderly Caregiving and Time Spent on Leisure: Evidence from Time Use Survey (Rokicka & Zajkowska, 2020)	Poland	• Time Use Survey, 2013 • Cross-sectional (n=38.967) • Respondents aged 15 years or older	Spending any time on physical care of a dependent adult household member, other help to a dependent household member, help to a nondependent adult	• Physical activity (time spent on physical exercise, productive exercise, sport-related activities) • Hobbies (time spent of entertainment and culture,	• Caregivers are more likely to spend less time on physical activity, hobbies and social life • Time poverty is predominantly experienced by those providing care to a household member

			household member, help to an adult from another household	arts, hobbies and unspecified leisure) • Social life (socializing with family, visiting and receiving visitors, celebrations, telephone conversations and other social life)	• Reductions in leisure time are involuntary and more affected during weekends than on working days
Family caregiving and emotional strain: association with quality of life in a large national sample of middle-aged and older adults (Roth et al., 2009)	United States	• REGARDS study, 2003-2007 • Cross-sectional (n=43.099) • Respondents aged 45 years and older	• “Are you currently providing care on an ongoing basis to a family member with a chronic illness or disability? This would include any kind of help such as watching your family member, dressing, or bathing this person, arranging care, or providing transportation?” • When identified as caregivers additional questions about cohabitation and relationship with care recipient, frequency of care and strain	• Health related QoL (SF-12 with mental and physical component summary) • Depressive symptoms (4-item short form of the CES-D) • Social contacts (number of friends, number of relatives, number of social contacts seen per month)	• Women were more likely to be caregivers than men • Afro-Americans were more likely to be caregivers than Whites • More caregivers (15.2 %) had depressive symptoms) than non-caregivers (12.1 %) • Caregivers reporting high strain were found to report worse values on all dependent variables • Those providing 20 or more hours care per week reported higher levels of depressive symptoms than those providing less than 20 hours care per week • Afro American caregivers were more likely to be live with their care recipient and provide more hours of care than white caregivers • White caregivers were more likely than Afro American caregivers to report mental or emotional strain as a result of caregiving
Short- and medium-term effects of informal care provision on health (Schmidt & Westphal, 2015)	Germany	• German Socio-Economic Panel (SOEP), 2002-2010 • Cross-sectional (n=29.080) and longitudinal (after 1, 3, 5 and 7 years)	“What is a typical day like for you? How many hours do you spend on care and support for persons in need of care on a typical weekday?”	• Mental and physical health (SF-12)	• No effects of informal care on physical health in the short- and in the medium-run • Short-term effects of informal care on mental health attenuate over time

		• Female respondents aged 18 years and older			
Health effects of caregiving: The Caregiver Health Effects Study: An Ancillary Study of the Cardiovascular Health Study (Schulz et al., 1997)	United States (North Carolina, Maryland, Pennsylvania)	• Caregiver Health Effects Study, 1993/1994 • Cross-sectional (n=819) • Respondents aged 65 years and older	Potential caregivers were defined as individuals whose spouse had difficulty with at least one ADL or IADL due to physical or health problems or problems with confusion	• Physical functioning (ADL, IADL) • Psychological well-being (e.g. depressive symptoms by 10-item CES-D) • Perceived health (5-point scale from poor to excellent) • Health behaviours (e.g. eating less than three meals a day, not having enough time to exercise) • High blood pressure (e.g. seated diastolic blood pressure exceeding 90 mm Hg) • Blood chemistries (e.g. measurement of cholesterol) • Medication use • Cognitive functioning (modified Mini-Mental State examination; Digit Symbol Substitution)	• Non-caregivers report higher levels of health status than those living with a disabled spouse, those providing care or those reporting strain associated with caregiving • Strained caregivers report lower level of health, more depressive symptoms and anxiety symptoms, are more likely to report inadequate time for sleep, self-care and other health-related activities
Participation in socially productive activities and quality of life in early old age: findings from SHARE (Siegrist & Wahrendorf, 2009)	14 European countries	• SHARE wave 1 and 2, 2004/2005 and 2006/2007 • Cross-sectional (wave 1: n=14.517, wave 2: n=16.627)	Social productive activities: • Doing voluntary or charity work • Caring for a sick or disabled adult • Providing help to family, friends or neighbours	• QoL (CASP-12)	• North-South gradient in QoL • Decrease in QoL among people who gave up volunteering within the two years under study • QoL increased among those who initiated volunteering or informal help • Giving up caring for a person was associated with an increase in QoL

