PhD thesis

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A Mixed methods Investigation into Physical Activity in Carers for those with Dementia

A thesis submitted to Middlesex University
in partial fulfilment of the requirements for the degree of
Doctor of Philosophy

by
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Preface

In the last twenty years increased interest in health benefits of physical activity as well as the negative effects of physical inactivity sparked numerous studies, campaigns, programmes and helping to breach the gap between the healthcare and the fitness industry. Encouraging people to reach the physical activity guidelines and tackling sedentary lifestyle to prevent the onset of chronic conditions have become national priorities. Due to health benefits of regular physical activity, the focus of research endeavours in the past decade has been related to exploring and reducing barriers to physical activity participation amongst the least active, such as frail individuals, people living with comorbidities, informal caregivers, and people from different minority/ethnic groups. Being involved in the fitness sector as a practitioner for the past twelve, and as an academic for the past seven years, I too share the passion for exploring ways to increase exercise adherence amongst special populations and lead projects in the communities where physical activity participation remains low.

Before my academic journey, I aspired to become a professional dancer. Besides studying at Conservatory for Music and Classical Ballet Ljubljana, I also participated in national and international competitions in modern dance, for which I was awarded a golden plaque in a non-Olympic discipline by Olympic committee of Slovenia. After I suffered an injury, I became engrossed in exploring various exercise regimes to recover, which led me to pursue an undergraduate degree in kinesiology at University of Ljubljana. During and after the work placement I worked with individuals living with different chronic conditions and felt I needed to deepen my knowledge of exercise recommendations and considerations when working with special populations. This encouraged me to pursue a postgraduate degree in Sport, Exercise and Physical Activity for Special Populations and Healthy Ageing (SPHA) at Middlesex University. Halfway through my degree I was introduced to Dementia Club UK. A charity offering support to people living with dementia and their family carers. As a volunteer and later a trustee I assisted with a delivery of exercise sessions for people with dementia and their caregivers and got an opportunity to converse with the service users. I noticed the sessions were attended mainly by older carers looking to spend some quality time with their spouses and to get a respite from their daily routine. While talking to the carers, many confined how challenging providing care to their loved ones with dementia can be. This inspired me to explore physical activity perceptions amongst the caregivers of those with dementia and measure the effects of a home-based ballet programme (designed by me) on carers' balance for my MSc dissertation. I became fascinated with the topic and astounded by the lack of research exploring exercise adherence amongst informal carers of people with dementia and decided to investigate the topic further by pursuing a PhD.

As I had never been a caregiver, I wanted to get a glimpse of how it might look like and got a job as a Personal Health Assistant at My Care My Way project in the borough of Kensington and Chelsea. Though my main job was delivering home-based exercise sessions to homebound individuals, including people with dementia I got a chance to experience how challenging activities of daily living (ADLs) can be for the clients and how much support they need to perform daily tasks, such as combing their hair or remembering to take medication. I also noticed disparities in care provision amongst the spouse and offspring carers. While spouses had the same place of residence and were completing most of the daily tasks together, offspring carers did not cohabit with their parents and only stopped by to check if everything is ok. Whilst supporting clients with exercises and ADLs, my visiting time was filled with stories of the past. Clients shared their experiences and ventures as children and young adults, and reminisced about how immensely life has changed since. Apart from being mesmerised by their storytelling, I began to wonder whether views and values elderly clients grew up with influenced their current perceptions of physical activity, well-being and healthcare. When I was introduced to the Life-course theory by my supervisory team, I was convinced it would be an appropriate approach to explore a deeper understanding of physical activity perspectives amongst informal carers of people with dementia.

Though there are a number of informal caregivers providing care to people with dementia in the UK, they are also an extremely hard to reach group. During data collection for my first study, I noticed organisations and charities offering support to informal carers and people with dementia were protective of their service users. Attaining gatekeepers' permission became a mission in itself. I travelled across London visiting multiple charities, organisations, and support groups. After some time, and many closed doors I attained permission to approach potential participants from The Liberal Jewish Synagogue – Singing for the Mind, Green Candle dance company – Remember to Dance and Ashford place. I also registered Middlesex University on Join Dementia Research platform, which allows researchers to advertise their research projects and connect with individuals who want to participate in studies related to dementia. Once I was allowed to invite participants, I found that carers were reluctant to take part in my study due to lack of time and finding it challenging to separate themselves from their loved ones with dementia. While I was rethinking my data collection approach, one of the charities I obtained gatekeepers' permission from advertised an activities coordinator vacancy. Although I was unsuccessful, I was offered a post to lead a project called Dementia Voices Brent (DVB). The project aimed to create a safe and supportive environment for people with memory loss to share their voices, raise awareness of dementia and influence policies. As the project lead, I got an opportunity to act as an advocate for people with dementia and contribute towards dementia friendly London. Together with the DVB members we co-designed 'Look Into my Life with Dementia', an informative event for relatives and carers of people with dementia residing in care homes. The event took place in Jewish Choice Care Campus and aimed to raise dementia awareness amongst the relatives and provide them with an immersive experience of how it looks like to live with the condition. DVB was also a part of 'The UK Network of Dementia Voices' and the 'People's Panel' - a group supporting London Health Board and Dementia Friendly London initiative by reviewing priorities and supporting sector groups where agreed. The first meeting took place in the City Hall, where DVB members advised on changes that could make buildings, such as the City Hall more dementia friendly. The second meeting was held in the Alzheimer's Society headquarters where health and social care pathways for people with dementia and their carers were discussed. The last meeting took place in the Transport for London (TfL) headquarters where members shared challenges they face while using public transport. As a result, TfL included the chapter 'Older and Disabled passengers' in 'The Big Red Book', which provides guidelines to the bus drivers in London on how to recognize and assist someone with a hidden disability, such as dementia. DVB members also shared their views on assistive technology with Vodafone representatives and helped to draft a course for people with dementia, their carers and general public in cooperation with North West London College. As the project lead, I got an opportunity to represent DVB voices in a steering group, which was attended by Brent CCG, North West London College, Community Action on Dementia, and Memory service representatives. I participated in 'Dementia Friendly Faith Community in Brent', which was held at BAPS Shri Swaminarayan Mandir in Neasden, and APPG on Dementia 2019 – Hidden no More: Dementia and Disability report launch, which was led by MP Debbie Abrahams, Robert Courts, and Baroness Greengross.

Leading DVB project not only expanded my understanding of challenges people with dementia and their carers experience daily, but also deepened my knowledge of various sectors in England and how they work together to form policies, strategies and execute agreed plans. It allowed me to be a part of the change I read about while conducting the literature review and opened an opportunity to reach and invite more informal carers to participate in my study. While the pool of potential participants grew, I encountered new challenges. Carers that agreed to be interviewed for my first study frequently cancelled and/or rescheduled the visits. Often the person they cared for required an emergency visit to the GP or they felt unsettled, which resulted in multiple trips and a prolonged data collection process.

In the second study carers were asked to complete a standardised questionnaire, which was handed out in person at carer support groups, dementia cafes and carer centres, and was also available online, which made the recruitment and data collection process easier. However, at the end of year 2019

Covid-19 pandemic struck. I was no longer able to work in other jobs and support myself, and had to move back to my home country, Slovenia. During my stay at home, I became interested in how Slovenia is supporting people with dementia and their informal carers. As elsewhere around the world the generational gap in Slovenia is increasing, which made me wonder whether the three age groups of informal carers found in the first study are present in Slovenia as well. After discussing my observations with the supervisory team, it was decided to continue collecting data in Slovenia. Though organisations and charities had to abide by the pandemic-related restrictions and reduce their services or even close their premises, the number of caregivers looking for support online increased. This allowed me to reach a considerable number of informal carers of people with dementia on online forums and websites across the UK and Slovenia and complete the data collection process for my second study.

In autumn 2020 I secured a job as an assistant sonographer in a private clinic and returned to the UK. While the restrictions imposed during Covid-19 were slowly easing and life returned to the pre-pandemic state, I focused on analysing data and writing up study two as well as continuing with the academic work at the University. Getting an opportunity to lecture foundation, undergraduate and postgraduate students, prepare content and supervise MSc SPHA students over the past seven years also uncovered passion for teaching. I enjoy supporting and guiding students in their own academic journey and see how they mature to critical thinkers and uncover topics they feel passionate about. Lecturing and supervising students from different countries, cultures and religious beliefs challenged my tacit knowledge and encouraged me to become more reflective and learn how to adapt my approach to teaching and supervision in order to provide the best guidance to students.

During summer 2021 I also attended Research Students' Summer Conference 2021: Knowledge in Action at Middlesex University where I was awarded a prize for an outstanding oral presentation.

While data analysis of the second study confirmed the three age groups of informal carers (50-60, 60-70 and 70+), I began to wonder about the cultural differences between the carers in the UK and Slovenia. Though both countries are in Europe and considered to be developed, I observed differences such as intergenerational cohabitation and different views on 'duty of care'. The history of the countries and previous political regimes are also very different, which can significantly affect residents' perceptions of welfare, healthcare, and social care. Moreover, Slovenia has a considerably lower number of charities and initiatives supporting people with dementia and their carers compared to the UK. Though Slovenia frequently participates in European projects aiming to increase awareness of dementia and improve quality of life of people living with the condition, the projects and programmes are rarely aimed at meeting the needs of informal carers and have not yet been evaluated for its efficiency. After discussing the observations with my supervisory team and given the fact that the countries have not yet been compared in this context, we agreed that exploring cultural differences between Slovenia and the UK would add a valuable and novel insight to the topic.

During my write up period I got an opportunity to lead another project called Fit4Life at Age UK Westminster. Within my role I designed, implemented, and led Exercise at Home programme, which aimed to improve exercise adherence of frail, housebound individuals living with multiple chronic conditions in Westminster. I also trained volunteers on safe exercise delivery and offered work placements to MSc SPHA students from Middlesex University. Soon after the implementation, the programme was nominated for ActiveWestminster Award out of 300 projects. Though we did not receive the award, the contributions of the programme were acknowledged and applauded by the reviewers. Since the programme launch, we have made over 200 contacts and helped to improve exercise adherence of more than 50 frail, housebound Westminster residents. Working with clients who are housebound, isolated, and live with various conditions and mobility difficulties made me realize how complex support for such service users can be. It expanded my knowledge of different social and healthcare services and allowed me to build connections with Social Prescribers, Well-being Coaches, Social workers, Community physiotherapists, and other organisations in the borough. I also got an opportunity to represent Age UK Westminster as one of the stakeholders in developing new NHS Frailty framework, which aims to establish collaborative and integrated approach in preventing and managing frailty in Westminster. Being a part of the Frailty group allowed me to experience and be a part of the changes proposed in the NHS Long Term Plan – Ageing Well 2019 and interact with representatives from Community Neurorehabilitation Service (CLCH), Westminster Older Peoples Mental Health Service (CNWL), Acute Frailty Team -Imperial, Central London Planned Care (CLCH), Care Navigation and Complex Case Management (HCL) and others.

I always had the urge to explore, understand and improve. However, throughout my PhD journey I learned how to explore in order to understand, and consequentially improve. It deepened my understanding of different research methodologies, how to employ them to attain knowledge, and most importantly, how to utilise the knowledge gained. Being able to lead projects in the community whilst conducting my research allowed me not only to read about, but also experience challenges informal caregivers and people with dementia live with, how these are approached through policies, and incorporated in national plans. Over the course of seven years, I came to understand that besides research skills, researchers have to be accomplished project managers, resilient, out-of-the-box thinkers, and above all passionate about the topic of interest.

Abstract

With the higher prevalence of an ageing population worldwide, dementia has been recognised as a public health priority. Considering that people with dementia require a high level of support, informal care provision is crucial to delay institutionalisation and prevent low quality of life for individuals living with the condition. Though caregiving can be rewarding, it can be extremely intense and could negatively impact caregivers' well-being and quality of life. Therefore, the drive to support informal carers of people with dementia has become a national and international priority. Regular physical activity has been linked with improvements in various aspects of physical and psychological functioning, however current figures show that physical activity adherence of informal carers of people with dementia remains low. The aim of this thesis was to explore the complexity of informal caregivers lives in relation to physical activity and well-being in two different countries (the UK and Slovenia) through a mixed methods approach. Adopting a qualitative dominant, sequential exploratory design, this research was conducted in two phases starting with the qualitative and followed by the quantitative data collection phase and analysis. The qualitative resulted in a theoretical underpinning of the physical activity and well-being perceptions of informal carers of people with dementia, which was then further tested through quantitative methods, enabling the generalisation of the qualitative findings.

Study 1 adopted a 'Life-course' theoretical perspective and used narrative inquiry. Six participants, 50+ years of age, providing non-paid care to a person with dementia at least 5 hours per day, and living in the UK were interviewed. Interviews were recorded, transcribed verbatim and analysed according to Fraser's phases 3 to 6 and incorporated Alwin's 5 life-course principles. The analysis resulted in four major themes which implied that there are 3 age groups of carers (50-60, 60-70 and 70+). The findings suggested that the era carers were born in and consequentially the relationship they had with the care receiver, significantly influenced their perceptions of physical activity and well-being, as well as actions they made while providing care. Study 2 explored if these findings could be generalised to a wider population in both UK and Slovenia. 166 informal caregivers 50+ years of age, providing non-paid care to a person with dementia at least 5 hours per day, and living in the UK and Slovenia took part in a standardised questionnaire aiming to obtain carers' quality of life, relationship style with the care recipient and physical activity perceptions. Study 2 confirmed the findings found in Study 1 and revealed further significant differences between the age groups of caregivers and their role as carers, information and advice availability, relationship style, current physical activity participation, beliefs and knowledge of exercise, and actions taken to stay healthy. Study 3 explored whether there are differences between the age groups cross-nationally in Slovenia and the UK. No interaction effects were found between the age groups and nationality, however the analysis revealed significant main effects between the age groups/nationality and role as a carer, information/advice availability, and current physical activity participation. Variables such as relationship style, beliefs and knowledge about exercise showed significant main effects for age groups and none for nationality. This suggests that nationality and culture might be a significant factor in how informal carers perceive their role, seek advice and information and how frequently are they physically active, as well as what kind of activities they prefer. In addition, the study also confirmed that the three distinct groups of informal carers 50-60, 60-70 and 70+ years of age are present cross-nationally.

Overall, this PhD thesis showed that informal caregivers of people with dementia are not a homogenous group as frequently portrayed by researchers, policy makers and health care providers but differ based on the era they were born in, their relationship with the care recipient, their perceptions and knowledge of exercise and the values and beliefs they grew up with. Increasing physical activity uptake among this population does not depend merely on the number of the physical activity programmes available to this population but might be differentiated and tailored more specifically to each group ensuring that other barriers experienced by specific groups are addressed as well.

KEYWORDS: Informal caregivers, dementia, physical activity, life-course, narrative, generations, cross-cultural, Slovenia, the UK

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This thesis would not be possible without all the organisations, charities, initiatives and leaders in the UK and Slovenia who believed in the benefit of this thesis. Thank you to Dementia Club UK, The Liberal Jewish Synagogue – Singing for the Mind, Green Candle dance company – Remember to Dance, Join Dementia Research initiative, Ashford place, Spominčica and all the informal carers of people with dementia who, despite all the challenges took time and shared their invaluable inputs.

I would like to express gratitude to my late grandparents Mari and Gojko, who enabled me to start my academic journey abroad, my grandmother Sidonija for 8 years of uplifting letters, my brother Bor for reminding me that there is no greater freedom than choosing your own path, my extended family members for encouraging words whenever I visited my home town, and my parents Ljiljana and Tomaž for their unconditional love and support. Thank you for always standing by me.

Lastly, I would like to thank Mr Ben Underwood, Mrs Ellie Constantinidou, Miss Danielle Norville, Mr Colin Allison for their kindness and for cheering me up whenever we crossed paths on Hendon campus, and a handful of friends who stayed in touch and shared their lives with me during this journey.

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A Mixed methods Investigation into Physical Activity in Carers for those with Dementia – Rationale

The population worldwide has increased rapidly in the past few years. One of the reasons is because the population is ageing (Hayter, 2017). There are now over 15.5 million people aged 60 and above living in the UK making up to 23% of the population (Office for National Statistics, 2021) and by the year 2045 the proportion is estimated to increase to a quarter of the population (Hayter, 2017). Even though some of the elderly might be in very good health, others might need assistance in daily life activities, such as feeding, washing, dressing, toileting, handling transportation and mobility (Burton and Sumukadas, 2010), which increases pressure and demand for healthcare and social services (Hayter, 2017).

With advancing age, a gradual degenerative series of irreversible alterations of body systems can occur (Judge, Lindsey, Underwood, and Winsemius, 1993; Cadore, Rodríguez-Mañas, Sinclair, and Izquierdo, 2013), such as reduced maximal aerobic capacity, muscle performance and bone density (Hultquist, 2010). Moreover, individuals aged 60 or more are found to be at a higher risk for falls, cardiovascular diseases, metabolic diseases, cancer, osteoporosis, rheumatoid arthritis, osteoarthritis, and dementia (Townsend, Williams, Bhatnagar, Wickramasinghe, and Rayner, 2014). As a result of these factors in the past few years outpatient appointments, hospital admissions and inpatient episodes increased significantly with more than half of the patients being people aged 65 or more ([2]Age UK, 2017). This has led to an increased need for home care and residential care placements as well as the need for informal care (Beesley, 2006). During COVID-19 pandemic the numbers of people in need of intensive care increased and the numbers of health professionals available to provide help reduced. In parallel charities and organisations offering support to both people with dementia and their carers had to close their premises. This resulted not only in substantial pressure on the healthcare workforce but also on the informal caregivers of people with long term chronic conditions, such as dementia (Carers UK, 2020). Even though COVID-19 restrictions have eased in 2021, the pandemic exposed the fact that the health and social care systems failed to provide sufficient support for both the end-users and its workforce. This led to a series of strikes by the NHS health workers in 2023, which further restricted access to health and social care ([1]Alzheimer's Society, 2020; Office for National Statistics, 2023).

Low exercise adherence due to lack of time and motivation, suffering from depression, age related physical alterations and at the same time providing highly demanding care, puts carers of people with dementia at very high risk of losing physical and psychological health, and reduce the ability to care. Therefore, more programmes and/or pathways in order to promote existing programmes designed specifically for carers of people with dementia are needed (Alzheimer's Society, 2016; Sörensen et al., 2002).

Even though poor exercise adherence and consequentially poor quality of life of carers of people with dementia represent big issues to the individuals and the whole of society, there is limited research done on how to increase exercise adherence and physical activity participation amongst this population specifically. Therefore, the main aims and objectives of this PhD thesis were:

Aims:

- To contextualize the complexity of lives of informal carers of people with dementia and to investigate if exercise and physical activity played any part.
- To identify key motivational factors and barriers for physical activity participation and understand how caring for a person with dementia has influenced a carer's life, physical activity participation, well-being and their relationship with the care receiver.
- To investigate whether there are cross-national and cultural differences or similarities between informal caregivers of people with dementia in Slovenia and the UK, and their perceptions of physical activity, and well-being.
- To consider evidence to provide information in order to develop new programmes and/or pathways, to promote physical activity and improve exercise adherence amongst informal carers of those with dementia.

Objectives:

- To review literature and evaluate how healthcare practices, physical activity, well-being, and caregiving perceptions might have changed throughout history and informed caregivers' knowledge of physical activity and influenced decisions they make about their health.
- To gather life course views and physical activity perspectives of informal carers of people with dementia.
- To examine the differences between caregivers and their perceptions of elements/facets of their lives including physical activity and well-being, through a validated questionnaire.
- To examine the national and cultural differences among the Slovenian and British informal carers and how they perceive their roles as carers, their burden associated with care provision and other elements/facets of their lives including physical activity and well-being.