		and longitudinal (n=8.896) • Respondents aged 50 years and older			
Informal care and the impact on depression and anxiety among Swedish adults: a population-based cohort study (Stratmann et al., 2021)	Sweden	• Swedish PART study, wave 1 (1998-2000) and wave 3 (2010) • Cross-sectional (n=9.346) and longitudinal (n=5.108) • Respondents aged between 18 and 65 years living in Stockholm	• “Are you currently responsible for the care of a long-time sick or disabled family member?” • “Are your opportunities for work or leisure activities limited by this care responsibility? Are your opportunities for spending time with friends and family limited by this care responsibility? Does your responsibility for care lead o conflicts with family and friends?”	• Self-reported depressive symptoms: no depressive symptoms (<20), mild (20-24) and severe (>30) depressive symptoms • Anxious distress (DSM-5, five questions) • Diagnosed depression (ICD-10 codes: F32-33) • Clinically diagnosed anxiety (ICD-10 codes: F40-41)	• The proportion of women was highest in those giving informal care and experiencing limitations • Caregivers experiencing limitations in work or leisure activities and times with friends and family have a 2-fold higher risk of suffering from anxious distress and depressive symptoms compared to non-caregivers • Caregivers with limitations even had an increased risk of depression even 10 years later
Revisiting longer-term health effects of informal caregiving. Evidence from the UK (Stöckel & Bom, 2022)	United Kingdom	• UKHLS, 9 waves between 2009 and 2019 • Longitudinal (Panel A=126.067; Panel B=82.940) • Respondents aged 16 years and older	• “Is there anyone living with you who is sick, disabled or elderly whom you look after or give special help to (for example a sick, disabled or elderly relative/husband/ wife/friend etc.)?” • “Do you provide regular service or help for any sick, disabled or elderly person not living with you?” • Low (<10 hours per week), medium intensity	• Mental and physical health (SF-12)	• Informal care leads to a small and short-lived increase in physical health among high-intensity caregivers providing <20 h of weekly care • For caregivers’ mental health outcomes there are immediate and persisting negative effects of providing care, mostly incurred by high-intensity caregivers • Negative mental health effects of informal care persist up to four or five years • The provision of care (irrespective of intensity) to a partner does have a strong, negative effect on mental health, while the interaction term for parental care insignificant across all time-periods, for high intensity caregivers

			(between 10 and 20 hours) and high intensity caregivers (more than 20 hours)		only the total group is associated with lower mental health
Explaining the gender gap in the caregiving burden of partner caregivers (Swinkels et al., 2019)	The Netherlands	• The Netherlands' Older Persons and Informal Caregivers Survey, 2015 • Cross-sectional (n=1.611) • No age exclusion but due to focus on caregiving for a spouse average caregiver age is 73 years	• Only care recipients and their partners giving informal care are included in the study	• Burden ("On the scale below, 0 means you now feel that caring for or accompanying your partner is not hard at all and 100 means you now feel that caring for or accompanying your partner is much too hard. Please indicate an X in the scale how much of burden you feel caregiving is at the moment.")	• Female caregivers reported a greater experienced burden than male caregivers • This gender gap is mostly explained by secondary stressors, such as relational and financial problems and problems combining different tasks • Providing more hours of care means a greater burden for men but not for women • Men seem to respond more strongly to the severity of the caregiving situation and for women the caregiving situation itself seems to be what causes the strain
Positive Aspects of Caregiving: Contributions of the REACH Project to the Development of New Measures for Alzheimer's Caregiving (Tarlow et al., 2004)	United States	• Resources for Enhancing Alzheimer's Caregiver Health (REACH), 1996-2000 • Cross-sectional (n=1.229) • No age exclusion	• Family members who lived with the care recipient with dementia, providing care for at least six months and provided at least four hours of care each day	• 11 Positive Aspects of Caregiving (e.g. "Providing help has made me feel useful")	• Caregivers frequently reported that caregiving made them feel needed, useful and good about themselves • Caregiving enabled them to appreciate life more, to develop a more positive attitude toward life and strengthened their relationships with other
The pains and reliefs of the transitions into and out of spousal caregiving. A cross-national comparison of the health consequences of caregiving by gender	17 European countries	• SHARE, wave 1, 2, 4, 5 and 6, between 2005 and 2015 • Longitudinal (n=43.435) • Respondents aged 50 years and older	• "Is there someone living in this household whom you have helped regularly during the last twelve months with personal care, such as washing, getting out of bed, or dressing?"	• Degree of frailty (Frailty Index, 40-items)	• 3.5 % of men and 4.2 % had a transition into and 2.3 % of both genders out of spousal caregiving • Transitioning into caregiving is associated with increased frailty levels in all four European contexts (Northern, Western, Southern and Eastern) • No gender differences in the association between transition into spousal care and health