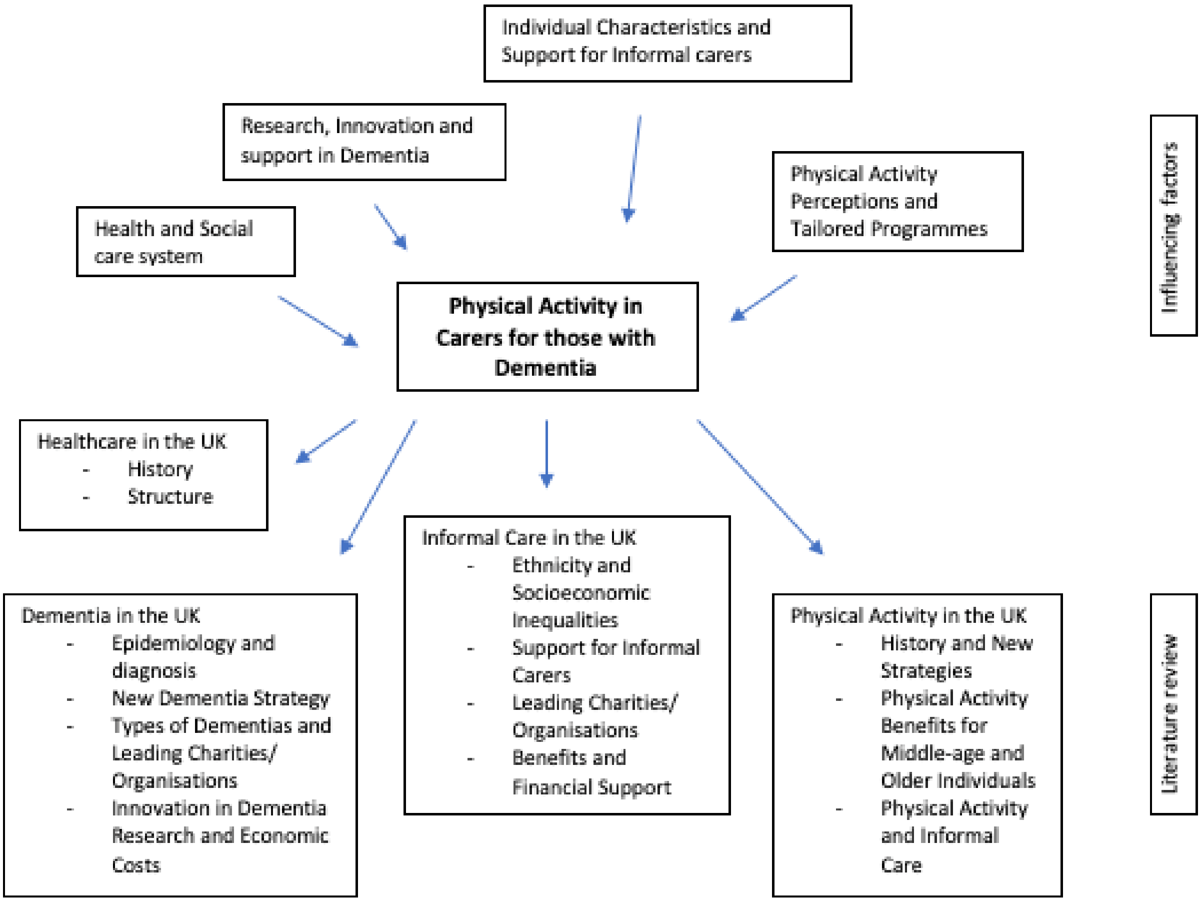
Research Questions:

- What are physical activity and well-being perceptions of carers of people with dementia through a life course approach?
- Are physical activity and well-being perceptions of family carers of people with dementia different between offspring carers 50-60 years old, spouse carers 60-70 years old, and 70+ years old?
- Are physical activity and well-being perceptions of family carers of those with dementia different between the three groups: offspring carers aged 50-60, spouse carers aged 60-70, and spouse carers aged 70+ between the UK and Slovenia?

CHAPTER ONE

Dementia has been recognised as a public health priority by the World Health Organisation. Increased dementia prevalence is consequentially driving the growth of informal care. The informal carers have been recognised as a vital part in long-term care provision for people with dementia Worldwide. This chapter will provide a background on healthcare, dementia, informal care, and care burden in the UK, as well as support available to the informal carers of people with dementia. The chapter will also provide background on physical activity, describe the importance of physical activity for informal caregivers, as well as what physical activity programmes are currently available. The literature review included a broad range of literature and concepts in order to provide a detailed overview of the complexity related to informal care and consequentially health and quality of life of informal carers of people with dementia.

The structure of the health and social care services has changed immensely over the last century which not only had an impact on carers' perceptions and knowledge of the services available to them but also directly influenced policies and the type of support intended to improve carers' well-being and quality of life. Research and innovation in the field of dementia as well as programmes for people with dementia offered by charities, institutes and organisations often, directly or indirectly include informal carers too, influencing their understanding and choices they make regarding their health and well-being. Furthermore, individual characteristics such as ethnical background, gender, socioeconomic inequalities, and support tailored to informal carers have a direct impact on the burden of care and an opportunity to attend physical activity programmes. And lastly an overall perception of physical activity and availability of tailored physical activity programmes for informal carers influence physical activity adherence amongst this population. An overview of the literature review search is mapped out in the image below.


Individual Characteristics and Support for Informal carers
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Influencing factors
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Literature Review on Dementia, Informal Care and PA in the UK

Healthcare in the UK

In 1920s, prior to the establishment of the National Health Service (NHS) in the UK, the main health providers were personal general practitioners (GPs) whose service was extremely limited and included a fee. In theory the GPs were entrusted with various roles including resolving acute disease cases, disease prevention, antenatal supervision, child welfare, physical culture, management of venereal diseases and industrial medicine (Rivett, nd.). However, in reality, the GPs were not able to provide the extensive service they were tasked with. The overcrowding in the inner cities led to poor hygiene, which resulted in lice infestation, numerous infections, and diseases such as diphtheria, scarlet fever, lobar pneumonia, and tuberculosis and thus increased the demand to be seen by the GP (Rivett, nd.). Before the second World war, CAH Watts one of the GPs working at that time recalled waiting rooms filled with more than 60 patients waiting to be treated. There was rarely any assessment involved. The doctors noted the patient's complaint, and the dispenser administered a remedy. Though there were a few treatments available, such as antiserum, insulin, morphine derivatives and sulphonamides the mortality amongst patients was extremely high (Rivett, nd.). In contrast to the upper-class, who received more attention, better service and had access to medicine, people in the working-class did not have such privilege. It was common amongst this class to expect treatments not to work and accept the inevitable. Children and adults dying from infectious diseases was the way of the world.

The lack of systematic health care provision led to an idea of a "*hierarchical system of primary care centres linked with district hospitals and regional centres with university teaching hospitals*" (Rivett, nd., no pagination). In 1943 the Ministry of Health considered the transition from the wartime emergency medical services to a health service available to all the citizens. When labour party came to power, the NHS Act was accepted, which led to establishment of the NHS on the 5th of July 1948 (Rivett, nd.). For the first time in the history an access to medical care was "*based on the clinical need, not on ability to pay*" (NHS, 2013, pp.2). At first the function of the NHS was diagnosis and treatment of disease, however the current NHS plays an important "*role in both preventing ill health and improving the physical and mental health of the population*" (NHS, 2013, pp.2).

There are numerous organisations and regulatory bodies that make up the modern NHS. The latest structure consists of:

- **Government/Prime Minister** who works on a national level and decides the level of the funding allocated to the NHS as well as on the top-level priorities.

- **Secretary of State for Health and Social Care** who works on a national level and is responsible for the work of the Department of Health and Social Care including oversight of the finances, overall NHS delivery and performance and health and social care policy.
- **Department of Health and Social Care** (DHSC) which works on a national level and helps to deliver the objectives set by the Government as well as plans the direction of the future healthcare. Though the services are provided to both, adults, and children the social care is an adult service.
- **Department for Education** (DfE) which operates on a national level and is responsible for children's services and education (i.e. higher and further education policy).
- **Care Quality Commission** (CQC) which operates on a national level and is an independent regulatory body for health and social care service providers and reports back to the Secretary of State for Health and Social Care. The main purpose of the CQC is to inspect, rate and monitor services to protect the end users.
- **NHS England**, which operates on a national level and is a single regulatory body overseeing the planning, delivery, transformation, funding, and an overall performance of the NHS in England.
- **NHS Digital**, which operates on a national level and is tasked with developing and operating the national IT and data services aiming to improve health and care.
- **NHS England Regional Teams** (seven teams) which operate on a regional level and are responsible for maintaining the quality, financial and operational performance of the NHS organisations in the same region. They work closely with the integrated care systems.
- **Transformation Directorate at NHS England**, which operates on national and regional levels and leads the digital transformation of the NHS and social care.
- **Academic Health Science network** (AHSN) (15 regional networks) which operate on a regional level and oversee the clinical research, informatics, innovation, and training and education in healthcare in order to improve the health of the population.
- **Integrated Care systems** (ICSs) which operate on a regional level and aim to integrate and join health and social care services and improve the health of people living in the local area. ICSs were established across England on the 1st of July 2022.
- **Integrated Care Partnerships** (ICPs) which operate on a regional and local level and aim to produce an integrated care strategy involving the NHS care board and the local authorities/organisations that fall within the same ICSs.
- **Primary Care Networks** (PCNs) which operate on a local level and are formed out of GP practices working together with mental and social care, pharmacies, hospitals, voluntary

services, and community in order to provide personalised care in the local area. Though the PCNs are currently not legal entities they have a great impact on the quality of care delivered.

- **Service providers** (primary care, secondary care trusts, third sector and private sector) which work on a local level and include providers such as general practices, hospitals, district nursing services, mental health providers, ambulance services, community, and integrated providers.
- **General practices** which work on a local level providing pro-active health care, advice, and treatment (NHS, 2023).

The NHS is funded mainly from general taxation and National Insurance contributions, however a proportion also comes from prescription and dental service charges (The Kings Fund, 2023). Some of the practices also generate a small 'local income' via car parking charges and private provision of services (NHS, 2023). The current budget of £168.8 billion allocated to the NHS in 2023/24 is set to ensure the delivery of the three main tasks: to recover the core services and productivity, deliver the NHS Long Term Plan and to transform the NHS for the future ([1]NHS, 2023). The digitalisation of the NHS and the establishment of the ICSs is being highly prioritised. Mainly due to the challenges the NHS has been facing in its 8 decades of operating, such as "*rising costs of new drugs and treatments, increased demand from an ageing and growing population*" and declined overall performance resulting in long waiting times (Powell & Harker, 2023, no pagination). While some of the services have improved, the operational level has still not reached the pre-pandemic performance (Powell & Harker, 2023). In order to ensure easy access to primary care services the NHS England is planning to empower patients by improving digital infrastructure, NHS App functionality and reach the target of 75% of adults in England to be registered on the App by March 2024, implement modern general practice access by simplifying online requests/response, make the care navigation more efficient and by transitioning to digital telephony and build capacity by supporting the establishment of larger multidisciplinary teams and continue to recruit/retain doctors/nurses in general practices ([1]NHS, 2023). Transforming and improving the digital infrastructure of the NHS England will result in greater connectivity, useability and interoperability amongst the services and help to transform health care. By the end of 2024 NHS England is planning to increase the usage of electronic patient records by up to 90%, continue developing digital products and services, improve and '*accelerate the uptake of the most promising Artificial Intelligence technologies'* ([1]NHS, 2023, no pagination).

Establishing ICSs means that the NHS, local authorities and the third sector, such as charities will be able to work together and collectively design/deliver health and care services that best suit the local population ([1]NHS, 2023). Each ICS includes Integrated care boards (ICBs) formerly known as Clinical Commissioning Groups, with a responsibility for NHS planning and budgeting, ICPs responsible for developing a strategy to meet the health and care needs of people living in the local area and local authorities with a responsibility for social care ([1]NHS, 2023). The integrated approach is aiming to improve health outcomes, experiences with and access to health services, reduce health inequalities and help '*the NHS to support wider social and economic development*' (Sanderson et al., 2023, pp.1). ICSs might especially prove useful for individuals living with multiple conditions in need of advanced care and support. For example, people with dementia often live with several other conditions such as diabetes, hypertension, cardiovascular disease, visual and hearing impairment, and musculoskeletal disorders (NICE, 2018). Hence, they often require access to multiple health and social care services at once ([1]Dementia UK, 2023). They might also reduce burden of the family carers providing care to people with dementia by signposting carers to the right support for their as well as the carees' needs, provide more options, reduce the time people with dementia and their carers have to share the same information with various healthcare professionals, and reduce barriers for individuals with dementia and their carers in accessing services ([1]Dementia UK, 2023). However, the ICSs are in their infancy, therefore it is too soon to establish the value of the new integrated system for people with dementia and their carers.

Apart from the NHS reorganisation, on 7th September 2021 the government proposed a new plan for adult social care reform, which introduced a 'cap' on the amount individuals in England will need to spend to fund their personal care over lifetime (Department of health & Social Care, 2022). The cap proposed in the reform was set at £86,000. In addition, the capital thresholds (the financial limit at which individuals become eligible for support from the local authority) '*will rise to £100,000 from the current £23,250, as a result individuals with less than 100,000 of chargeable assets will never contribute more than 20% of these assets per year*' (Department of Health & Social Care, 2022, no pagination). Individuals with chargeable assets of £20,000 or less will not need to contribute anything for their care, which is an increase from previous £14,250 (Department of Health & Social Care, 2022). The new rules were planned to be implemented by October 2023, however the Government announced that the cap will be delayed for two years and come into effect in October 2025 (Foster, 2022). While the newly introduced cap has been positively accepted, not everyone will benefit equally from it. According to Alzheimer's Society, only one in five people living with dementia will be able to reach the cap ([1]Alzheimer's Society, 2022). People with dementia and their carers are the largest users of health and social care services so many may struggle with catastrophic costs of care. Fiona Carragher, Director of Research, and Influencing at Alzheimer's Society raised a concern over the fact that under the Government's current arrangements the wealthiest "*people with dementia would see their average spend on care reduced by 26 %, while the least wealthy would see a drop of just 14 %"*

([1]Alzheimer's Society, 2022, no pagination). However, until the cap is in place the exact evaluation of the efficacy/benefit for people with dementia and their carers remains uncertain.

Dementia in the UK

Dementia is an umbrella term used to describe a variety of symptoms affecting persons' behavioural and cognitive abilities, such as loss of memory, difficulties with problem solving, communication and reasoning (National Institute for Health and Care Excellence, 2018). It has been estimated that there are more than 55 million people living with dementia worldwide and the numbers are predicted to increase up to 139 million in 2050 (WHO, 2022). According to Alzheimer Europe estimating the prevalence of dementia in Europe report (2019) there are 7,853,705 people living with dementia in the European Union and 9,780,678 in the broader European region, of which 1,031,396 live in the UK. Though the prevalence of the condition in Europe and in the UK has slightly improved in the past years it has been predicted that the numbers of people with dementia will rise by almost 80% in 2050 (Jönsson et al., 2023). According to the Office for Health Improvement & Disparities (2023) the drop in diagnosed dementia cases could be a consequence of the Covid-19 outbreak and must therefore be interpreted with caution. During the pandemic, all health services in the UK were under a tremendous pressure from the increased number of people in need of help and at the same time reduced number of healthcare workers available (Hazan et al., 2023). Moreover, due to the pandemic restrictions the access to health and social services was reduced, which had a significant impact on people with dementia in terms of receiving timely diagnosis, support, and susceptibility to contracting the virus (Liu et al., 2021).

The dementia diagnosis pathway in the UK comprises of different types of assessments and varies between individuals. Most commonly the first step involves a visit to a local surgery, where a health professional, such as a nurse or the persons' GP carries out initial assessment. The assessment includes examining a personal medical history (including medication, medical history of close family members and discussing current symptoms), physical examination (i.e. testing co-ordination, hearing, and sight to rule out other conditions such as stroke and Parkinson's disease), blood test, ECG, and examining individual's mental abilities. In case the GP assumes the symptoms are caused by dementia they will refer the person to a local memory clinic or to specialists/consultants, such as old age psychiatrists, general psychiatrists, geriatricians, and neurologists (Alzheimer's Society, 2023). Other professionals also commonly involved in the process of dementia diagnosis are mental health nurses, psychologists, occupational therapists, social workers, and dementia advisers (Alzheimer's Society, 2023). The assessments conducted by specialists might include mental ability tests, such as Mini-Mental State Examination (MMSE), Montreal Cognitive Assessment (MoCA) and ACE-III test. These tests are usually used in conjunction with brain scans such as computerised tomography (CT) scan, which is used to detect signs of stroke or brain tumours and/or a magnetic resonance imaging (MRI) scan, which is used to detect the type of disease causing dementia (i.e. damage to blood vessels or a shrinkage of a specific part of the brain) (Alzheimer's Society, 2023). In case the results of the CT and MRI scans are inconclusive specialists might conduct positron emission tomography (PET) or perfusion single photon emission computed tomography (SPECT) scan (Ferrando and Damian, 2021). Both scans use nuclear neuroimaging techniques in order *"to reveal functional alterations underlying various neurodegenerative diseases"* (Ferrando and Damian, 2021, pp.1). Though the procedure of attaining dementia diagnosis is a fairly well-established process in the UK, how quickly a person receives the diagnosis varies from a few weeks to more than year (Alzheimer's Society, 2023). There are, however, a number of private clinics available in the UK, allowing individuals who are able to cover the financial costs of dementia assessment to avoid extensive NHS waiting times and receive the diagnosis and consequentially appropriate treatment/care faster (Jitlal et al., 2021).

Amongst other characteristics such as gender, ethnicity, language, dementia awareness and place of residence, low socioeconomic status has been linked to premature mortality, reduced access to specialised diagnostic services, as well as access to care, treatment, and support for people with dementia (Alzheimer's Society, 2021; Jitlal et al., 2021; Watson et al., 2020). Covid-19 pandemic further exacerbated this gap and in combination with reduced GP capacity, referral rates to the local memory services dropped to only 58% (Hazan et al., 2023). While the GP *"referrals to memory services in England have returned to pre-pandemic levels, the estimated dementia diagnosis rate fell by 5.4% between March 2020 and February 2023"* (Hazan et al., 2023, pp.2). According to Alzheimer's Research UK (2023) more than 33.000 people aged 65 and more are waiting for up to a year to be seen by a specialist in the memory clinic, and for people with early onset dementia (individuals younger than 65 years of age) the waiting time can be up to four years. Despite the lack of evidence showing direct economic and societal benefits (Aldus et al., 2020; Hazan et al., 2023) timely dementia diagnosis allows people with dementia and their carers to attain a meaningful post-diagnostic care plan and access treatment and support, which significantly impacts their quality of life and well-being (Hazan et al., 2023). Hence major dementia charities, advocacy and research organisations have been endorsing and advocating for early and accurate dementia diagnosis ([1]Alzheimer's Society, 2023; Alzheimer's Research UK, 2023).

Following the Prime Minister's challenge on dementia 2020 (Department of Health, 2015) which prioritised increased dementia diagnosis rates, the government in the UK shifted from condition-specific strategies to a multimorbidity approach and accepted 'major conditions strategy' in January

2023. The new strategy aims to increase healthy life expectancy and alleviate pressure on the health services over the next five years by combining health strategies for conditions such as cancer, heart disease, musculoskeletal disorders, mental ill-health, dementia, and respiratory diseases (Department of Health & Social Care, 2023). The multimorbidity approach, though criticised by some condition-specific organisations/campaigners, has been positively accepted by healthcare leaders (McCay & Lowe, 2023). According to Department of Health & Social Care (2023) one in four adults in the UK is living with at least two major health conditions and the numbers are projected to rise by 2040 to over a third. Coordinating care, complying with multiple treatment plans, and accessing different services can significantly increase pressure and burden of individuals living with multiple conditions as well as their caregivers (McCay & Lowe, 2023). This has been well documented in people with dementia and their carers (Dalgarno et al., 2021; Smith et al., 2021; Sharkey & Coates, 2023). Consequentially, the new strategy was welcomed by Kate Lee, chief executive of the Alzheimer's Society and Debbie Abrahams MP, Chair of the All-Party Parliamentary Group (APPG) on Dementia, however they both noted that any strategy addressing dementia should take into account the complexity of the condition and be "*suitably specific, bold and ambitious*". The multi-comorbidity approach currently proposed does not offer enough details to know whether this will be the case (Hicks, 2023, no pagination).