(Uccheddu et al., 2019)			• Focus on spouses only and transitions into and out of caregiving (exact timing of transitions not known)		• Transitions out of caregiving are associated with better health, but only for females in Southern and Eastern countries • Health effects of spousal caregiving are strongest for men and women living in Southern and Eastern countries
Informal care in Europe. Findings from the European Social Survey (2014) special module on the social determinants of health (Verbakel et al., 2017)	20 European countries	• ESS, wave 7, 2014 • Cross-sectional (n=28,406) • Respondents aged between 25 and 75 years	• Positive answer to the question whether one spends any time looking after or giving help to family members, friends, neighbours or other because of long-term physical ill health or disability, long-term mental ill health or disability or problems related to old age • Focus on caregivers overall and intensive caregivers (eleven hours of care or more per week)	• Mental well-being (8-item sum score about respondents' feelings or behaviours during the past week, e.g. felt depressed, sleep was restless, enjoyed life)	• On average 34.3 % were informal caregivers and 7.6 % intensive caregivers • Large differences between countries, informal care overall ranged from 43.6 % in Finland to 8.2 % in Hungary, intensive care was less prevalent in Nordic countries • Middle and higher educated respondents had higher odds of providing care, no education differences in intensive care • Caregivers reported lower levels of well-being than non-caregivers • Care was more detrimental for the mental health of females than for males • Negative associations between caring and mental health are stronger for intensive caregiving
Social productivity and depressive symptoms in early old age-results from the GAZEL study. (Wahrendorf et al., 2008)	France	• GAZEL, 2005 • Cross-sectional (n=14,477) • Respondents aged between 52 and 66 years	• Social productive activities during the last month (doing voluntary or charity work, caring for a sick or disabled adult, providing help to family, friends or neighbours)	• Depressive symptoms (CES-D, 20 items)	• Prevalence of informal help is highest (94.6 %), 54.3 % do voluntary work and 26.4 % care for a person • Activities with a high degree of autonomy and perceived control (e.g. voluntary work) are negatively related to depressive symptoms • For caring for a sick person as activity with a low degree of autonomy there is a positive association with depressive symptoms

Gendered experiences of providing informal care for older people: a systematic review and thematic synthesis (Zygouri et al., 2021)	• Systematic search in PubMed, PsycINFO, Scopus and Cumulative Index to Nursing and Allied Health Literature • Search items: Informal care/family care/caregiver/care/spouse care AND caregiving/elder-care/gerontolog/geriatric/ageing/aging/aged/seniors AND gender/gender role/gender norm/gender relation/gender identity/gender continuum/feminin/masculin/biological sex • Inclusion criteria: Peer-reviewed qualitative studies and qualitative data from mixed method studies on adults, informal primary family caregivers at the time of the interview to older relatives aged 60 years and above with mental and physical health needs, any residencies where primary caregiving takes place independently of geographical and cultural context, studies focus exclusively on the participants' caregiving experiences and provide a gender analysis or report outcomes concerning participants' gender • Studies written in English or Greek from 2000 to 2020 • n=21	• Affection, reciprocity, feelings of compassion and the duty to provide care appeared as common motivators for both women and men • Providing intensive informal primary care to older people affects both men' and women's mental and physical health • Women caregivers influenced by traditional feminine roles are much more emotionally involved in caregiving
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Source: Own representation based on different sources, see column "Study name".

Table A 2: PHQ-8. Items, Answers with factor, Scale and Interpretation.