Besides the traditional medical model of dementia care which prioritises organisational processes and needs, person-centred care is detrimental in dementia care and has been advocated internationally by various health and social care organisations (Kelly et al., 2023). Established by Tom Kitwood in the 1980s, the person-centred dementia care model focusses on four areas:

- understanding the viewpoints, experiences and perspectives of dementia by engaging directly with individuals diagnosed with the condition and their caregivers,
- supporting the personhood of people with dementia, which is concerned with how individuals living with the condition perceive themselves (in the broader socio-economic aspects and the individuals' intersecting identities),
- meeting the five core psychological needs, which are attachment (to have connection, trust, security and close connections with people), comfort (calming of anxiety, soothing pain, empathy and support from another person), identity (a sense of self and continuity with the past), inclusion (to belong and have a social interaction) and occupation (use of skills, sense of agency, taking part in meaningful activities), and
- acknowledgment of negative interactions that undermined personhood (intimidation, withholding, outpacing, infantilization, labelling, disparagement, accusation, treachery, invalidation, disempowerment, imposition, disruption, objectification, stigmatization,

ignoring, banishment, and mockery) and encouraging positive interactions called ‘positive person work’ which support personhood (celebration, collaboration, creation, facilitation, giving, holding, negotiation, play, recognition, relaxation, stimulation, validation, holding, and facilitation) (Kitwood, 1998).

Types of Dementia

The most common cause for dementia is Alzheimer's disease, which affects nearly 60% of the population diagnosed with dementia in the UK (DementiaUK, 2023). There have been multiple risk factors associated with Alzheimer's disease, such as older age, female biological sex, genetics, smoking, diabetes mellitius, obesity, high blood pressure and inactive lifestyle. However, the exact cause of the disease remains unknown (Niu et al, 2017; DementiaUK, 2023). Alzheimer's disease is characterised by the accumulation of amyloid-ß plaques and neurofibrillary tangles in the brain contributing to the loss of function and connections between neurons, and cell death (Shcherbatykh et al., 2007). The amyloid-ß plaque is formed when a larger protein called amyloid precursor breaks down and forms smaller components leading to neuronal toxicity in the central nervous system (Ma et al., 2022). Alzheimer's disease usually affects the hippocampus and entorhinal cortex first, which results in difficulties with memory, particularly short term and learning new information (Alzheimer’s Society, 2022). As the disease progresses more of the brain tissue deteriorates leading to further distortions in memory, language, visual systems, decision making, planning and spatial awareness. Overtime, people living with Alzheimer's disease lose their independence and the ability to perform activities of daily living (Alzheimer’s Society, 2022).

The second most common type of dementia is Vascular dementia, which affects up to 20% individuals diagnosed with dementia in the UK (Alzheimer's Society, 2020). Vascular dementia results from a lack of blood supply to the brain as a consequence of a stroke, series of smaller strokes or thickening of small vessels that lie deep in the brain obstructing blood flow particularly to the subcortex (Tariq and Barber, 2017). Though some of the risk factors for Vascular dementia have been well established, such as hypertension, hyperlipidaemia, smoking, cardiac disease, diabetes mellitius and inactive lifestyle (Venkat et al., 2015; Qiu et al., 2005) some researchers suggested that any change to cerebral blood flow including hypotension might lead to Vascular dementia (Moretti et al., 2008; Emdin et al., 2016; Kleipool et al., 2019; Xia et al., 2023). Though Alzheimer's disease and Vascular dementia can co-exist, individuals diagnosed with Vascular dementia can, unlike with Alzheimer's disease, experience both either a very sudden loss in cognitive and physical abilities or a gradual onset (Venkat et al., 2015; British Heart Foundation, 2023).

Frontotemporal dementia is the third most common type of dementia encompassing a group of neurodegenerative diseases affecting the frontal and temporal lobes of the brain, resulting in "*progressive deficits in behaviour, executive function, or language"* (Bang et al., 2015, pp.1672). Unlike the first two types, frontotemporal dementia is the leading cause of the early-onset dementia affecting individuals younger than 65 years of age (Vieira et al., 2013; Chu et al., 2022). The most important risk factor for this type of dementia is genetics (Bang et al., 2015).

While the investments in research endeavours to prevent and treat dementia have been substantial and there have been advances made in developing the immunotherapy drugs to slow down disease progression, the cure remains unknown (NHS, 2021). There are however multiple approaches known to have positive effects on preventing specific types of dementias. For example, leading a healthy lifestyle with a balanced diet low in saturated fats and sugar, and regular exercise has been associated with reduced risk of vascular dementia (Lin et al., 2015) as well as reduce the symptoms of Alzheimer's disease and slow down the disease progression (Liu-Ambrose et al., 2016; Aczel et al., 2022).

Leading Dementia Charities and Organisations

There are numerous dementia charities, organisations and services held at local venues all around England, Wales, and Northern Ireland. The leading dementia charity in the UK is Alzheimer's Society, which was founded in 1979 and is an active member of the Alzheimer Europe and Alzheimer's Disease International ([1]Alzheimer Europe, 2023; Alzheimer's Disease International, 2023). Some of the services offered by the Alzheimer's Society are dementia support line (telephone service offering personalised support, advice and information), dementia support forum (online forum where people with dementia can connect, share stories and ask/give advice), education/training for health and social care professionals and carers of people with dementia, seminars/webinars/workshops and information about daily living with dementia, help with care, legal/financial advice available on their website and monthly newsletter (Alzheimer's Disease International, 2023). There are also more than 3000 local services throughout the UK running caregiver/peer support meetings, memory/dementia cafes, respite care for informal carers and meaningful engagements/activities for people with dementia (i.e. Singing for the Brain) ([1]Alzheimer Europe, 2023). Alzheimer's Society also influences local authorities and policy makers, campaigns for better quality of life for people with dementia and funds a variety of initiatives and research projects aiming to help improve diagnosis pathways, care and support, and develop a cure for all-cause dementia ([3]Alzheimer's Society, 2023).

Apart from Alzheimer's Society other organisations supporting people with dementia in the UK are Dementia UK (a charity offering specialist dementia support provided by admiral nurses), Contented

Dementia Trust (a charity offering people with dementia and their carers practical advice and information on how to manage and live well with dementia via the SPECIAL method), The Lewy Body Society (a charity whose purpose is to support research and spread awareness of dementia with Lewy bodies), Age UK (one of the largest charities in Britain supporting people over the age of 50 years and offering advice/support on a range of conditions including dementia), The Research Institute for the Care of Older People (RICE) (a charity with its own memory clinic, focusing on research and services to improve cognition and brain health of people with dementia and related conditions), Dementia Concern (a charity working directly with the NHS and local GPs offering dementia care services such as dementia advisors, community support workers and social clubs), CAD-Brent (a charity advocating for Dementia friendly Brent offering a variety of activities and services for people with dementia and general public, such as Community Champions and Brent Dementia Peer Support Service), Arts4dementia (a charity supporting arts venues to become dementia friendly and help them develop programmes specifically for people with dementia), Dementia Club UK (a charity offering professional advice and a variety of activities for people with dementia and their carers) and many others. The research shows that activities/services such as Dementia and Memory Cafes and visual arts programmes are beneficial for people living with dementia and increase their well-being and overall quality of life (Greenwood et al., 2017; Windle et al., 2018; Innes et al., 2022).

Innovation in Dementia Research and Economic Costs

The United Kingdom is considered as one of the leading countries in dementia research. As a result of the Prime Minister's Challenge on Dementia 2020 (Department of Health, 2015) and a set target to identify treatment by 2025 (UK Dementia Research Institute, 2023) in 2017 Medical Research Council (MRC), Alzheimer's Society and Alzheimer's Research UK founded UK Dementia Research Institute (UK DRI). The institute is located at University College London with centres spread across the universities in the UK including University of Cambridge, Cardiff University, University of Edinburgh, Imperial College London, King's College, and the University of Surrey. UK DRI is currently made up of more than 750 researchers and world-leading experts in *“biomedical, care and translational dementia research”* (UK Dementia Research Institute, 2023). To date, UK DRI has launched three multi-million pound projects (Adeno-associated Virus Vector Core in 2019, Multi-'omics Atlas Project in 2020, and IPSC Platform to Model Alzheimer’s Disease Risk in 2021) and two platforms (Proteomics Platform in 2021 and Biomarker Factory in 2022) with an aim to accelerate and drive the scientific breakthrough in dementia research. While the progress in understanding biological mechanisms underpinning dementia and what can lead to cognitive degeneration has been slow, several new drugs and treatments have been announced at the beginning of the year 2023, the most recent being donanemab and lecanemab ([1]UK Dementia Research Institute, 2023). Both of the drugs are anti-amyloid therapy drugs and were shown to slow down the progression of the early symptomatic Alzheimer's disease by up to 35% ([1]UK Dementia Research Institute, 2023). As a result, lecanemab has been granted an accelerated approval by the U.S. Food and Drug Administration (FDA) in January 2023 (Mahase, 2023). However, despite the FDA approval, many scientists are questioning the effectiveness and the value of the newly available treatment. Besides the potentially life-threatening side effects, such as brain swelling and intracerebral haemorrhaging, the treatment does not offer a cure or reverse the damage already caused to the brain. Moreover, it is priced at £24,230 per patient per year, which is a significant amount considering the vast prevalence of people living with the condition (Mahase, 2023). Lecanemab is currently not available in the UK, however the approval request to the Medicines and Healthcare Products Regulatory Agency (MHRA) has been submitted in May 2023 ([2]Alzheimer's Society, 2023). If the approval is granted, the National Institute for Health and Care Excellence will review the application and decide whether the treatment is cost effective and whether it will be offered by the NHS (Mahase, 2023, pp. 1). However, despite the first generation of treatments becoming available, sustained investment in dementia research is crucial in order to improve and implement diagnostic techniques and develop new disease modifying treatments ([1]Alzheimer's Research UK, 2023; [1]UK Dementia Research Institute, 2023; Mahase, 2023).

Between the years 2019 and 2020 the UK government together with the National Institute for Health Research (NIHR), MRC and the UK DRI invested £104.7 million towards dementia research and committed to increase the funds to £160 million by 2024/25 ([1]Alzheimer's Research UK, 2023). In March 2023 NIHR invested a further £11 million to support projects developing digital innovations for early dementia detection and diagnosis (NIHR, 2023). While the Major Conditions Strategy announced earlier this year (2023) does not specifically provide details on dementia strategy, Health and Social Care Secretary Steve Barclay noted that investments in dementia research with specific focus on incorporating technology in dementia diagnosis and treatment are vital (NIHR, 2023). Moreover, investing in dementia research also proved to have a significant economic impact ([1]Alzheimer's Research UK, 2023). It has been reported that during the years 2019/20 every pound invested generated £2.59 within the UK economy. In parallel with the government's manifesto commitment to increase the funding to £160 million by 2024/25, this might mean that every pound "*invested will generate £3.96 in economic impact*" ([1]Alzheimer's Research UK, 2023, pp.2).

Dementia not only has a detrimental effect on the well-being of the people diagnosed with the condition and their families, but also represents a mounting social and financial cost to the society (Landeiro et al., 2018). Even though the costs of dementia are "*dependent on the international* *variation in spend on health and social care services"* (Prince et al., 2015, pp.57), it has been predicted that the cost will reach $2 trillion by 2030 globally (Prince et al., 2015) and up to £47bn in the UK by 2050 (Luengo-Fernandez et al., 2011; [1]Alzheimer's Research UK, 2023). According to Jönsson et al. (2022) a rough estimation of the mean costs for all patients by region from 17 European countries were the highest in the British Isles (73,712 EUR) and the lowest in Eastern Europe and Baltics (7938 EUR) though these estimations can vary significantly based on the balance between the formal and informal care.

Informal Care in the UK

Informal carers, such as spouse, partners or adult children provide unpaid care to a family member or a friend who needs assistance with activities of daily living (such as personal hygiene, feeding, dressing and mobility) and instrumental activities of daily living (such as shopping, transportation, financial assistance, managing medication and hospital appointments) (Allen et al., 2019) due to their illness, frailty, disability, or a mental health problem ([1]Age UK, 2017). Numerous reports and studies showed that without informal carers' support *"people with dementia would have a poorer quality of life and would need institutional care more quickly"* (Brodaty et al., 2009, pp.217; Hellis & Mukaetova-Ladinska, 2022; Foley et al., 2022; [4]Alzheimer's Society, 2023). Moreover, the NHS equally acknowledged the vital role and contributions of the informal carers noting that their work is "*critical and underappreciated… not only to loved ones, neighbours and friends, but to the very sustainability of the NHS in England"* (Foley et al., 2022, pp.5). The latest Census 2021 estimates there are 5.7 million unpaid carers in the UK ([1]Office for National Statistics, 2023). However, Carers UK report in 2022 showed that the number of informal carers might be as high as 10.58 million across the UK, which is equivalent to one in five adults ([2]Carers UK, 2022). Of these, current figures show that there are approximately 700,000 informal caregivers in the UK caring for a person with dementia and around 1.8 million individuals providing some sort of support to a person with dementia in England ([4]Alzheimer's Society, 2023).

Nearly 12% of the carers aged 65 or more provide up to 100 hours of informal care per week, which is extremely challenging and puts a lot of strain on carer's physical and psychological health ([1]Age UK, 2017). Carers providing such extensive care are mostly home bound and have limited free time to take part in any physical activity, which might put them at risk of having low fitness levels, muscle strength and range of motion. Therefore, there is a big possibility that the carers themselves might suffer from age related impairments and disease. According to the Princess Royal Trust for carers, almost two-thirds of older carers reported that they had health problems or a disability of their own, and 72% reported feeling pain or discomfort ([2]Age UK, 2017). Moreover, carers' burden concerning physical and mental health has been recognised as a top concern in 2022, with 4.87 million informal carers expressing worry about the impact caring has on their physical and mental health ([2]Carers UK, 2022).

Caregiving is associated with high levels of stress, anxiety, depression, sleep disturbances and social exclusion (Ferrara, Langiano, Di Brango, De Vito, Di Cioccio, and Bauco, 2008; Martin, Gilbert, McEwan, & Irons, 2006; Zarit, and Femia, 2008). This can lead to reduced carer's quality of life, which is defined as a perception of an individual's position in life in relation to their physical and psychological state, their personal beliefs, goals, expectations, standards, and social relationships within the environment they live in (WHO, 2017). Even though all carers face difficulties of the care burden, it has been suggested that caring for people with dementia might be more challenging than caring for patients with other illnesses and/or physical disability (Alzheimer's Association, 2007; Argimon et al., 2004; Brodaty, and Donkin, 2009; Ory et al., 1999; Sallim et al., 2015; Vellone et al., 2012). During the COVID-19 outbreak informal carers reported higher levels of fear and uncertainty, which together with increased needs of the person they care for and reduced medical and social support negatively impacted informal carers' burden (Bailey et al., 2022). More than half of the informal carers (58%) reported their physical and mental health worsened during the pandemic and most of them (64%) were not able to take any breaks (Carers UK, 2020).

Because of the degenerative nature of the disease, over time the person's living with dementia cognitive and functional status declines, which results in developing psycho-behavioural disturbances (Vellone et al., 2012). Accordingly, a high correlation between social stigma, caregivers' stigma and depressive symptoms was found (Magana et al., 2007; Werner et al., 2012; Mak, and Cheung, 2008). Furthermore, poorer sleep quality was noted as a reflection of the persons' diagnosed with dementia sleep patterns (Creese et al., 2008). Deficient sleep was associated with lower mental and physical health status of the carers of people with dementia, as well as a greater number of depressive symptoms (Creese et al., 2008). Because of the emotional attachment between family carers and people living with dementia it has been suggested that they also face chronic stress of anticipatory grief (Holley, and Mast, 2009; Kentish-Barnes et al., 2009; Lai et al., 2013; Lombardo et al., 2012). Highly acute psychological stress, while providing care to people with dementia might also affect the level of secreted norepinephrine, which is associated with a higher risk of cardiovascular diseases (Aschbacher et al., 2007; Aschbacher et al., 2006) and makes them more vulnerable to infections than the rest of the population of a similar age (Vedhara et al., 1999). Restricted free time, not being able to separate themselves from the person they are taking care of (Losada et al., 2011) and the burden of care are just some of the factors that prevents the informal carers from attending normal social and recreational activities. Accordingly, Lacey, McMun and Webb (2018) found that caregiving was associated with higher adiposity among men and women caregivers compared to adults not providing care and was particularly high in women 65+ years of age providing care and working full-time. These factors have been linked to depression, physical performance difficulties and health related symptoms (Mausbach et al., 2011).

Defying the exact costs of informal care is challenging because of various factors that need to be considered while making the calculations (Beesley, 2006). Moreover, there are as well, individual costs of care that are frequently overlooked, such as travel costs, additional household expenses or services, and personal non-financial costs of care, such as social exclusion, adverse effects on health and weakening of personal relationships with other people and family members (Beesley, 2006). Taking into account that the NHS and Social care are facing big financial challenges and together with the increasing cost of living crisis, the costs are estimated to be high (Carers UK, 2022). According to the [4]Alzheimer's Society (2023) a person living with dementia might spend approximately £100.000 on their support and care over their lifetime. In parallel, the proportion of the informal carers expressing financial concern and worry about their ability to cope with the increasing costs has increased to 2.2 million ([4]Alzheimer's Society, 2023). According to the Carers UK State of caring report 2023 (Carers UK, 2023) *"60% of informal carers were worried about the impact of caring responsibilities on their finances"* (Carers UK, 2023, pp.7), 58% reported they had to restrain from participating in hobbies/leisure activities and 34% said they had to cut back on food and heating. Though the UK government has announced a 'cap on care costs' up to £86.000 on personal care, this has been postponed until 2025 and is not going to cover the costs of daily living ([4]Alzheimer's Society, 2023).

Currently, 40% (£13.9 billion) of total costs of dementia care in the UK is allocated to unpaid care (Wittenberg, 2019). However, even though the costs to support the informal care are high, in 2021 their contribution saved £162 billion per year of total annual cost of health spending in England and Wales (Petrillo & Bannett, 2023), which almost equals the total annual cost of health spending (Buckner, and Yeandle, 2015; Petrillo & Bannett, 2023). Heléna Herklots, former Chief Executive of Carers UK noted that if even a small percentage of people were unable to provide care the economic impact would rise catastrophically (Buckner, et al., 2015). This proved to be true during the Covid-19 pandemic when the value of care provided by the informal carers rose to a staggering 530 million per day (Bailey et al., 2022).

High financial as well as non-financial costs are a burden to informal carers of people with dementia and consequently to the society. Current economic cost to the UK of caring for people with dementia is £34.7 billion and is estimated to increase up to £94.1 billion by 2040 (Wittenberg, 2019; [4]Alzheimer's

Society, 2023). Taking into account that there will be about 1.7 million informal carers needed for people with dementia by 2050 (Lewis et al., 2014; [2]Age UK, 2017) and that the majority of them will be aged over 60, which is the population at higher risk for age related diseases, the costs could rise enormously.

Ethnicity and Socioeconomic inequalities

Even though dementia can affect individuals from various backgrounds, ethnicities, and communities there are substantial inequalities in dementia risks, diagnosis, and management observed in the UK, which consequentially affect informal carers of people with dementia (Alzheimer's Research UK, 2022). Research suggests that caregivers from Black, Asian, and Minority Ethnic (BAME) communities are more likely to care for a family member with dementia and struggle to cover the costs of care in comparison to their White British counterparts (Kevern et al., 2023). Moreover, apart from the increased prevalence, BAME communities experience a delayed dementia diagnosis rate and consequentially a postponed use of dementia services (Nair et al., 2022). Dodd et al. (2020) found that individuals from BAME communities were less likely to be assessed for dementia, and when they did, they scored lower than White British individuals. Which means they have already progressed to an advance stage of the condition when receiving a diagnosis. This was mainly due to the fact that BAME communities might come for assessment at a later stage (Dodd et al., 2020). Similarly, Kevern et al. (2023) observed that among the South Asian communities in the UK, people with dementia received diagnosis later due to family expectations, caring responsibilities, cultural values, financial concerns, and culturally inappropriate practices. Though many areas of service provision for people with dementia and their carers showed no sign of inequality (Dodd et al., 2020) there is evidence that "*specialist dementia services might disadvantage people from communities where there are lower levels of awareness about dementia and greater levels of stigma"* (Dodd et al., 2020, pp.623).

Caregivers of different ethnic backgrounds caring for their loved ones with dementia also find adapting practices which have high significance in their culture, such as eating and drinking challenging (Nair et al., 2022). Being able to participate in festivals, provide culturally familiar foods and maintain food-related roles (i.e. females preparing food) can have a positive effect on people with dementia and their carers as it promotes social interactions and relatedness. Accordingly, informal carers expressed a need for healthcare professionals to be mindful of different cultural backgrounds and provide contextually relevant advice to support carers in managing culturally significant practices while providing care to their loved ones with dementia (Nair et al., 2022).

Recent studies also showed that sexuality and gender can shape experiences of care and influence how informal carers perceive and access support (Barnes et al., 2024). It has been reported that LGBTQ+ carers are less satisfied with the support and social services offered to unpaid carers and have consequentially poorer health outcomes (Barnes et al., 2024). According to Di Lorito et al. (2021) past experiences such as legal discrimination and homophobia can influence perceptions of services and promote closeted existence and resistance to obtain support. Moreover, poor awareness of the unique challenges LGBTQ+ carers experience and poor representation amongst the staff working in social and health care services might exclude carers from important legal decisions such as Advance Care Planning, Advanced Decision to Refuse Treatment and Do Not Attempt Resuscitation (Di Lorito et al., 2021).

People with early-onset dementia and their carers might also face difficulties with accessing dementia services, age-appropriate activities and peer support groups as the majority are designed for older individuals with progressed dementia (Cations et al., 2017). Though the services might be recommended by health professionals they are often associated with and/or advertised as geriatric services, which causes reluctance to use the services among this population (Cations et al., 2017). Another barrier people with early-onset dementia and their carers face are that the services are not flexible and do not take into account that the individuals diagnosed, their families and friends might still be in full-time or part-time employment and have other care responsibilities (Cations et al., 2017). Evidence suggests that when individuals with early-onset dementia receive their diagnosis, they are not sufficiently supported at their work and face employment inequalities (Ritchie et al., 2022). In case people with early-onset dementia cannot maintain or find alternative employment they have to fully rely on the support of their partners/spouse, which can be extremely burdensome for the caregivers (Ritchie et al., 2022). Offspring carers face similar challenges, as they might still be in full-time employment and at the same time provide care to their parents with dementia. According to [1]Carers UK (2022) 75% of employed informal carers worry about continuing to manage both, work, providing care and keeping up with the high cost of living. Though informal caregivers of a dependant with a long-term condition such as dementia are eligible for carer's leave from work, the leave is unpaid with a maximum duration of one week per year (Brione, 2023).

Covid-19 pandemic further exacerbated inequalities observed before and created new ones. Giebel et al. (2021) reported that people with dementia and their carers did not find adapted forms of support, such as online activities and video calls equally useful. Online activities excluded individuals who did not have internet access and/or suitable devices (Farre et al., 2023) and were described to be of lower quality. The long waiting times and poor communication between the services during the pandemic resulted in delayed access to support, which increased fear of isolation and stress among both people with dementia and their carers (Giebel et al., 2021). While the intensity of care during Covid-19 increased amongst all the ethnic groups of informal caregivers, 46% of BAME carers reported providing more care due to closure of community and local services compared to 35% of White British carers (Carers UK, 2023). In parallel, Giebel et al. (2021) also observed inequalities in service provision and access during the pandemic based on the area people live in, also known as the "postcode lottery". The term referring *to "people living in different postcodes within a city and being able to access various services purely based on which clinical Trust or local authority covers particular postcode"* (Giebel et al., 2021, pp.1282). People with dementia and their carers who did not meet the criteria for financial support nor felt comfortable covering the costs themselves lingered in the middle of the socioeconomic ladder and expressed feeling distraught for not being able to access dementia support (Giebel et al., 2021).

Support for Informal Carers

There are support services available to carers, such as providing help with housework, special equipment or alterations to the home, emotional support in the form of professional counselling, access to exercise and social activities, and financial support ("Health and Wellbeing", Carers Trust, 2017). However, not all of the carers are entitled to the services mentioned. In order to get support, carers have to pass an assessment by the local council ("Health and wellbeing", Carers Trust, 2017). According to Beesley (2006) only a minority of carers get support, mainly because of the overly restrictive regulations. There are also charities and organizations offering free support and programmes for the carers such as support groups or information programmes, online discussions, and support forums like 'Talking Point' and 'Carers Trust'. However, even though, on average, the interventions have shown to be successful in reducing carers' burden (Gitlin et al., 2003; Olazarán et al., 2010), increasing subjective wellbeing and knowledge of providing care, not all of the carers benefited equally (Sörensen et al., 2002). Moreover, intervention effects were larger for increasing caregivers' knowledge of care rather than decreasing caregivers' burden and depression (Sörensen et al., 2002). Furthermore, it has been suggested that dementia caregivers benefited less than those of other groups (Sörensen et al., 2002). This might be because of higher levels of stress and depression, experiencing health problems of their own, having restricted free time, and not being able to separate themselves from the person they are taking care off (Losada et al., 2010). Mausbach et al. (2011) proposed that depressive symptoms occurred as a consequence of high stress, which interfered with informal carers' normal social and recreational activities and interestingly, Lu and Austrom (2005) reported that the carers of people with dementia who were experiencing high levels of depression, stress, physical performance difficulties and more health related symptoms were less likely to engage in health-promotion actions and ask for professional help.

In order to combat the negative effects of care on informal carers' health and well-being, existing '*interventions have focused on care-related stressors and mental health outcomes'* (Farran et al., 2008, pp 2). However, few studies have looked at physical activity interventions for family carers of people with dementia, even though the benefits of regular physical activity, such as lower stress and depressive symptoms, lower risk of cardiovascular diseases and chronic conditions are well known (Farran et al., 2016). There is a lack of research in understanding perceptions of physical activity of informal caregivers of people living with dementia, as well as understanding specific challenges, attitudes and needs different groups of informal carers, such as spouse and offspring have (Greenwood et al., 2019; Tatangelo et al., 2018).

Leading Charities/Organisations Supporting Informal Carers in the UK

Some of the main charities/organisations supporting informal carers in the UK are Carers UK, Carers Trust, Princess Royal Trust for Carers, Crossroads Care, Action for Carers, Carers Direct, Dementia Carers Count, Alzheimer's Society, Age UK, and others providing legal and financial advice, as well as separate charities focusing on a specific disability, disease, and mental health.

Carers UK has been established in 1988 as Carers National Association and was renamed to Carers UK in 2001. The charity provides support and information to informal carers, shares insights learned from carers to local authorities, and other organisations, and campaigns for change that will improve caregivers' quality of live and allow the carers to provide care '*without putting their lives on hold'* ([1]Carers UK, 2023, no pagination). The main source of information is provided via their website, factsheets, and a guide. In case carers have a question about caring they can call their Helpline or send an email, and should the caregivers want to connect with others, they can do so via the Carers Connect forum or Care for a Cuppas Zoom sessions. The latest campaigns generated by Carers UK are Cost of Living Crisis, which shows the unprecedented financial hardship faced by informal carers, Right to Carer's Leave which called to support carers who struggle with balancing caring responsibilities and work, and resulted in Carer's Leave Bill being brought forward in May 2023, Carers Active which showed that informal carers face significant challenges in being physically active and resulted in Carers Active April campaign in 2022 and 2023 – a month long campaign aiming to raise awareness of physical activity among the cohort and Making Caring the 10th Protected Characteristic which aims to establish informal care for a disabled, chronically ill or senior family member/friend as a protected characteristic ([1]Carers UK, 2023). The latter has become one of the key objectives of the Carers UK 'Vision 2025' strategy (Carers UK, 2021).

Carers Trust is a charity partnering with local carer organisations to provide support and funding, deliver innovative programmes, raise awareness, and influence policy makers. It has been operating since 2012. Since then, its UK-wide network grew to 126 organisations providing support to informal carers (Carers Trust, 2023). The services provided by the network organisations can vary, however in general they provide "*emotional and practical support for carers including providing care in the home to enable carers to take a break, emergency services offering help in crisis, outreach work in GP surgeries and hospital wards to reach carers who are not aware of the suppor*t", financial advice and information about the benefits carers are entitled to. They also offer carers voice and peer support groups, social activities, and training for informal caregivers (Carers Trust, 2023, no pagination).

Princess Royal Trust for Carers in Hampshire was founded by Princess Anne in 1991 and is currently co-ordinated by The Carers Trust. It is a national network of 144 carer centres providing support, information and help to informal carers in the UK. "*Each centre is an independent charity funded by the local authorities, primary care trusts, social services and other organisations"* (Princess Royal Trust, nd.). The charity provides information regarding disability aids, benefits, and emotional support. Carers can contact the charity when they are in need of support such as liaising with Social Services, GPs and other healthcare providers, as well as Benefits Agencies. Caregiver can access some information regarding the health and wellbeing, financial support, and emergency planning via the charity's website (Princess Royal Trust, nd.).

Crossroads Care is a national network of Crossroads Schemes, which provide carers a respite from their caring responsibilities via a care support worker providing practical help at clients' home. The Schemes operate across England and offer different services such as respite in the community, companionship visits, and lifestyle support besides the main - care at home support ([1]Carers Trust, 2023). The home visits however are not free of charge. Overall Crossroads Care schemes will charge £21.20 per hour or £15.90 per half an hour (Crossroads Care South East London, 2023).

Action for Carers is a charity supporting informal carers across Surrey and is a network partner of the Carers Trust. The charity also works closely with Carers UK and other organisations in the county. Some of the services they offer are Action for Carers Helpline, which is a 1:1 support delivered via phone, Carer Hubs, Moving and Handling team, Hospital Advisors, and over 30 Support Groups which run online and in person (Action for Carers Surrey, nd.).

Dementia Carers Count was founded in 2018 and is currently the only charity in the UK aimed solely at supporting informal carers of people with dementia. They offer free courses helping carers to manage their role, such as Meaningful activities and Sundowning, and maintain their health and well-being. The courses are designed and delivered by healthcare professionals. Carers can also connect with other individuals providing care to their loved ones with dementia via the Carer Forum, access additional information via the Dementia Carers Count website and call a free support line should they need someone to talk to (Dementia Carers Count, 2023).

Besides people living with dementia Alzheimer's Society also supports their informal carers. Through their website carers can attain information on how to look after their health, get practical advice on how to provide care for their loved ones with dementia, and where to turn when in need of professional support (i.e. GPs and healthcare professionals). Caregivers can also join online discussion forums such as Talking Point, access publications, reports, and research on the latest innovation in the field, attain information on respite, care homes and support with care, as well as find what financial and legal support they are entitled to ([5]Alzheimer's Society, 2023). Alzheimer's Society branches and partnering organisations, which can be found all over UK offer more personalised support for informal carers, such as in-person peer support groups and various social activities ([5]Alzheimer's Society, 2023).

Age UK is a charity offering support to individuals 50+ including informal carers of people with dementia. On their website caregivers can find information about support available while providing care and locate local Age UK charities offering online and in-person carers' groups, Memory cafes, day centres, and financial and legal advice. Via the main Age UK website caregivers can also attain details on how to support their loved ones as dementia progresses (i.e. individuals with dementia being admitted to a hospital/care home, and end of life care) and access publications and booklets.

Benefits and Financial Support

Informal carers are entitled to a range of benefits and financial support schemes such as Attendance Allowance, Bereavement Support Payment, Carer's Allowance, Cold Weather Payment, Council Tax Support, Free prescriptions for over 60s, Housing Benefit, Blue badge, Universal Credit, and others to help them with care, boost income or help with covering bills (Age UK, 2023). The most widely used benefit is Carer's Allowance, which is worth £76.75 per week since April 2023-2024. However, in order to meet the eligible criteria, the individual in need of care must already receive benefits such as Personal Independence Payment, Disability Living Allowance, Attendance Allowance and/or Adult Disability Payment. In parallel, the person providing care should spend at least 35 hours per week caring for the individual in need and their weekly earnings must not exceed £139 after tax and National Insurance contributions (Age UK, 2023). If the carer is of State Pension age and their pension equals

£75.75 or more per week, they will not be eligible for Carer's Allowance, however they might receive increased Pension Credit. In case the individual providing care is under the State Pension age they might receive Carer's Credit instead of Carer's Allowance, which helps to fill the gap in the caregivers' National Insurance record (Age UK, 2023). However, despite the benefits offered, carers report struggling to make the ends meet (Carers UK, 2023). According to the Carers UK State of Caring report (2023) 34% of carers receiving Carer's Allowance struggled to afford daily necessities such as food and 71% of the recipients worried about the living costs and whether they will manage to cover them in the future. Moreover, the benefit recipients were also more likely to reduce participation in leisure activities/hobbies and seeing family/friends, as well as had to use their life savings to be able to cover the costs of care. Individuals providing more than 50 hour of care per week, cohabiting with the care recipient, and providing care for more than 10 years, which is frequently the case with carers of people with dementia reported higher financial concern (Carers UK, 2023).

While the support available to informal carers of people with dementia might seem vast, caregivers continuously report lack of support from services in the UK (Herron & Runacres, 2023; Francis & Hanna, 2022; Larkin et al., 2022; Hargreaves et al., 2022). Barriers to access diagnostic and post-diagnostic support was often the main reason carers' needs were not met. A systematic review exploring informal caregivers' experiences of UK dementia services (Francis & Hanna, 2022) found that carers felt they did not receive sufficient information after diagnosis nor were they confident where and how to obtain it. Similarly, Herron & Runacres (2023) also found that carers felt unsupported during the diagnosis process and had to search for information and support services on their own. It has been reported that caregivers found navigating through an extensive network of support services and projects confusing and laborious, which resulted in carers not receiving the support needed (Hargreaves et al., 2022). Though when adequate support was provided to the carers, they found it very useful (Francis & Hanna, 2022). This highlights that services and information available are beneficial and can potentially help caregivers with their role, however they are difficult to access. Timely delivery and access of the information is vital for the carers and the cared-for individuals as it allows them to plan care, aid decision making and engage in relevant services (Hargreaves et al., 2022; Francis & Hanna, 2022). Well timed and crafted information delivered via a medium carers can make use off is imperative to help them "*cope with the changed and changing nature of their relative's/friend's condition"* (Larkin et al., 2022, pp.251).

Another factor that might be hindering access to support for informal carers is the short existence of the programmes (mainly in the third sector). This is frequently observed in smaller charities/organisations, which have limited capacity to fund new projects, maintain the already existing ones and/or '*offer longer-term contracts for staff without reliable source of funding'* (Larkin et al., 2022, pp.252). This means health care professionals as well as carers might not be aware of the full list of services available to the carers of people with dementia. Moreover, in case the carers depend on a specific service and/or build a trusting relationship with a member of staff a closure of such service can be damaging to carers' well-being and ability to provide care (Larkin et al., 2022). Overall innovative and effective services for carers exist, however for these to be successfully sustained, offered to, and accessed by carers across the UK, the framework, as well as professional and financial support need to be in place.

Physical Activity in the UK

Physical fitness and recreational activities, such as horse riding and team sports have been a part of the British culture for centuries. However, the first shift in how people perceived physical fitness happened in the Victorian era. Then, great physical fitness became a value, which inspired different cultural movements and trends such as muscular Christianity (Watson et al., 2005). Portable home gyms, use of illustrated exercise guidebooks and first leisure/gym facilities grew in popularity. In the early 19th century physical activity was mainly concerned with improving health and fitness of the nation for military purposes (Zweiniger-Bargielowska, 2006) and civic virtue (Zweiniger-Bargielowska, 2011). Stirred by the physical movement in Germany and Sweden and in anticipation of the second World War, Britain focused on increasing fitness levels of young men primarily, because many were identified as being unfit to join the army (Marino, 2013). Improving fitness level of the youth became a military and political focal point, which led to physical education becoming a part of the curriculum in British schools (Marino, 2013). Worldwide, as well as in the UK health and good physical fitness became the norm and it was largely associated with patriotism (Marino, 2013). The industrial innovation and progressive urbanisation after the WWII led to a trend of physical de-conditioning amongst the population and resulted in a steep rise in noncommunicable diseases. '*England has recognised the links between the physical inactivity and disease since the mid 1970s, however it was not until the early 1990s*' that campaigns to promote physical activity and healthy life style became a government responsibility (Milton & Bauman, 2015, pp.2). Since then, there have been a few major campaigns to improve the fitness level of the British citizens and reduce physical inactivity.

One of the latest strategies announced by the Department for Culture, Media & Sport called 'Get Active' aims to increase physical activity participation amongst the citizens of all ages and to present a framework for sustaining the practice (Department for Culture, Media & Sport, 2023). The government is planning to achieve this by working with stakeholders such as the NHS, private companies and the third sector organisations across the country. The main priorities of the ‘Get Active’ strategy are:

- To ensure the partners, stakeholders and the government are focused on increasing physical activity and reducing the gap on inactivity of 'hard to reach' groups by 2030. This will be achieved by ‘*a new cross-government approach for activity for all, with clear metrics and targets for the sector, held to account by a joint government and sector National Physical Activity Taskforce*’ (Department for Culture, Media & Sport, 2023, no pagination). An increased focus will also be placed on evaluation of the interventions to understand how they are helping people get more active and demonstrate their value. Facilities/organisations successfully showing an impact on physical activity levels in the community will receive a further multi-million pound investment ensuring continuation of their work.
- Making sure physical activity and sport is inclusive for everyone. In addition to promoting women's and disability sport, tackling cultural issues which reduce physical activity participation will be ‘*relentlessly tackled*’ (Department for Culture, Media & Sport, 2023, no pagination).
- And lastly, ensuring the sector is sustainable, financially resilient, and robust. This will be achieved by assisting the sector to secure additional financial support ‘*to help it continue to grow and thrive*’, and by harnessing the opportunities offered by innovation and technology (Department for Culture, Media & Sport, 2023, no pagination).

Since the previous strategy called 'Sporting Future: a new strategy for a more active nation' announced in 2015, the Sport and Physical Activity sector in the UK made a significant progress in increasing the physical activity levels amongst the British citizens. This was achieved by introducing new national campaigns, more accurate ways of measuring the impact of interventions/initiatives on physical activity levels, as well as recognising physical activity barriers certain minority groups and communities might experience (Department for Culture, Media & Sport, 2023, no pagination). Sport England introduced the 'Active Lives Adult Survey' to provide an insight into activity levels and behaviours of adults in the UK, and to measure how many individuals are meeting the recommended levels of physical activity (Department for Culture, Media & Sport, 2023). The latest Active Lives Adult Survey report released in April 2023 showed that between November 2021 and November 2022 62% of adults aged 55-74 and 41% of adults aged 75+ were active, indicating a decrease in physical activity levels with age (Sport England, 2023). The report also showed that individuals with a long-term health condition and/or disability were less likely to be active than people without (47% versus 68% respectively). Though, Covid-19 pandemic resulted in a significant drop in the activity levels between the 55-74 and 75+ age groups, the levels of active individuals in both groups rose to pre-pandemic levels by November 2022 (Sport England, 2023). Data attained via the 'Active Lives Adult Survey' is invaluable, however, apart from the demographic differences (i.e. gender, socio-economic and working status, age, sexual orientation, ethnicity, disability, and long-term health conditions) it does not provide information on other barriers and facilitators for physical activity participation, such as caring for a loved one with dementia (Sport England, 2023).

In order to improve physical activity participation amongst the least active, Sport England launched a national campaign called 'We Are Undefeatable' in 2019 ([1]Sport England, n.d.). The aim of the campaign is to support individuals living with various long term health conditions and to increase their physical activity participation ([1]Sport England, n.d.). The campaign's website offers plenty of information on physical activity, how to begin and what activities to choose from (We Are Undefeatable, 2024). People interested can also download the 'Five in Five' booklet which includes a number of exercises, watch videos showing three ways to increase physical activity throughout the day, and read inspiring stories from other people who became physically active despite their condition/s (We Are Undefeatable, 2024). Amongst the 15 charities supporting the campaign are also Alzheimer's Society, Age UK, Parkinson's UK, and Mind (We Are Undefeatable, 2024).

Musculoskeletal (MSK) health hubs is another novel, UK-wide programme aiming to improve fitness and well-being of people with MSK conditions, such as arthritis, osteoporosis, sarcopenia and chronic pain (UKactive, 2023). The programme launched in 2022 and was designed by Ukactive, GoodBoost, Orthopaedic Research UK, Arthritis Action, and ESCAPE-pain (UKactive, 2023). Transforming leisure centres, gyms, and swimming pools into MSK health hubs could help '*reduce health disparities by providing local, supported, self-management options for people'* with MSK conditions and consequentially reduce the burden to the NHS (Department for Culture, Media & Sport, 2023, no pagination). Currently there are 85 leisure centres and swimming pools nationwide delivering the programme and the number is expected to increase to 100 (UKactive, 2023). Successfully implemented MSK health hubs have the potential to help people manage their own health, and be adapted to support other long-term conditions, such as diabetes and cardiovascular disease (Department for Culture, Media & Sport, 2023, no pagination).

Apart from the national campaigns and initiatives, physical activity programmes, such as group walks and exercise classes tailored to meet the needs of people living with chronic conditions and disabilities are delivered by non-profit organisations all over the UK.