Items	Answers with factors				Scale	Interpretation
Over the last two weeks, how often have you been bothered by one of the following problems?	Not at all	Several days	More than half the days	Nearly every day		
Little interest or pleasure in doing things	0	1	2	3	0-24	0-4: Minimal depression
Feeling down, depressed, or hopeless	0	1	2	3		5-9: Mild depression
Trouble falling or staying asleep, or sleeping too much	0	1	2	3		10-14: Moderate depression
Feeling tired or having little energy	0	1	2	3		15-19: Moderately severe depression
Poor appetite or overeating	0	1	2	3		20-24: Severe depression
Feeling bad about yourself - or that you are a failure or have let yourself or your family down	0	1	2	3		Ten or higher: Depressive disorder
Trouble concentrating on things, such as reading the news-paper or watching television	0	1	2	3		
Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3		

Source: Own representation based on Kroenke et al. (2008).

Table A 3: CESD-8. Items, Answers with factors, Scale and Interpretation.

Items	Answers with factors				Scale	Interpretation
How much of the time during the past week...	None or rarely none of the time (less than 1 day)	Some or little of the time (1-2 days)	Occasionally or moderate of the time (3-4 days)	Most or all of the time (5-7 days)		
... did you feel everything you did was an effort?	0	1	2	3	0-24	Higher scores indicate a greater frequency and sever- ity of depressive complaints.
... was your sleep restless?	0	1	2	3		
... were you happy?	0	1	2	3		
... did you feel lonely?	0	1	2	3		
... did you enjoy life?	0	1	2	3		
... did you feel sad?	0	1	2	3		
... were you unable to get going?	0	1	2	3		

Source: Own representation based on Van de Velde (2009).

Table A 4: EURO-D scale. Items, Answers, Scale and Interpretation.

Dimension	Items	Answers		Scale	Interpretation
Depression	In the last month, have you been sad or depressed?	Yes	No	0-12	The maximum score is 12 “very depressed” and the minimum score is 0 “not depressed”. A scale score of four or higher is defined as “case of depression” and a scale score below four as “not depressed”. The list of 16 questions is reduced to twelve final items.
Pessimism	What are your hopes for the future?	Any hopes	No hopes		
Wishing death	In the last month, have you felt that you would rather be dead?	Any mention of suicidal feelings	No such feelings		
Guilt	Do you tend to blame yourself or feel guilty about anything?	Obvious guilt or self-blame	No such feelings		
	So, for what do you blame yourself?	Examples given constitute obvious excessive guilt	Examples given do not constitute obvious excessive guilt		
Sleep	Have you had trouble sleeping recently?	Trouble in sleep or recent change in pattern	No trouble sleeping		
Interest	In the last month, what is your interest in things?	Less interest than usual mentioned	No mention of loss of interest		
	So, do you keep up your interests?	Yes	No		
Irritability	Have you been irritable recently?	Yes	No		
Appetite	What has your appetite been like?	Diminution in desire for food	No diminution in desire for food		
	Have you been eating more or less than usual?	Less	More		
Fatigue	In the last month, have you had too little energy to do things you wanted to do?	Yes	No		
Concentration	How is your concentration? For example, can you concentrate on a television programme, film or radio programme?	Difficulty concentrating on entertainment	No such difficulty mentioned		
	Can you concentrate on something you read?	Difficulty concentrating on reading	No such difficulty mentioned		
Enjoyment	What have you enjoyed doing recently?	Fails to mention any enjoyable activity	Mentions any enjoyment from activity		
Tearfulness	In the last month, have you cried at all?	Yes	No		

Source: Own representation based on Mehrbrodt (2021); Prince et al. (1999).

Table A 5: CASP 12-item version. Items, Answers with factors, Scale and Interpretation.

Dimension	Items	Answers with factors				Scale	Interpretation
		Often	Sometimes	Rarely	Never		
Control	My age prevents me from doing the things I would like to do.	1	2	3	4	12-48	Higher scores indicate a higher QoL. Some items are reversed in their coding.
	I feel that what happens to me is out of control.	1	2	3	4		
	I feel left out of things.	1	2	3	4		
Autonomy	I can do the things I want to do.	4	3	2	1		
	Family responsibilities prevent me from doing the things I want to do.	1	2	3	4		
	Shortage of money stops me from doing things I want to do.	1	2	3	4		
Pleasure	I look forward to each day.	4	3	2	1		
	I feel that my life has meaning.	4	3	2	1		
	On balance, I look back on my life with a sense of happiness	4	3	2	1		
Self-realization	I feel full of energy these days.	4	3	2	1		
	I feel that life is full of opportunities.	4	3	2	1		
	I feel that the future looks good for me.	4	3	2	1		

Source: Own representation based on Bamicha and Verropulou (2023).

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