Physical Activity Benefits for Middle-age and Older Individuals

Age is associated with a gradual degenerative series of irreversible alterations of body systems such as loss of balance, muscle mass and bone density (Judge, et al., 1993; Cadore, et al., 2013; Townsend et al., 2014; Shur et al., 2021). The process of complex physiological changes that happen as people age, can also lead to development of various chronic conditions, such as rheumatoid arthritis, type 2 diabetes mellitus, atherosclerosis and other cardiovascular (CVD) diseases, macular degeneration, and neurodegenerative disorders (Prasad et al., 2012; Shur et al., 2021).

Life expectancy of British public has increased significantly over the past few years. In 2023 there were 11 million people over the age of 65 living in England and this number is projected to increase by 10% in the next five years (Reeves et al., 2023). Moreover, the increase in number of individuals aged 85 years and over, the age group most likely to use health and social care services, is predicted to increase by 62.7% by 2043 (Reeves et al., 2023). Though the ability of modern medicine to sustain life is admirable, growing number of older people, who are more likely to live with various chronic conditions, is posing a considerable burden to health and social care services (Kingston et al., 2018; Watt et al., 2023). By 2040 almost 1 in 5 people living in England will live with at least one major illness (Watt et al., 2023). Multimorbidity (living with more than one condition) '*increases the likelihood of hospital admission, length of stay and readmission, raises healthcare costs, reduces quality of life, and increases dependency, polypharmacy*' (taking more than one medication) and mortality (Kingston et al., 2018, pp.374).

Though the likelihood of being diagnosed with a long-term condition increases with age, it is not inevitable part in later life (Reeves et al., 2023). Lifestyle factors such as physical inactivity, smoking, being overweight/obese, and consumption of unhealthy foods contribute to development of many chronic conditions and are associated with multimorbidity (Hurst et al., 2021). In order to increase healthy life expectancy and reduce the pressure on health and social care system, health and social care leaders advised the next elected government to prioritise prevention rather than following the current NHS model which, focuses on emergency interventions and pharmaceutical maintenance (NHS Confederation, 2024).

Regular physical activity is associated with reduced risk of morbidity and all-cause mortality among men and women of any age and has been thus recognised as one of the best preventative and curative measures for poor physical and psychological health (Dhuli et al., 2022). Evidence suggests that individuals who are physically active are less likely to be diagnosed with major non-communicable diseases, such as type 2 diabetes mellitus, CVD, hypertension, dementia, and cancer (Reiner et al., 2013; Dhuli et al., 2022; Shakoor et al., 2023; Bloomberg et al., 2023). Moreover, it has been shown that individuals already living with chronic conditions were able to increase their life expectancy for the same number of years like individuals living without chronic conditions when adopting a healthier lifestyle, such as becoming more physically active and eating a healthy diet (Chudasama et al., 2020). A recent review of literature by Huang et al. (2023) also found that regular or bouts of physical activity improve sleep outcomes of healthy working-aged adults, older individuals, and co-morbid population. These findings agree with Mochón-Benguigui et al. (2021) who showed that reduced sedentariness and higher levels of overall physical activity among elderly were associated with improved objective and subjective sleep quantity and quality measured by the Pittsburgh Sleep Quality Index. According to a systematic review by Vanderlinden et al. (2020) taking part in a moderate intensity exercise programme, three times per week for 12 weeks to 6 months showed significant improvements in sleep outcomes (Vanderlinden et al., 2020). Both, lack of good quality sleep and physical inactivity negatively affect cognitive function and performance of individuals aged 65+ and consequentially increase the risk of developing dementia in later life (Payton et al., 2020; Bloomberg et al., 2023). In a longitudinal study, Bloomberg et al. (2023) explored relationship between sleep and physical activity on cognitive decline among English population aged 50 years or older and showed that frequent, higher intensity physical activity combined with good quality sleep for at least 6-8 hours per night was associated with higher cognitive scores at baseline and improved cognitive health of individuals 50+ years of age.

Increased morbidity and mortality, especially amongst older individuals is linked to higher prevalence of mental health disorders such as depression and anxiety (Sing et al., 2023). Feelings of excessive and persistent worry, fear of demise, isolation, lack of social support and loss of independence associated with ageing can significantly affect older peoples' quality of life and well-being (Ofosu et al., 2023). A vast number of studies showed that physical activity could be as effective treatment for anxiety, depression and psychological distress as psychotherapy and pharmacotherapy (Sing et al., 2023; Ofosu et al., 2023). Physical activity stimulates various neurogenic processes, such as regulating growth factors, and stimulating neurogenesis and angiogenesis, which are important for optimal brain functioning (Kandola et al., 2018). For example, research has shown that physical activity particularly impacts and improves functioning of the hippocampus, a region of the brain regulating feedback of stress responses from the hypothalamic-pituitary-adrenal axis (Anderson & Shivakumar, 2013). Furthermore, physical activity known for its anti-inflammatory properties can also improve elevated levels of inflammatory markers called pro-inflammatory cytokine C-reactive proteins which are usually present in anxiety disorders, and consequentially prevent the onset of chronic inflammation (Kandola et al., 2018). However, to date the information about the most optimal physical protocol to reduce anxiety symptoms and promote physiological changes lacks clarity (Kandola et al., 2018; Kandola et al., 2021; Ofosu et al., 2023). For instance, a prospective cohort study with a sample of 60,235 participants from the UK Biobank with a mean age of 56 years found that the biggest reduction in anxiety and depression levels was observed when sedentary behaviour was replaced with 60 minutes of moderate-to-vigorous activity, which resulted in *'13% lower depression symptoms scores and 7% lower anxiety symptom scores'* (Kandola et al., 2021, pp.10). In contrast, LeBouthiller & Asmundson (2017) showed that general psychological distress and anxiety were improved only by aerobic exercise, while resistance training positively affected anxiety sensitivity, distress tolerance and intolerance of uncertainty only. There is no doubt that physical activity is beneficial in reducing anxiety symptoms, however further research is needed in order to better understand the effects different mode, frequency, intensity and type of physical activity have on mental disorders amongst middle age and older individuals.

Physical activity also proved to be effective in maintaining balance and decrease the risk of falls and fractures amongst the middle-age and older individuals (Thomas et al., 2019; Papalia et al., 2020). Altered balance has an extensive influence on an individual's quality of life and well-being (Overstall et al., 1977; Siren, and Hakamies-Blomqvist, 2009). Moreover, it is the greatest contributor towards falls (Madureira et al., 2007; Clemson et al., 2012). Therefore, it can affect activities of daily living and lead to loss of independence (Lajoie, and Gallagher, 2004). Falls are being recognized as one of the contributing factors to morbidity and mortality and are the most frequent type of accident of the elderly living in the UK (Age UK, 2010; Soomar & Dhalla, 2023). More than 3.4 million people aged over 65 suffer from falls every year, moreover it has been estimated that among 500 admissions to hospital every day, due to falls, 6.5% people never go home (Annual European Home and Leisure Accident Surveillance Survey (EHLASS), 2000). Falls are not only costly for the individual, but also for the whole health and social care system. Only hip fractures cost NHS and social care approximately £2.3 billion per year (Age UK, 2010; Office for Health Improvement & Disparities, 2022). It has been suggested that a falls prevention strategy might reduce the number of falls by 15-30% (Age UK, 2010). Furthermore, Li et al. (2003) reported that fear of falling occurred among older individuals if they had fallen or not, which significantly reduced their confidence in everyday tasks and resulted in self-induced restrictions in physical activity. According to Suzuki, et al. (2002) 16.3% of 135 participants aged 60 years or more expressed very high fear of falling, which contributed to psychological conditions such as depression. Moreover, fear of falling is not only associated with fragile elderly. Bruce et al. (2002) showed that fear of falling has been independently associated with healthy, high-functioning older women. Physical activity interventions such as multi-component exercise programmes (Papalia et al., 2020), resistance exercises, falls prevention programmes (Devasahayam et al., 2023), Tai Chi (Cadore et al., 2012) and dance (Shepherd, 2003) have all shown to have a substantial influence on risk factors, associated with ageing and individuals' physical impairments such as poor balance (Merom et al., 2013; Kattenstroth et al., 2013) and consequentially reduce the risk of falling (Thomas et al., 2019).

Physical Activity and Informal Care in the UK

A number of studies have shown that informal carers' physical and mental health, as well as overall well-being are frequently affected by the responsibilities they have as caregivers (Alzheimer's Society, 2015; Burton, and Sumukadas, 2010). Consequentially, informal caregivers' health and well-being has been shown to be worse than that of the general population (^{1}Carers UK, 2020). According to ^{1}Carers UK (2020, pp.1) 6 out of 10 individuals (61%) providing substantial amount of care, such as caregivers of people with dementia said, *'their physical health has worsened as a result of caring, while 7 out of 10 (72%) said they have experiences mental ill health.'* Not being able to leave the person they care for (Losada et al., 2010), struggling with various health conditions on their own, feeling tired, and finding it difficult to adapt to constantly changing routines of the care receivers, are preventing informal carers to participate in regular physical activity, which is making their overall health even worse (Horne et al., 2021).

Though informal carers of people with dementia often prioritise the needs of the person they care for and/or their family (^{1}Carers UK, 2020), previous study by this researcher found that the carers of people with dementia expressed concern about their health and felt balance and good physical condition are crucial when providing care (Hubej, 2017). One of the participants said,

> *"...you know because I have to do most things I'm the one that is climbing on the chair reaching things em, I'm the person that does most of the odd jobs around the house...I think balance is very important you know...I do run up and down the escalators and things like that..."*

Moreover, they expressed fear of getting ill or having to go to the Hospital:

> *"... because I panic that if anything happens to me I couldn't go into hospital because I'd had to make some arrangements for X, so em yeah. If I think that I'm going to go down or if there's something that could go wrong I do tend to investigate it straight away, because em you know it would be an awkward situation if I'd had to go."*

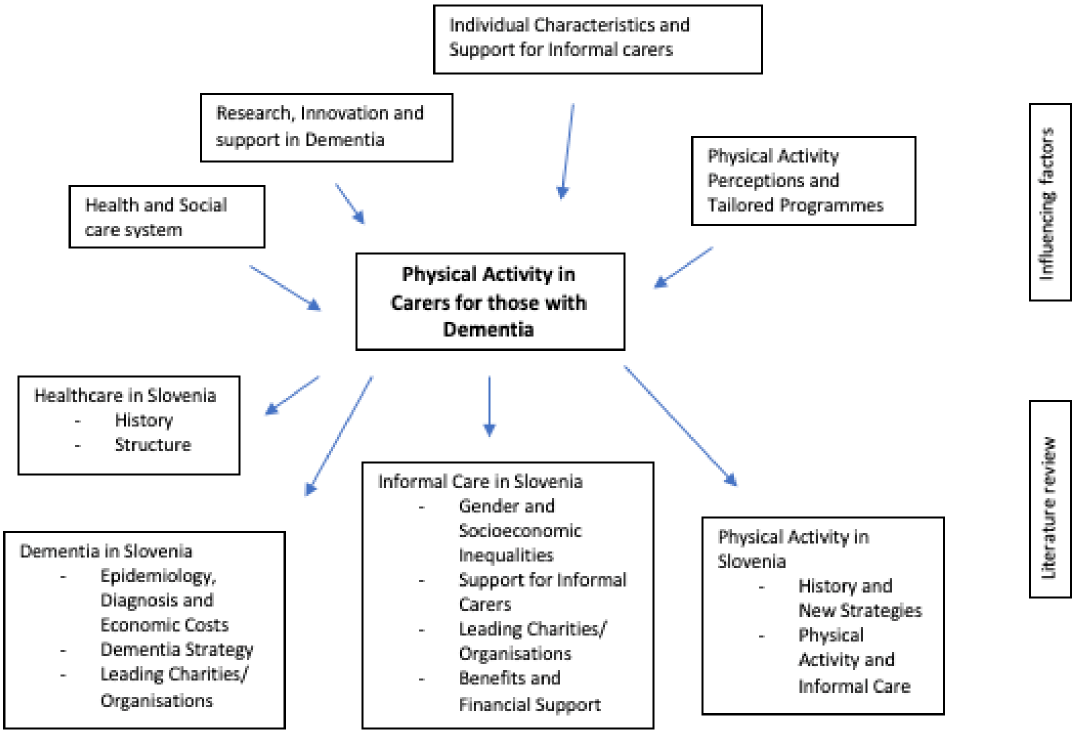
Physical activity programmes available only to the informal carers of people with dementia in the UK are scarce, however exercise and physical activity programmes designed for both, the carer and the care receiver are offered in multiple charities and dementia cafés across the UK. Informal carers can also access general physical recommendations on websites from charities and organisations such as

Alzheimer's Society, Age UK and Carers UK. The latter offers more detailed physical activity guidelines via the online 'Carers Active Hub' ([1]Carers UK, 2023). By joining the Hub, carers can sign up for the Carers Active newsletter and Facebook group, access Carers Active exercise session recordings and watch bespoke activity well-being videos created by 1FitLife ([1]Carers UK, 2023). However, even though the joint sessions with the care receiver, and online physical activity guidelines and exercise videos are commendable, informal carers remain underactive and do not meet the recommended physical activity guidelines ([1]Carers UK, 2021).

In the past few decades, the increasing prevalence of dementia and the growing knowledge of the disease influenced numerous policies, strategies and resulted in an establishment of various charities, institutes and organisations focusing on improving well-being as well as social and health care services for informal carers. However, even though the support has increased, informal carers of people with dementia report feeling unsupported. There is a scarce body of research exploring potential differences in how various groups of informal carers perceive providing care, physical activity, and how an overall understanding of the health and social care systems influence decision making this population makes about their health. Doing all the work that care requires and being affected by its burden, going through natural aging processes, which have a significant impact on ones' physical and psychological health and not being able to obtain support/attend activities puts informal carers of people with dementia in great risk for their health and well-being, and consequentially at a high risk of losing the ability to care (Carers: looking after yourself, 2016).

CHAPTER TWO

Due to Covid-19 pandemic, a part of data collection for this PhD thesis was conducted in Slovenia. As elsewhere around the World, the numbers of people with dementia in Slovenia and consequentially their informal carers are increasing. The health and social care in Slovenia is under a tremendous pressure, and is heavily relying on the support provided by the informal carers. This chapter will provide a background on dementia, informal care, and care burden in Slovenia, support available to the informal carers of people with dementia in Slovenia and provide a description of physical activity programmes in connection to informal care in Slovenia. An overview of the literature review search is mapped out in the image below.



Literature Review on Dementia, Informal Care and PA in Slovenia

Healthcare in Slovenia

Slovenia is a central-south European country with a diverse landscape, spreading over 20,000 square kilometres (Hlebec et al., 2016). The country declared its independence from Yugoslavia and its socialist regime on the 25th of June 1991, and became a member of the European Union on the 1st of May 2004. By constitution Slovenia is a parliamentary democratic republic with a head of state (the president) and a head of government (the prime minister). Since 1992 the Slovenian health care system operates as a public institute (Slovenian national health insurance system – ZZZS) bound to provide health insurance, which is compulsory for all residents and citizens of the Republic of Slovenia. Even though social health insurance system provides almost universal coverage, individual charges ranging between 10 - 90% of the service price are applied to almost all health services financed by the state (OECD, 2021). This resulted in a high uptake of additional voluntary health insurance (VHI) in order to counteract the high costs of out-of-pocket co-payments (Kramer, 2016). In case individuals who are liable for VHI and do not decide to purchase one, there is a system of penalties in place (3% of the premium price for each 12 months ranging up to 80% of the premium price) (Kramer, 2016). Certain groups of people including children (16 years old or less), students (in continuous, full-time education 26 years old or less), pregnant women, people with long-term or chronic conditions and unemployed or people on low incomes are entitled to a free healthcare and exempt from user charges (OECD, 2021). Other insured persons can implement their rights within the framework of the public and private health care services (healthcare providers contracted to the ZZZS) including primary, secondary, and tertiary services. The benefits also include access to pharmaceuticals, medical devices, sick leave exceeding 30 days, some travel costs to health facilities, emergency care and nursing care in inpatient/residential settings (OECD, 2021). Despite the near universal coverage, the Slovenian population felt their medical needs were not met, mainly due to increased costs and substantial waiting times. Shortage of health care staff, in particular primary care physicians and nursing staff in hospitals as well as low availability of private alternatives, substantially increased waiting time for elective surgeries (99% of patients had to wait more than 3 months for a hip replacement surgery) and dental care (OECD, 2021).

In 2019, only 10.2% of total health spending in Slovenia was allocated to long-term care (LTC), which was considerably less compared to the EU as a whole (16.3%). Though some financial benefits were available to people in need of LTC (i.e home-based help with ADLs), they were not sufficient to cover any significant services needed. After the Covid-19 pandemic, which highlighted the need for further investments in the health care systems and infrastructure, the Slovenian government announced EUR

79 million investments in setting up a LTC system that combines health and social care services (OECD, 2021). The LTC Act was accepted in December 2021, which includes novelties such as one-stop shops services for preserving users' independence, newly defined care categories and a new assessment tool for evaluating the level of LTC needs (Euro Carers, 2023).

One stop shops are described as services located at the regional offices of the Health Insurance Institute of Slovenia offering people in need of LTC all the information necessary and a chance to apply. Depending on the level of care required, potential LTC users will be classified into five categories and receive financial support aligned with the services needed in each category (EUR 340 monthly for people with less care needs and up to EUR 1,870 for people with high care needs) (Euro Carers, 2023). According to the LTC Act, each user will receive a recommendation of services such as help with ADLs, nursing care, e-care services (worth up to EUR 31 per month), and services to strengthen and sustain independence (worth between EUR 348 and EUR 696 per year). People in need of LTC will be assessed based on eight criteria which are '*mobility in the home environment, cognitive and communication skills, behaviour and mental health, self-care, ability to cope with any disease or treatment, usual activities and social contacts, ability to act outside the home environment, and household activities*' (all related to medical needs rather than the social component) (Rupel, 2022, pp.1).

The Act will be financed from the state budget and newly introduced compulsory LTC Insurance, which will be paid by all persons included in the compulsory health insurance scheme. The rates and a contribution base for the compulsory LTC Insurance will be introduced in a new act (presumably in June 2025). Until its adoption, the LTC Act will be financed via 3.8% of funds collected by the Health Insurance Institute of Slovenia and 2.2% of funds collected by the Pension and Disability Insurance Institute (Euro Carers, 2023).

Though the Act might be a step in the right direction especially due to the demographic change in Slovenia and more people needing LTC, it has been widely criticised (Euro Carers, 2023). In addition to not taking recommendations of the pilot project in 2018 into account (to test the efficacy of one-stop shops, new services for preserving users' independence and new assessment protocols), the Act fails to provide apt financial assessments and projections (funding needed to sustain LTC services has been calculated based on the current situation and did not consider the number of users resulting from the Act, nor the cost of the services offered under the Act per user). Additionally, there are a few controversial issues with the needs assessment for the LTC services eligibility and quality assurance (Rupel, 2022).

Dementia in Slovenia

As elsewhere around the world, Slovenia is too following the ageing trend (Pavlič et al., 2021). In 2018 the overall population in Slovenia was 2,066,880 and the number was predicted to increase to 2,073,067 by 2025 (Alzheimer Europe, 2019). Though the overall increase might not seem substantial, the increase in numbers of people over the age of 65, in particular over the age of 85 will almost double by 2050 (from 34,773 in 2018 to 74,751 in 2050) (Alzheimer Europe, 2019). The risk of developing various chronic conditions, including dementia increases exponentially with age (Wittenberg et al., 2019). In parallel with the growing number of seniors in Slovenia, the number of people with dementia is expected to increase from 34,137 in 2018 to 65,892 in 2050, representing 3.40% of the population (Alzheimer Europe, 2019).

The cost of dementia in Slovenia is divided into subgroups, such as basic diagnostic investigations (estimated cost at EUR 7 million), formal and informal home help (estimated cost at EUR 265 million) and nursing home placements (estimated cost at EUR 105 million) (Županič et al., 2022). However due to unreliable "*national epidemiological and health economic data, the financial costs of dementia in Slovenia may be over or underestimated*" (Županič et al., 2022, pp.76).

In order to get dementia clinically diagnosed, people in Slovenia, as in many other countries worldwide, are encouraged to visit their primary care physician first, who discusses the signs and symptoms with the patient, conducts a memory screening test and blood diagnosis. According to the outcomes the primary care physician then refers the patient to the specialist either a psychiatrist and/or neurologist. The specialists then conduct further investigations such as, CT, MRI and PET scans "*and/or a lumbar puncture to measure proteins in the cerebrospinal fluid*" (Alzheimer's Disease International, 2021, pp.4). The diagnosis can also be attained via private psychiatric and neurological clinics across Slovenia. As soon as the diagnosis is confirmed, people affected are provided with a treatment plan, and together with their family/friends with information on further support, such as legal advice, social activities etc. (Alzheimer's Disease International, 2021).

Spominčica – Alzheimer Slovenia is the leading, non-profit, interdisciplinary, professional association offering help and support to people living with dementia and their informal carers in Slovenia (Spominčica – Alzheimer Slovenia, 2023). The organisation is a part of Alzheimer Europe and Alzheimer's Disease International and is widely spread throughout the country. There are currently 12 Spominčica branches which work alongside other organisations offering support to elderly/retired individuals such as, day-care centres, intergenerational centres, libraries, and parishes. Some of the branches are integrated in facilities such as care homes and psychiatric hospitals. Spominčica offers counselling sessions (via phone and one-to-one), peer support groups, Alzheimer Cafes, befriending opportunities, and publishes a monthly newsletter full of valuable and practical information for people with dementia, their relatives, and informal carers. The organisation also advocates for a timely dementia diagnosis, spreads awareness of dementia in Slovenia via initiatives such as 'Prijatelj Spominčice' (aka Dementia Friends) and offers dementia training to key workers (police, firefighters, civil servants, pharmacists, shop assistants etc.) as well as informal carers and relatives of people with dementia (Spominčica – Alzheimer Slovenia, 2023). One of the most aspiring programmes in order to share dementia awareness and knowledge amongst the Slovenian population is the establishment of nationwide Dementia Friendly Spots (DFS). The DFS programme funded by the Ministry of Labour, Family, Social Affairs and Equal Opportunities and the Ministry of Health, connects a wide range of organisations and companies in a network of sites providing local support and information to people with dementia, their relatives, informal carers and individuals who might cross paths with people with dementia on a daily basis, such as key workers and neighbours (Alzheimer's Disease International, 2019). Since 2017 when the first DFS was registered at The Human Rights Ombudsman office, the network of DFS grew to 200 members in 2019 (Alzheimer's Disease International, 2019) and currently encompasses 390 registered DFS across Slovenia ([1]Spominčica – Alzheimer Slovenia, 2023). Though the idea of DFS programme and the number of registered partners is admirable and corresponds with the Alzheimer Europe Strategic Plan (2021-2025) (Alzheimer Europe, 2021) as well as Dementia Management Strategy in Slovenia (Alzheimer Europe, 2022), the effects of the programme and its individual branches are under researched. Before becoming a DFS the organisation/company and its employees have to complete a training offered by Spominčica – Alzheimer Slovenia and exhibit dementia information leaflets and brochures in a place where they are easily seen and accessed. However, as the network of organisations and companies that can become DFS is extremely broad (from banks to health care facilities) the form and level of help offered to the general public, people with dementia and their carers, and consequentially its effects might vary.

Spominčica – Alzheimer Slovenia also participates in the preparation of the Dementia Management Strategies in Slovenia. The latest strategy was approved by the Government of the Republic of Slovenia on the 6th of July 2023. The strategy followed the recommendations and commitments accepted on the European Union and World Health Organisation level, as well as strategies successfully adopted by other countries (Alzheimer Europe, 2022). The Slovenian National Dementia Strategy until the year 2030 focuses on continuing support of dementia prevention programmes, timely diagnosis, and treatment, as well as improving care after receiving dementia diagnosis, including palliative care, social support networks and informal care (Alzheimer Europe, 2023). '*The ten objectives of the strategy are:*

1. *Promotion of preventive programmes to reduce risk factors and to maintain and strengthen health in the community with different approaches to individual groups and individuals.*
2. *Diagnosing the early stages of neurocognitive disorders, improving access to quality, safe and effective health care, and treatment.*
3. *Improving access to appropriate and coordinated post-diagnostic multidisciplinary treatment for people with dementia, including integrated treatment, LTC, social services, support for families or caregivers in the local environment, and access to palliative care.*
4. *The use of modern information and communication technologies for the treatment and support of people with dementia.*
5. *Respecting the dignity of people with dementia, reducing stigma, and raising awareness among the wider society and the professional public for the development and establishment of dementia friendly communities.*
6. *Education of all professional groups in the field of dementia management.*
7. *Establishing national dementia data collection.*
8. *Promoting modern dementia research.*
9. *Establishing National Dementia Centre.*
10. *Appropriate treatment of persons with dementia during epidemics and other emergencies.’*

(Alzheimer Europe, 2022, pp.1).

Though there are numerous projects, programmes, and initiatives for people with dementia, their relatives and informal carers offered by Spominčica – Alzheimer Slovenia, their effects have not been extensively evaluated. There seemed to be a greater focus on exploring the awareness of dementia amongst the general public (which is crucial for a timely diagnosis, reducing stigmatisation and discrimination) (Felc, 2022; Felc et al., 2021; Felc et al., 2019) and on dementia prevention measures (Ribarič, 2022). While raising awareness and diminishing the risk of developing dementia were two of the seven areas included in the Global dementia action plan 2017-2025, increasing research across all the areas (such as easier access to dementia diagnosis, improving care and treatment for people with dementia and supporting carers) is as equally important ([1]WHO, 2017). Future research is needed in order to explore and evaluate the impact of the programmes, projects and initiatives offered to people with dementia and their informal carers in Slovenia.

Informal Care in Slovenia

Views and perceptions of informal care in Slovenia are extremely contrasting, which might be a consequence of the country's previous political system and welfare arrangements, as well as the overall cultural practices and care models (Peña-Longobardo & Oliva-Moreno, 2021). As a post-socialist country Slovenia relies on “*a combination of conservative-corporatist and social-democratic models of care provision, along with underdeveloped long-term care systems and strong family elderly care responsibility*“ (Hvalič-Touzery, 2022, pp.2). Accordingly, Slovenians believe care for the elderly should be provided by the state (only 7.1% is convinced that it should be delivered by family, friends, and relatives) (Pavlič et al., 2021), yet most of the care in Slovenia is provided precisely by the informal carers (Euro Carers, 2023; Hvalič-Touzery et al., 2022; Pavlič et al., 2021). This confirms the country’s strong familial care regime, where the family is assumed as the main care provider. Considering the task division in care, Rodrigues et al. (2022) describes the form of familialism in Slovenia as prescribed familialism, as opposed to supported familialism. Prescribed familialism is an ideology where the family members are obliged by law to care for an elderly family member and/or provide financial support to cover the costs of formal care provision (Rodrigues et al., 2022). In supported familialism, families, relatives and friends providing unpaid care are actively supported by public policies, usually through financial benefits or care respite schemes (Rodrigues et al., 2022).

Socio-economic and gender inequalities have been associated with familialistic care regimes, in particular prescribed familialism as families have to rely on their own resources to meet the needs of the individual(s) they care for (Saraceno, 2016). This means that not all families are able to finance full or partial payment of the formal care services and therefore potentially experience higher burden of care (Filipovič Hrast et al., 2020). In Slovenia caring for an elderly parent, parent-in-law or a partner is understood to be a predominantly female role (specifically wives' and daughters'), which can result in an unequal division of care responsibilities and consequentially cause higher care burden (Filipovič Hrast et al., 2020). According to Šadl & Hlebec (2018) daughters, in contrast to sons provide care to their elderly parents regardless of circumstances. The sons get involved mainly when they live in the same household as their elderly parent(s) and/or when there is no other choice. Differences in gender were also found in the intensity of the care provision (in connection to the ADLs and the instrumental activities of daily living (IADL)) where daughters were providing more intense care than the sons (Šadl & Hlebec, 2018). Supported familialism on the other hand can diminish social and gender inequalities by offering financial support to informal carers. This provides families with an opportunity to defamilialise care by being able to pay for formal care services or being compensated for the care provision (Rodrigues et al., 2022).

Latest figures show that 33.1% of Slovenians over the age of 40 provide care for at least 4 hours a day for a family member 65 years of age or older. And 43.1% of them are assisting their loved ones with ADLs (which is considered to be the most demanding type of care) (Dolničar et al., 2021). In parallel, elderly in need of care showed strong preference to be assisted, or cared for by their family members, relatives, or friends regardless of their living status (Galof et al., 2019). As a result, 20.2% of individuals aged 60 or more are cared for solely by informal carers, 1.1% by formal caregivers and 3.2% receive a combination of both formal and informal care (Filipovič Hrast et al., 2020). Though the home care services provided by the formal carers are used as a substitute or a complementary service to the informal care, they are a subject to the individual health and needs evaluation, "*minimal subsidies from municipalities, and additional co-payment by the service users"* (Filipovič Hrast et al., 2020, pp.2).

Thus, many families cannot financially afford it (Filipovič Hrast et al., 2020). In order to ensure suitable living conditions and care for the elderly family members and combat the rising costs of living as well as formal care services, many Slovenian families find solution in intergenerational cohabitation (Euro Carers, 2023).

Although Slovenia has recently accepted the new LTC Act and Dementia Management Strategy (with higher focus on informal care), some of the changes have not been implemented yet nor tested for its efficiency, and do not currently appear to counteract the unmet needs of informal carers (Hvalič-Touzery et al., 2022). The options, either specialised (i.e. respite care) or financial to assist Slovenian informal carers in their altruistic mission are scarce (Rodrigues et al., 2022). As family members, relatives and friends providing care are not health professionals, they face complex challenges while caring for their loved ones, such as (but not limited to) mobility assistance, unexpected home alterations, helping with personal hygiene, feeding, administering medication, and repositioning bedridden patients (Pavlič et al., 2021). Though there are a few educational programmes available for informal carers aiming to deepen the knowledge of the disease/conditions of the person in care, such as the community-based training provided by the Anton Trstenjak Institute of Gerontology and Intergenerational Relations (Euro Carers, 2023) and occasional events offered by Spominčica – Alzheimer Slovenia, informal carers in Slovenia expressed a need for more regular workshops provided by professional health workers such as the GPs (Pavlič et al., 2021; Euro Carers, 2023). Moreover, there are various barriers informal carers face that prevent them from attaining the training offered. For example, older individuals providing care (70+ years of age) might find it difficult to participate due to higher prevalence of health conditions they live with as well as transportation challenges, and younger carers (50+ years of age) might lack time due to being employed full-time and have other family care responsibilities (Ramovš et al., 2019). Therefore, despite the emphasis to support informal cares stated in recent policies, caregivers in Slovenia are more or less left to themselves to acquire information and knowledge about providing and organising care for their loved ones. If they are able, they look for information online, access it via other types of media (magazines, newspapers), ask a neighbour/friend, but mostly they develop the knowledge of care based on their own personal experiences (Pavlič et al., 2021).

Beside the lack of knowledge of care and the conditions individuals in need of care live with, it is important to address other experiences informal carers might experience while providing LTC, such as loneliness, fear of death, depression etc. (Pavlič et al., 2021). GPs in Slovenia are less likely to discuss quality of life, goals and preferences with their frail elderly patients and people living with dementia. Discussing palliative care, treatment limitations and overall multidisciplinary care options with patients and their informal carers is considered rather a private matter (Klok et al., 2018). This might be a consequence of the country's previous socialistic regime and cultural perceptions where '*death was pushed into the sphere of the private, and the Church'* (Kolk et al., 2018, pp.61), which explains the lack of hospices and palliative care wards in the hospitals in Slovenia. In addition to the challenges and care burden experienced by informal carers, individuals providing care for people with long-term conditions, like dementia experience anticipatory grief (Dehpour & Koffman, 2023). A complex phenomenon also described as a pre-death grief, which is directly connected to the caregiver burden (Liew et al., 2020). Additional support to discuss this matter, together with health and psychosocial support for informal carers remains underdeveloped and underestimated in Slovenia (Pavlič et al., 2021).

With the increases in retirement age many informal carers, especially offspring are still in full-time employment, which significantly raises the intensity of care provided by this population (Peña-Longobardo & Oliva-Moreno, 2021). High intensity of care has been linked with decreased overall health and well-being, challenges in the workplace, and worsening of the social and family relationships (Kolodziej et al., 2022; Pavlič et al., 2021). People of working-age in Slovenia are therefore significantly '*reducing their working hours, resigning from their jobs, or simply curtailing their leisure activities in order to informally care for relatives or friends'* (Pavlič et al., 2021, pp.168). Family members with caring responsibilities (except the ones with a family assistant status) who opt for a part-time employment instead of full-time cannot '*retain the full level of social security benefits nor do they receive any compensation for lost income'* (Rodrigues et al., 2022, pp.5).

Many studies looking at the effects of the Covid-19 pandemic on informal carers in Europe have found that the intensity of care provided during the outbreak increased and further exacerbated the already present challenges faced by individuals providing care (i.e. care burden, sleep disturbances, diminished access to health and social care services, activities and overall social support) (Santini et al., 2022; de Vries et al., 2022; Socci et al., 2021; Rodrigues et al., 2021). The caregiving situation specifically worsened for informal carers providing care for people with dementia (Budnick et al., 2021). In Slovenia the situation was no different. Hvalič-Touzery et al. (2022) explored the subjective care burden during the Covid-19 amongst the informal caregivers of older adults in Slovenia reported that providing care to a person with dementia or other severe memory loss was one of the strongest predictors for self-reported care burden. These were followed by the higher hours and duration of care, provision of ADLs and insufficient financial support (Hvalič-Touzery et al., 2022). Accordingly, 28.3% of the informal carers reported decreased psychological well-being, 26.9% experienced worsened financial situation and 17.5% found their health had deteriorated (Hvalič-Touzery et al., 2022). The weakness of prescribed familialistic care regime with minimal financial support (distinctive for Slovenia) was exacerbated during the pandemic, putting more pressure on the already overburdened informal carers providing care for people in need of high care intensity (i.e. people with dementia).

Physical Activity in Slovenia

The contemporary sport policy system in Slovenia is largely routed in the country's previous political arrangements. In the establishment of Yugoslavia, sport was seen as a priority and used as a means of enhancing Yugoslavs' national identity. *'Athletic movements called Sokols were central to nation-building in the multi-ethnic population'* (Horvat & Mason, 2022, pp.745). Sokols were nationalised during the Kingdom of Yugoslavia and began to be funded by the federal budget (Pavlin, 2008). The novel arrangement supported mass participation (recreation) which *was 'seen to be an important factor in national stability, enlightening of the public and militarisation of society'* (Horvat & Mason, 2022, pp.745). Later the new Communist regime embraced in the Federal Yugoslavia led to the Sokol movement being dispersed and changed to physical culture (Pavlin, 2008). The importance of physical culture further intensified the belief amongst people that there is no quality of life without physical activity (Horvat & Mason, 2022). In the 1970s, after the declaration of the Slovene Constitution, the physical culture was no longer led by the federal state, instead it was '*carried over to the republic level and municipalities'* (Horvat & Mason, 2022, pp.745). As a result, local self-government units were established with an aim to improve management of the sport infrastructure, provide more structured funding source, increase research and education in sport, ensure success of professional athletes and increase participation in recreational sport (Horvat & Mason, 2022). The pursuits for a democratic independent country, led Slovenia to utilise sport as a means of promoting national identity among the citizens and in the international context (Topic & Coakley, 2010). During the *"Yugoslav era, Slovenian athletes reaped international successes"* in gymnastics, basketball, skiing, ski jumping and Nordic skiing, which were later perceived as Slovene national sports (Horvat & Mason, 2022, pp.746).

The current Slovene sport system is divided into a governmental/public sphere and non-governmental/civil sphere both operating on a national and local level, with structural links to the ones originated in Yugoslavia (Horvat & Mason, 2022). Moreover, Slovenia adopts a Sports Act which has been in force since 1998. The Sports Act states what the sport policy system should provide, such as every resident of the Republic of Slovenia has an opportunity to participate in sport irrespective of their gender, race, social status, religion, language and nationality or any other personal circumstance, an opportunity for sport participation in a safe and healthy environment, sports heritage conservation care, sustainable development, promotion of sporting behaviour and safe sport and the strengthening of moral and ethical values and avoidance of unfair achievement of results (Horvat & Mason, 2022; Zakon o športu, 2017). The act also provides the basis for the National Programme of Sport (NPS) which provides a *strategic, "financial, professional and organisational directives needed for the realisation of the Sports Act"* (Horvat & Mason, 2022, pp.748). Amongst the others, one of the priority areas identified by the NPS is Sport for senior citizens. According to the NPS 2014-2023 the actions regarding the Sport for senior citizens are to ensure that individuals 64 years of age and older are entitled to at least two hours of sport activities per week free of charge and to encourage intergenerational cooperation through sport (Jurak & Pavletič Samardžija, 2014).

Sport (recreational and elite) in Slovenia is funded by the public fund allocated on an annual basis according to the Annual Programme of Sport (Kolar et al., 2010). The largest funders are local communities which contribute approximately 70% of public funds for sport (Horvat & Mason, 2022).

Suitable climate conditions and geographical position of Slovenia offer an opportunity to its residents to participate in sport during winter and summer. This shaped the perceptions and attitudes of Slovenes towards sport and is "*highly linked to the historical development of sport, national identification and culture"* (Horvat & Mason, 2022, pp.753). Slovenia has a diverse green landscape and large outdoor areas offering the public to be physically active free of charge. Consequentially Slovenians "*placed first in the category of using natural outdoor areas for PA in the EU"* (Horvat & Mason, 2022, pp.753). Besides the vast outdoor space, almost every school (either primary or secondary) has its own gymnasium, which is also used outside of the curriculum hours. Public sports facilities and natural areas intended for public use are build and maintained by the state and local communities.

Physical Activity and Informal Carers in Slovenia

Slovenes are considered to be one '*of the most physically active nations in the European Union'* (Horvat & Mason, 2022, pp.743). It has been reported that 55.9% of adults in Slovenia (25 to 74 years of age) regularly participate in some form of PA and reach or exceed the recommended amount of PA to maintain health (Petrič & Remec, 2018). Only 12.2% of adults (25 to 74 years of age) reported not participating in any form of PA (Petrič & Remec, 2018). The inactivity amongst the residents was largely associated with "*functional limitations, low subjective well-being, poor social support, memory decline, depression and older age"* (Gomes et al., 2017, pp.73). A study exploring health and well-being of older adults living in Slovenia over the course of 8 years found that 2/3 of the participants reported decline in motor abilities and their overall health over the years, and thus reduced their PA levels (Teraž et al., 2022). The most commonly reported forms of PA amongst the active participants were walking, gymnastics, dancing, gardening and working on the vineyards, orchards and the olive groves (Teraž et al., 2022).

To combat the rise in chronic conditions due to modern lifestyle and ageing, Slovenia has invested a lot of effort in adapting, developing, and exploring new programmes and initiatives in order to track PA of people living in Slovenia as well as increase their exercise adherence. For example, Together for Health programme – a comprehensive chronic disease prevention programme is accessible to all adults in Slovenia free of charge (the costs are covered by the compulsory health insurance scheme) (WHO, 2021). The Together for Health programme consists of three types of activities: preventive examinations (for early detection of risk factors for developing chronic conditions) conducted at general practices, group workshops and one-to-one consultations (to support individuals who wish to change their lifestyle) carried out at health promotion and health education centres, and health promotion activities taking place in the local communities (Skupaj za Zdravje, 2021). The services and activities are run by qualified health professionals such as, the GPs, nurses, physiotherapists, and kinesiologists (WHO, 2021). The programme and its separate activities have not been yet evaluated.

A non-governmental organisation The School of Health Association also offers physical activity programmes and lectures on healthy lifestyle and nutrition available to Slovenian residents, with particular focus on the elderly. The organisation is supported by the Ministry of Health and Ministry of Labour, Family and Social Affair, local communities, and private donors. Currently there are 246 groups operating in 91 of the 212 municipalities across all Slovenian regions, with 4756 members accessing the service (Šola Zdravja, 2021). The programmes "1000 movements" and "method 23+5" developed by the School of Health Association are free of charge and led by qualified volunteers as well as fitness practitioners. The "1000 movements" programme combines elements of aerobic, resistance, flexibility and balance exercises and runs outdoors, six days a week from 7.30-8.00 in the morning. The 'method 23 + 5' is delivered online and includes 23 full-body exercises and finishes with performing circumduction with 5 different parts of the body (Širaiy et al., 2020). Though Širaiy et al. (2020) reported improvements in balance (52%), shoulder mobility (41.29%) and social life (70%) in participants after taking part in both programmes, the sample only included participants with no reported chronic conditions, younger than 70 years of age of which most of them were female (96%).

Daily centres of activities for elderly is another organisation with eight branches spread across the country's capital city Ljubljana and funded by the Municipality of Ljubljana and the Ministry of Labour, Family, Social Affairs and Equal Opportunities. The branches are visited by 30-100 people a day and host 30-35 different activities per week, such as board games, foreign language lessons, exercise classes, support sessions for people living with dementia, yoga, dancing, computer classes, trips, and others. All the activities are free of charge or occasionally require a symbolic contribution from the participants (WHO, n.d.). According to Kumše (2016) who evaluated the efficacy of one of the branches the majority of service users were people aged 60-70 (64%), followed by individuals 70-80 years of age (16.1%) and lastly 50-60 years of age (13.3%). The smallest percentage of service users were older than 80 years (6.2%). Though the service users were pleased with the quality and variety of the programmes offered by the centre (99.5%) the services such as the exercise and dementia support sessions were not evaluated in detail nor were the characteristics of the individuals attending those sessions.

The country has a well-established national physical fitness surveillance system which '*has been collecting annual fitness and health data from schoolchildren in primary and secondary schools for over three decades'* (Jurak et al., 2022, pp.1). With an aim to promote, maintain and track the physical fitness and physical literacy across citizens' lifespan, the researchers have adapted the initial screening battery and developed SLOfit Lifelong, which is available to all adults and seniors (Jurak et al., 2022). The new screening test and its features have been digitalised, which created a possibility to create more holistic communication channels offering the users to share their data with health professionals and attain information regarding health online (Jurak et al., 2022). Though the effectiveness and usage rate of the system amongst different groups of adults/older adults have not been explored yet, the initiative provides a promising opportunity to form policies and conduct research on predictive measures of health and fitness.

In order to combat the rise in physical inactivity during Covid-19 pandemic Slovenia formed a multidisciplinary group of experts such as kinesiologists, sport scientists, environmental physiologists, medical doctors and epidemiologists to draft a set of national PA guidelines (Morrison et al., 2020). The guidelines emphasized performing physical activity outdoors, which was possible due to the country's natural green landscape and the proximity of national parks and rural areas (Morrison et al., 2020). For the people who were mostly housebound, such as elderly and other groups at higher risk of contracting the virus, Slovenia implemented four other strategies. Those were televised home physical activity, short exercise sessions led by fitness practitioners and broadcasted on national television at 6 p.m. every day, which was '*initiated by SLOfit and organised by Slovenian public TV, the Slovenian Olympic Committee (SOC) and Faculty of Sport at the University of Ljubljana'* (Morrison et al., 2020, pp.1547). Online platforms (exercise classes streamed on the online platforms such as Facebook and led by professional athletes to encourage exercise at home), School system (PA lessons for children in primary and secondary schools led by physical education teachers via media platforms) and Targeting child health (short exercise clips for children delivered via the national TV in the morning). Though the actions taken during the pandemic showed promising results there have been differences found across the sociodemographic groups (Žlender & Gemin, 2023). People 65+ years of age were less likely to be physically active in nature compared to the younger individuals, however the differences were not as drastic as in some other countries during the Covid-19 (Žlender & Gemin, 2023). Many senior citizens in Slovenia participated in outdoor activities and programmes prior to the pandemic, such as the ‘1000 movements’ and ‘method 23+5’ offered by the School of Health Association and activities in the Daily centres of activities for elderly. These services closed their premises during the Covid-19 outbreak and moved their activities online. Senior citizens reported gardening or household chores as a preferred type of activity during Covid-19 and though other activities have been offered online it is unknown how many seniors did access them and if they had the hardware to do so. Moreover, research into PA levels of different groups of people such as the informal carers during the pandemic in Slovenia has not been yet explored. However, Gomes et al. (2017) found that people who were providing help to another individual for 12 consecutive months showed higher levels of physical inactivity.

CHAPTER THREE

This chapter presents the research methodology and discusses the chosen methodological approach, philosophical underpinning and provides the rationale for the data collection and analytical procedures for the first and second study. Firstly, an overview of the overall paradigm is provided, followed by qualitative, quantitative, and mixed methods methodology subsections, and how the approaches were applied in separate studies.

Methodological approach

Paradigm

A paradigm is a set of shared worldviews and understandings of reality that guide researchers' inquiries (Creswell, 1998). The overall paradigm for this thesis is pragmatism. Pragmatism acknowledges qualitative and quantitative views on the world (Dewey, 1925b/2008) and sees them as equally important. Unlike the post-positivists that claim that *"the world exists apart from our understanding of it*" (Morgan, 2014, pp.1048) and constructivists that state that "*the world is created by our conceptions of it"* (Morgan, 2014, pp.1048), pragmatists believe both of these claims are important part of human experience (Dewey 1925a/2008). The nature of reality is no longer the main criterion for different approaches to research, instead the emphasis is on the continual interaction of beliefs and action. The awareness of the potential difference while acquiring knowledge one way rather than another and producing one kind of knowledge rather than another is integral part of pragmatic inquiry (Morgan, 2014). A pragmatic researcher is aware of the unpredictability of human nature and the possibility that unexpected data might emerge. This leads the researcher to reflect on past experiences and beliefs while choosing the research methods accordingly (Creswell and Poth, 2017). The problem of how much shared knowledge can be accomplished and what kind of shared actions are possible from that knowledge, pragmatists, rather than perceiving such concerns as a barrier see it as an inevitable part of social life, moreover it is considered as ethical because the individuals and the social communities can define the issues that matter most to them and approach them in ways that are the most meaningful to them (Dewey 1925a/2008; Morgan, 2014).

Mixed Methods

Mixed Methods (MM) methodology combines elements of qualitative and quantitative approaches to research *'for the broad purposes of breadth and depth of understanding and corroboration'* (Johnson et al., 2007, pp.123). The methodology has been commonly used in conjunction with a pragmatic paradigm (Creswell and Plano Clark, 2011). The philosophical underpinning of pragmatism offers a way for the researchers to address research questions that could not be answered by using solely a qualitative or a quantitative approach (Doyle et al., 2009). The benefits of combining both methods can result in neutralising respective weaknesses by drawing on the complementary strengths and consequentially, '*provide stronger and more accurate inferences'* (Sparkes, 2015, pp.49). Alongside triangulation, which can enhance the validity of the study, other benefits of using MM methodology include generalisation, completeness, hypothesis development and testing, assisting sampling and instrument development and testing (Sparks, 2015). MM methodology has been widely used in the field of health and healthcare (Creswell & Plano Clark, 2011) due to its ability to not only capture the complexity of human phenomena, but also seek '*to provide hard data for the decision makers who seek to determine health care policy'* (Doyle et al., 2009, pp.184).

Despite the vast benefits of MM methodology, mixing methods has been criticised by methodological purists, who believe that qualitative and quantitative research methods cannot be mixed due to their ontological and epistemological differences (Creswell & Plano Clark, 2011). However, Onwuegbuzie (2002) argues that philosophies underlying research approaches lie on an epistemological spectrum with MM residing in the middle and that rather than on the incommensurability of paradigms, one should focus on their similarities. Teddlie & Tashakkori (2011) add that the researchers should follow a pragmatic approach concerned with the most appropriate methods to answer the research question(s) and redirect away from focusing on philosophical assumptions of ontology and epistemology. However, academics agree on the fact that without sufficient justification for mixing different methods the study can become disjointed and unfocussed. It is vital that the researchers aiming to employ MM design understand the purpose of the approach and what are they trying to achieve (Doyle et al., 2009). With that in mind Creswell & Plano Clark (2011) have defined four types of MM designs which are: the triangulation design (where both quantitative and qualitative methods are given equal weight and occur at the same time), the embedded design (where one of the methods is the dominant one and the other subservient), the explanatory design (where quantitative phase is followed by the qualitative in order to further explain or enhance quantitative findings) and the exploratory design (where qualitative phase forms the second, quantitative phase in order to develop and test instruments and/or theories). However, it is important to note that designs can be more user specific and complex in nature (Johnson & Onwuegbuzie, 2004). For example, a MM design can have multiple stages (i.e. qual → QUAN → qual) and dominance (i.e. qualitative dominant: QUAL + quan or quantitative dominant: QUAN + qual research) (Johnson et al., 2007) which can also emerge during the research process, depending on the conditions and information that is obtained (Johnson & Onwuegbuzie, 2004).

Sampling procedures in MM studies vary based on the research question and research design. The process of sampling strategies for MM design can be complex in general but is especially so '*for studies in which qualitative and quantitative approaches are combined either concurrently or sequentially*' (Onwuegbuzie & Collins, 2007, pp.281).

Besides deciding on the sampling scheme and design, the researchers should determine the appropriate sample sizes for each phase of the study (Onwuegbuzie & Collins, 2007). Sample size together with a sampling scheme "*determines the extent to which the researcher can make statistical and/or analytic generalisations"* (Onwuegbuzie & Collins, 2007, pp.287). In order to detect moderate effect sizes with .80 statistical power at the 5% level of significance Onwuegbuzie & Collins (2007) suggested minimum sample sizes for most common quantitative and qualitative research designs. These are as follows:

- Correlational → 64 participants for one-tailed hypothesis and 82 participants for two-tailed hypothesis.
- Casual-Comparative → 51 participants per group for one-tailed hypothesis and 64 participants for two-tailed hypothesis.
- Experimental → 21 participants per group for one-tailed hypothesis.
- Case Study → 3-5 participants
- Phenomenological → ≤ 10 interviews or ≥ 6 interviews.
- Grounded Theory → 15-20 participants or 20-30 participants.
- Ethnography → 1 cultural group or 30-50 interviews.

In general, however, while conducting quantitative research within the MM design, '*statistical methods are used to calculate the sample size by considering the variability in the estimate of interest and the probability of rejecting the null hypothesis*' (Kaur, 2016, pp.94). And when conducting qualitative research within the MM design, the sample size is based on data saturation, theoretical saturation, and informational redundancy (Onwuegbuzie & Collins, 2007; Kaur, 2016). For instance, a researcher would cease the data collection process when new themes would no longer emerge – reaching data saturation. Due to the complexity of MM studies in comparison to the monomethod studies Onwuegbuzie & Collins (2007) suggested following seven steps to sampling process: '*a) determine the goal of the study, b) formulate the research objective(s), c) determine the research purpose, d) determine the research question(s), e) select the research design, f) select the sampling design and g) select the sampling scheme*' (Onwuegbuzie & Collins, 2007; pp.290).

To address the research question regarding the PA and well-being perceptions of informal carers of people with dementia a qualitative dominant (QUAL → quan), sequential exploratory design has been implemented. The researcher relied on a qualitative, pragmatic '*view of the research process, while concurrently recognizing that the addition of quantitative data and approaches are likely to benefit most research projects'* (Johnson et al., 2007, pp. 124). The data was collected sequentially, meaning that the qualitative data collection phase and analysis was conducted before the quantitative data collection phase and analysis (Creswell & Plano Clark, 2011). This resulted in the theoretical underpinning of the PA and well-being perceptions of informal carers of people with dementia, which was then further tested through quantitative methods, enabling the generalisation of the qualitative findings (Bowling & Ebrahim, 2005). Data integration stage occurred in the interpretation stage of the whole thesis (Creswell, et al., 2003).

Qualitative Methodology

Qualitative research is a broad term consisting of various research methodologies aiming to describe and explain different dimensions of human lives and experiences, which could not be achieved by statistical analysis or quantification (Fossey et al., 2002). Though quantifying qualitative data is possible, every effort should be made to ensure that the narrative and the context of qualitative work is not lost in the process (Tenny et al., 2022). Employing qualitative research methodologies is appropriate (but not limited to) when the researcher is aiming to attain a deeper understanding of *'individuals' or groups' subjective experiences of health and disease*' (Fossey et al., 2002, pp.718).

When conducting qualitative research, *'the researcher is the main data collection instrument*' (Teherani et al., pp.669), which means that the researcher aims to answer the question why specific events occurred focusing on what they might mean to the individuals studied (Teherani et al., 2002). Qualitative data can be collected by following different methods such as structured, semi-structured or unstructured interviews, focus groups and participants or non-participants observations (Creswell, 2009). Though interviews and focus groups are the most popular methods for attaining qualitative data, interviews, mainly semi-structured or unstructured allow to delve deeper into social and personal matters and are appropriate to explore sensitive topics (DiCicco-Bloom & Crabtree, 2006; Tenny et al., 2022). Discoursing with informal carers of people with dementia about their health, quality of life and perceptions of care can potentially be a highly sensitive topic, which may be better discussed in a private setting rather than in a group. Moreover, as people with dementia are highly dependable on support provided by their carers at all times, it would be extremely challenging to arrange a suitable time, date and location to gather a group of informal carers at once. Therefore, unstructured interviews were considered as the most appropriate method for data collection in the first study. Even though semi-structured interviews are guided by a prompt sheet consisting of key questions helping to narrow the focus on the areas of interest, unstructured interviews offer a certain level of flexibility. They allow *'the researcher to follow the lead of the interviewee into how they construct particular phenomena, pursue emergent themes and thus gain new insights*' (Saks & Allsop, 2007, pp.75). Unstructured interviews have been used as a favoured data collection method in research exploring health and health care, as well as perceived as *'essential to the development of health policy and practice'* (Miczo, 2003; Saks & Allsop, 2007, pp.74).

In order to ensure the trustworthiness of the qualitative research and minimise researchers' bias, the application of standards of rigor is paramount (Johnson et al., 2020). Lincoln and Guba (1986) describe four well-established criteria for evaluating the quality of the qualitative research, which are: Credibility, Transferability, Dependability and Confirmability (Tenny et al., 2022)

The concept of credibility in qualitative work refers to the accuracy of the findings produced. Employing well thought procedures, such as triangulation and peer examination can help evaluate the credibility in qualitative research (Creswell, 2009). In the first study as a part of this PhD the following strategies were employed; first the researcher established a familiarity with the context and cultural background of the informal carers and made sure they were initially approached by the group coordinators rather than the researcher herself. This gave the participants an opportunity to read the Participant Information sheet in private and not feel obliged to participate. Only informal carers interested in taking part were included in the study. Moreover, during the interviews the anonymity, confidentiality and the withdrawal process were frequently repeated by the researcher making sure the participants were reminded of the research procedures. The researcher led a reflective journal throughout the research process critically reflecting on the literature reviewed, choice of the research methodology, relationship with the participants and others, tacit knowledge, and the overall experience. The interview transcriptions and the audit trail were reviewed by the researcher's supervisory team and the stories gathered during the interviews were read and confirmed by the interviewees in order to ensure the data collected was consistent with the findings.

Transferability is a concept concerned with the extent to which the research findings can be transferred to other contexts and situations (Given, 2008). To evaluate the level of transferability in qualitative research 'thick' or 'rich' descriptions can be used, which allow the readers to interpret the findings and draw conclusions themselves (Tenny, 2022). In the first study of this PhD transferability was addressed by providing detailed description of the research context, participant characteristics and research design as well as using purposeful sampling in order to recruit the participants (Given, 2008).

Dependability addresses the consistency and replicability of the research findings, and acknowledges the fact that in qualitative research *'the research context is open to change and variation'* (Lincoln & Guba, 1985; Given, 2008, pp.209). In order to assure dependability, the research design and all the alterations to it should be described in great detail, allowing other researchers to replicate the study and develop an understanding of the methodological approaches used as well as their effectiveness (Guba, I981). In the first study as a part of this PhD dependability was addressed by providing a detailed description of the methodology and the inquiry audit (Given, 2008).

Confirmability, often associated with objectivity in quantitative research represents a way of verifying that the phenomenon studied, and the meaning participants assign to their experiences are understood from a perspective of a research participant and not altered due to researcher's bias (Lincoln & Guba, 1985). Even though unique perspectives each researcher brings to the study cannot be denied, it is paramount that the researchers acknowledge this and use suitable *'methodological practices to respond to those biases'* (Given, 2008, pp.112). Confirmability can also be expressed by clearly describing the process of data collection and analysis, preserving an audit trail for independent reviewers, and asking selected participants to review the codes/categories/themes *'and meaning-making process in order to determine whether the researcher's interpretations are consistent with their perceptions'* (Given, 2008, pp.112). To further diminish the researcher's bias, *'qualitative researchers embrace the notion of reflexivity'* and lead a reflective journal throughout the data collection, analysis, and interpretation process (Given, 2008, pp.754). Before conducting the interviews for the first study as a part of this PhD the researcher reflected on her own experiences of physical activity, well-being and quality of life, alongside the assumptions of the possible outcomes.

There are different approaches to qualitative research which form a framework that shape research question/s, method/s used to attain data and the data analysis process. For the purposes of the first study, perceptions of physical activity, well-being and quality of life of informal carers of people with dementia were embedded in their life history, cultural background, age, social and familial support, and their relationship with the person with dementia, which influenced their experience as caregivers. Therefore Life-course approach has been used as an overall theoretical perspective and narrative inquiry as a method in order to attain data.

Even though research looking into physical activity, well-being and care burden of informal carers has been explored to a great extent, current figures show that physical activity adherence and overall well-being of informal carers remain low (^{1}Carers UK, 2022). Using other qualitative approaches such as interpretative phenomenological analysis, thematic analysis and grounded theory might offer a deeper understanding of the phenomenon, such as how informal caregivers perceive their role, physical activity and overall health, and uncover theories grounded in the data collected, however it fails to consider potential intergenerational differences and life trajectories across the life span, influencing perceptions and actions of the informal caregivers of people with dementia. Moreover, according to the systematic reviews of international (Lindsay et al., 2022) and the UK literature (Horne et al., 2021) on the prevalence of physical activity among informal carers the results were conflicting, suggesting the need for further research to better understand the complexity of informal caregivers' lives, physical activity behaviours and the associated health outcomes. Life-course approach offered a way to explore the influence of physical, psychological, social, and historical trajectories on how informal carers of people with dementia make sense of their experiences and consequentially take actions. It recognises that *'all stages of person's life are interactively intertwined, with the lives of other people in the society, and with past and future generations of their families'* (WHO, 2018, pp.1). The approach is not novel in the field of exploring chronic disease epidemiology, infectious diseases, ageing, longevity and wider notions of health and well-being (Ben-Shlomo & Kuh, 2002). However, it offers a new perspective on the lives of informal carers of people with dementia and their perceptions of physical activity and health.

Quantitative Methodology

Quantitative methodology is, in contrast to the qualitative based on statistical relations between the variables which are, in most cases numerical data (Alasuutari, 1995) or 'their *statistical interpretations under a reductionist, logical and strictly objective paradigm'* (Leung, 2015, pp.324).

Research rigour in quantitative research is attained through measurement of validity, reliability, and generalisability (Heale and Twycross, 2015). *'Validity is defined as the extent to which a concept is accurately measured in a quantitative study'* (Heale and Twycross, 2015 pp.66). The level of reliability tells how dependable, consistent and/or repeatable the study's data collection process, analysis and interpretation of the data collected is (Given, 2008). Generalisability relates to the sampling procedures (Garg, 2016) and the analytical process *'to determine the likelihood that the study's results might have occurred by chance'*, and offers for the findings to be generalised to a wider (target) population (Given, 2008; pp.372).

The target population is a group of individuals whose characteristics are an object of interest to the researcher and upon which the researcher aims to draw conclusions. The study population, however, is a fraction of the target population and is the population which is actually included in the study (Martínez-Mesa et al., 2014).

The most common and applicable reasons to justify the sample size needed to attain informative outcomes from a study are based on several factors such as intention to study (almost) entire population, available resources, desired level of accuracy and statistical power, and heuristics, meaning that the researcher chooses the sample size based on a rule/norm previously stated in the literature (Lakens, 2022). At times, the researcher can have no specific reasons to choose a certain sample size *'or does not have a clearly specified inferential goal and wants to communicate this honestly'* (Lakens, 2022, pp.2). The approaches, including the 'no justification' approach '*are not mutually exclusive and multiple approaches can be considered when designing a study*' (Lakens, 2022, pp.2). The value of the data collected, however, does not solely depend on the sample size justification, but '*on the extent to which the final sample size allows the researcher to achieve their inferential goals*' (Lakens, 2022, pp.2). The informativeness of the data collected and the sample size studied also depends on the details of the research question the researcher aims to answer.

In order to detect potential effects of the interventions, researchers conduct the significance testing, which is usually interpreted by the *p*-value. In general, the *p*-value shows the, *"compatibility between the observed data and what we would expect to see if all the assumptions used to compute the p-value were correct"* (Freire et al., 2019, pp.303). The value presents the probability that an observed difference is due to a random chance when the null hypothesis is true and presents the index for the strength of the evidence for the tested hypothesis against the null hypothesis. However, the *p*-value is used for more than just testing the null hypothesis, it tests all the assumptions. For example, if the researchers aim to test the difference in a between-group comparison using the t-statistic or a Chi-squared statistic the p-value presents, '*the probability that the difference would have been at least as large as its observed value if every model assumption (including the null hypothesis) were true'* (Freire et al., 2019, pp.303; Greenland et al., 2016). The *p*-value is usually set to <0.05, meaning that the null hypothesis is rejected if the probability of a Type I error is <5%.

P-values are closely linked to the confidence intervals, and even though a *p*-value can determine the strength of the observed findings, it cannot provide information on the precision of the results (Flechner & Tseng, 2011). The confidence interval on the other hand '*can be calculated around the point estimate of the result to provide a range of values within which the true values are certain to exist with a given level of confidence'* (Flechner & Tseng, 2011, pp.533). Meaning that we can use the confidence intervals to draw conclusions regarding the underlying population (Hazra, 2017). The narrower the confidence interval is, the more reliable the '*estimation of the underlying population parameter is'* (Hazra, 2017, pp.4126). As the p-values are generally accepted *at a p-value of <0.05 or 5%, confidence intervals are frequently calculated at a confidence level of 95%* (Flechner & Tseng, 2011, pp.533). Implying that if the estimation process were to be repeated continuously with random samples from the same population, '*then 95% of the calculated intervals would be expected to contain the true population mean'* (Hazra, 2017, pp.4126; Tan & Tan, 2010). The confidence interval is chosen by the researcher and can be calculated for any level of confidence, but mainly varies between 80 – 99% depending on the level of the precision of the estimate required.

One of the most commonly used quantitative data collection methods in social research are questionnaires, in which participants are invited to complete a set of questions aiming to obtain individuals' opinions regarding a particular topic or issue/s (Roberts, 2007; Shiraev & Levy, 2010). Questions included, could be open-ended, multiple-choice, or close-ended. In contrast to closed-ended and multiple-choice, open-ended questions allow participants to express and explain their perceptions and feelings (Shiraev & Levy, 2010). However, answers obtained via open-ended questions are challenging to interpret quantitatively. Moreover, certain participants such as people with little language proficiency might find it difficult to articulate their ideas (Shiraev & Levy, 2010).

The questionnaires can be completed in a direct or indirect way. Direct approach allows or requires from the researcher to maintain a direct communication with participants and is able to provide feedback or further explain questions asked (i.e. face-to-face and telephone surveys) (Shiraev & Levy, 2010). Indirect approach does not involve any direct communication between the researcher and the participants. The questions are typically written down and can be handed to the participants in person, sent via post, emailed, or can be available online (i.e. self-administered questionnaires) (Shiraev & Levy, 2010). While handing out questionnaires in person, might not be the most time and cost-effective option, it allows the researcher to reach population that might not have access to or is not proficient in technology use, such as elderly (Roberts, 2007; Shiraev & Levy, 2010).

In order to explore whether the informal carers' subjective interpretations from the first study could be applied to a larger population, the second study used a questionnaire and thereby adopt an associated objective and universal ontology. The questionnaire was constructed of a validated Carer Well-being and Support Questionnaire (CWS) designed specifically for carers of people with a mental health problem or dementia, The Relationship Questionnaire, and questions about exercise history and health behaviour (AARP, 2002).

The CWS consists of different parts aiming to attain carers' aspects on their general well-being (Part A: Well-being), their satisfaction with the support they may receive (Part B: Support), their need for support (Part C: Your Needs) and their personal characteristics (Part D: Background Information). The questionnaire has strong positive rating of internal consistency, content validity, structural validity, and moderate positive rating of reliability (Quirk et al., 2012). It has been recognised as the most appropriate instrument to assess the quality of life of informal carers of people with dementia (Dow et al., 2018). Findings from the first study suggested there might be differences in relationship styles between different age groups of informal carers and how they perceive their role as carers and consequentially provide care for their loved ones with dementia. Therefore, a well-established, 4-item self-report Relationship Questionnaire was added to measure adult attachment style (Bartholomew & Horowitz, 1991; Morales-Vives et al., 2021). The questions about the exercise history asked the informal carers to rate their exercise level for each age range (from 15 to 81+ years of age), inquired about their current and past physical activity participation, and the potential influence of an exercise programme on their caring role. They also had to answer questions about their exercise knowledge (i.e. how often do you think a person your age needs to exercise to be healthy?), to what level do they agree with statements about exercise (i.e. It is hard for me to fit exercise into my life) and rate how important they think exercise is to their overall health.

CHAPTER FOUR

Study 1

Perceptions of physical activity of carers of people with dementia through a life course approach

Abstract

Background: Informal carers, such as family members and relatives, have a crucial role in caring for people with dementia. However, due to one-sidedness of the condition the caregiving role negatively impacts caregivers' health, well-being, and quality of life. It is well known that they would highly benefit from a regular physical activity, however physical activity participation amongst carers of people with dementia remains low. This study looked at the complexity of life-course perspectives of carers to understand how caring has influenced their life and well-being and how it might reveal potential solutions to increase exercise uptake amongst this population.

Methods: This study adopted 'Life-course' theoretical perspective and used narrative inquiry as a method. Six participants (4 females and 2 males) were recruited from weekly dementia cafés, peer support project groups, carer support groups and charities across London UK. Eligible participants were non-paid caregivers (either family members, relatives, or friends), 50 years of age or more and providing care for an individual diagnosed with dementia at least 5 hours per day.

Results: After using Frasers analytical framework, four major themes emerged from narrations: 'Physical activity and Well-being, 'Sacrificing time', 'Changes in Help' and 'Plans for Future'. Taking into account the accumulation of the underlying social, behavioural, and biological processes that drove the impact of the life course on carers' health, findings suggest that there are three distinct groups of carers: partners 70+ years old, partners 60+ years old and offspring 50+ years old.

Conclusion: The era carers were born in and consequentially the relationship they had with the care receiver significantly influenced their perceptions of physical activity and actions they made while providing care. Acknowledging and understanding the differences between the 3 groups adds a greater depth to the current knowledge of physical activity barriers and facilitators informal carers face and potentially offers a way for the carers to change their behaviours regarding physical activity and build upon a health-promoting lifestyle.

Introduction

The ageing population in the UK is rapidly increasing. According to the Office for National Statistics (2022) there were 1.7 million individuals aged 85 years and more in mid-2020 and the numbers are predicted to double by mid-2045. Advanced age is highly correlated to an increased susceptibility to different diseases, including dementia (Townsend, et al. 2014). Over the past few years outpatient appointments, hospital admissions and inpatient episodes for dementia have increased significantly (Age UK, 2017). This has led to a greater need for informal health care. In England, there are currently over two million elderly informal carers who provide extensive care to older family members. This can put a lot of strain on carer's physical and psychological health. It has been suggested that due to the degenerative nature of the disease, providing care to a person with dementia is extremely challenging (Alzheimer's Association, 2007).

Informal carers, such as family members and relatives, have a crucial role in caring for people with dementia. Without their support, *'people with dementia would have a poorer quality of life and would need institutional care more quickly'* (Brodaty et al., 2009, pp 217). However, the caregiving role impacts carer's levels of stress and quality of life. The disease progression brings higher demands on care needs. From the milder - forgetting recent conversations to becoming delusional or even aggressive and becoming completely dependent in the last stage of dementia (Alzheimer's Society, 2015; Burton, and Sumukadas, 2010). Restricted free time, being unable to leave the person with dementia (Losada et al., 2010) and facing the chronic stress of anticipatory grief (Holley et al., 2009) are just some of the factors that prevents the carers from attending normal social and recreational activities. Accordingly, Lacey, McMun and Webb (2018) found that caregiving was associated with higher adiposity among men and women caregivers compared to adults not providing care and was particularly high in women 65+ years of age providing care and working full-time. These factors have been linked to depression, physical performance difficulties and health related symptoms (Mausbach et al., 2011).

This study looked at the complexity of life-course perspectives of carers to understand how caring has influenced their life and well-being and how it might reveal potential solutions to increase exercise uptake amongst this population.

The main aim and objectives were:

- To contextualize the complexity of lives of informal carers of people with dementia and to investigate how exercise and PA have played a part.
- To gather life course views and perspectives on PA of informal carers of people with dementia.
- To understand how has becoming a carer of a person with dementia influenced a carer’s life, PA, well-being and their relationship with their loved one with dementia.

The research question was: what are physical activity and well-being perceptions of carers of people with dementia through a life course approach?

Methodology

This study adopted a ‘Life-course’ theoretical perspective within an interpretive paradigm. The ontological approach was constructionist because the research question lies within a social construction of truth (Creswell, 2011). The epistemological perspective was transactional/subjectivist because the researcher and the individuals were interactively linked (Guba et al., 1994) and the method used was Narrative Inquiry.

Narrative Inquiry was chosen because people organize and share their life experiences in stories and choose to connect events in a way that is meaningful to them. They interpret the past rather than reproduce it as a chronologic set of events (Riessman, 2003), which makes narrated stories diachronic and unique to the individual (Bruner, 2016). Through storytelling, people express emotions, embody their identities, societies, and culture, which illuminates deeper meaning to the content told and not simply the content to which language refers (Riessman, 2000). Even though the stories represent partial, selective, and imperfect reality, they offer a new way of looking at and understanding individual accounts, ‘*privileges positionality and subjectivity*’ (Riessman, 2003; pp 2).

Structural approaches to lived lives require examination of syntactic and prosodic features of talk, therefore they are suitable for studies conducted with smaller numbers and detailed case studies comparing several narrative accounts (Riessman, 2003). In depth analysis of the stories can result in building theories that relate to language and meaning which could otherwise be overlooked. It is the investigators decision as to how detailed description of the text would be necessary.

This study utilised Alwin’s (2012) five principle stance on life course: life-span development, agency, time and place, timing and linked lives. The life-span development approach looks at individuals’ life span and the '*processes of growth involving both gains and losses'* (Alwin, 2012, pp.208) withing the multidimensional social and cultural contexts. This view not only perceives ageing as a time-dependent procedure but as a multidirectional and a dynamic process of change development unique to each individual. It is also characterised by an understanding that '*new situations encountered in adulthood are shaped by earlier experiences and their attached meaning'* (Black et al., 2009, pp.2), implying that how informal carers of people with dementia perceive their role, physical activity and well-being will be shaped by their previous experiences and relationships with providing care, health and social care, and physical activity. The notion of agency views humans as active contributors to the course of their lives and not merely passive recipients of a predetermined life course (Black et al., 2009). People shape their own lives '*through the choices and actions they take within social structures and historical circumstances'* (Alwin, 2012, pp.212).

Agency has a notable significance in the context of informal care. Family members, relatives and friends make a life changing decisions while choose to provide care to their loved ones with dementia. Though when considering agency, one needs to distinguish between the long-term goals, short-term strategic considerations and decisions made in acute situations (Kok, 2007). Another notion of Alwin's principle on life-course is time and place (Alwin, 2012). The principle explains that the lives of humans are intertwined and shaped by historical circumstances/events individuals experience over their life span. Due to changes and adaptations in societal rules, norms, beliefs, political arrangements, health, and social care etc. '*every birth cohort has a unique set of constraints and opportunities that shapes the courses of its lives'* (Kok, 2007, pp.6). Analysing narrations of informal carers of people with dementia through a life-course approach might explain connections between the demographic studied, their life courses and economic, institutional, and cultural changes (Kok, 2007). The context of timing as one of the principles of life-course points out that the consequences and the impact of the individual experiences, historical events and transitions are depended on their timing in people's lives (Alwin, 2012; Kok, 2007). '*Each life course transition is embedded in a trajectory that gives it specific form and meaning'* (Alwin, 2012, pp.212). For example, timing might affect informal carers' responses to providing care. Life-course theory suggests that informal carers' pre-existing behavioural patterns and development will shape how they contend with the out-of-sequence event, such as their loved one being diagnosed with dementia (Black et al., 2009). The last principle of linked lives explains that people's lives are lived interdependently and reflect sociohistorical influences (Black et al., 2009). Relationships between family members, relatives, friends, and a wider network of social relations influence how people interpret life events (Carr, 2018). The lives of partners, spouses and adult children are linked in a unique way, "*shaping and being shaped by each other in the continuing process of human development"* (Black et al., 2009, pp.3). Nonetheless, becoming an informal carer of a family member or a relative with dementia is complicated by the unforeseen and unknown, which might affect the relationship dynamic between the caregiver and care receiver.

The study also incorporated Heikkinen's (2011) "Accumulation model", which suggests that life events compound or accumulate and modify agency. In terms of health behaviour, the model implies that some of the factors that can put an individual at greater risk of contracting/developing different chronic conditions or enhancing good health accumulate over the course of life (Heikkinen, 2011). For example, poor nutrition and living conditions during childhood, lack of physical activity and unhealthy habits (such as smoking) in adolescence might lead to various health problems in adulthood and old age. Physical activity adherence and perceptions of well-being among informal carers of people with dementia might therefore vary depending on the carers' previous socioeconomic status and other social and demographic factors at all stages of the life-course (Heikkinen, 2011).

Sample

Six participants (4 females and 2 males) were recruited. According to Fraser (2004) studies with only a few participants can produce many "stories" and offer highly detailed material. Similarly, Morse (2000) states that there is an inverse relationship between the number of participants and useable data obtained from each participant, and therefore an in-depth interview of only 6-10 participants for narrative inquiry is reasonable.

The sample was recruited from weekly dementia cafés, peer support project groups, carer support groups and charities across London, UK. Eligible participants were informal caregivers (either family members, relatives, or friends), 50 years of age or more and providing care for an individual diagnosed with dementia at least 5 hours per day. A short presentation was delivered and participant information sheets as well as consent forms were given to people, who expressed interest in participating in the study.

According to Tarlow and Mahoney (2000) targeting and recruitment of any special population, such as elders and minorities is known to require more time, resources and can be exceptionally challenging. In contrast to the clinicians, who might have direct access to the target population of dementia caregivers, other investigators often face difficulties in obtaining an approval to a referral site, not due to the nature of the research but due to the needs of the host institution's gatekeepers own research agenda (Dowling and Wiener, 1997; Tarlow and Mahoney, 2000). Furthermore, smaller organisations, agencies supporting ethnic minorities and carer support groups frequently reported being overwhelmed with requests from outside professionals looking for research participants and declining all the requests for research referrals (Tarlow and Mahoney, 2000).

Ethics

In order to overcome the ethical challenges of working with those who are supporting vulnerable adults, different approaches were used (Lee & Renzetti, 1990). To minimize potential harm, psychological distress and discomfort to the participants, interviews took place in a quiet, private room at a familiar setting or with the participant's permission at their home. In case the participants became upset, the interview was immediately stopped, and they were offered a short break. If the participants were willing to continue with the interview after a break, the interview recommenced otherwise it was terminated. Data collected until the termination was analysed unless the interviewees requested for the data to be withdrawn. In that case those recordings were destroyed. Before the start of the study, participants received an information sheet with a detailed description of the procedure. Anonymity was assured and all names were removed during transcription and replaced by pseudonyms. Particular attention was placed on researcher reflexivity. While interviewing and analysing narratives the researcher was aware of her role as a co-author, the potential to facilitate or inhibit the narration and the devices storytellers used. The researcher acknowledged her part in affecting the stories, therefore an extensive self-reflective practice in a form of a reflexive journal was done (Lincoln and Guba, 1985) to maintain self-reflection in practice while conducting the interviews.

Data collection

The interviews took place in a quiet, private room at the organisation where people with dementia and their carers participated in a weekly dementia cafe. The researcher was known to the participants, which made them comfortable and less reserved. Participants' categorical characteristics were obtained followed by unstructured, conversational interviews. The interviews started by asking the participants to describe their perspectives and experiences with physical activity throughout their lives and to provide examples. Storytelling was encouraged by asking broad, open-ended questions in order to collect rich data. However, quite often participants referred to past life experiences while explaining their current well-being and physical activity perspectives without being prompted by the interviewer. The interviews were recorded and lasted for approximately 30-60 minutes. Topics covered carers' perceptions of physical activity and well-being and their experiences with care. Intonations, facial expressions, and body language were recorded contemporaneously, with notes taken shortly after each interview and incorporated in the process of transcription. Recorded interviews were transcribed verbatim shortly after they were conducted.

Data Analysis

Data was analysed according to Fraser's (2004) phases 3 to 6 and incorporated Alwin's (2012) 5 life-course principles. In cases where stories were not so obvious, the researcher focused on the six components identified by Labov (1972): abstract (a summary of the story), orientation (sets the scene), complicating action (what happens next), evaluation (the human consequences of the event), resolution (gives an ending), and coda (returns the story to the present) (Kim, 2015). According to Kim (2015) these form a good starting point for defining what stories are.

Stories were compared laterally against a significant trajectory point mutual to all interviewees, such as their loved ones being diagnosed with dementia. The researcher paid attention not only to content but also to how the stories were told; whether they circumvented a specific theme, described an experience, or tried to make a particular point (Fraser, 2004). Subsequently, stories were examined in order to identify their intrapersonal, interpersonal, cultural and structural aspects. Then the stories were categorized based on the major themes common to all interviewees. Within each theme, stories were grouped by time period, either before or after caregivers' spouse or parent was diagnosed with dementia. Participants have shared their own experiences and those from other carers. How they might differ and why it is called 'shadowed data'. Morse (2000) reported that using shadowed data is very important because it provides the researcher with an idea *"of the range of experiences and the domain of the phenomena beyond the single participant's personal experience"* (Morse, 2000, p.4), which enhances the analysis.

In order to see if there are any patterns and connections between different stories and narrators, the researcher noted narrators' age and relationship status with the care recipient. Finally, thematic similarities and differences were compared vertically and horizontally across individual accounts and focused down on the research question by looking across all events. In order to keep stories linked to narrators, they were marked with pseudonyms.

Findings and Discussion

Table 1 shows characteristics of the participants such as, their relationship with the care recipient, their age, care recipient age, diagnosis type and diagnosis duration. Table 2 illustrates each participant's biography based on key reported events.

Table 1: Participant Characteristics

	Relationship with the care recipient	**Age**	**Care recipient age**	**Diagnosis type**	**Diagnosis duration**	**Pseudonym**

1	Husband	83	80	ALZ	5 years	*Richard*
2	Wife	80	83	VD	5 years	*Beth*
3	Husband	75	70	ALZ	6 years	*Bob*
4	Wife	64	73	ALZ	4 years	*Fran*
5	Daughter	55	94	ALZ	6 years	*Abby*
6	Daughter	54	92	VD	10 years	*Anne*

*ALZ: Alzheimer's disease *VD: Vascular dementia

Table 2: Life Outline

	Life outline
Richard (husband, 83 years old)	*Richard was born during the war to a "working class family" and grew up in London. Richard's father drank and because of that they struggled financially. As a child he was sent to a farm, where he had to work and took care of his younger brother. After the marriage, Richard and his wife started planning their own, better life. They worked really hard and saved money. After a while they bought a house, in which they still live in. In his 40s Richard had to take care of his mother, who was bedbound. Moreover, one of his daughters was born with special needs and required additional attention. Nevertheless, with Richard's and his wife's help both of the daughters finished college and they live independent lives. Richard was always working hard, maintaining the house, and taking care of his family. He is very proud of what he has managed to achieve. He was always body aware, maintaining a healthy weight but he never went to a gymnasium. He had more important things to do, taking care of his family, house, and work.* *Richard is now taking care of his wife who has dementia. Seeing his partner fading away is very hurtful for Richard. He is trying not to dwell on it. He stays strong and manages everything like he used to, however he finds it very hard. Richard's priorities are very clear. He will take care of his wife and family as long as he can manage. One of his fears is dying before his wife does.*
Beth (wife, 80 years old)	*Beth was born during the war and grew up in London. Her father was a sailor and left when Beth was four years old. She was left on her own most of the time, as her mother had to work night shifts as a nurse. Beth describes herself as being very active when younger; going to the cinema and "just doing stuff". As a teenager she was introduced to ballet by her sister and later on that become her profession. She did a lot of touring with the company and attended various performances and events. Dancing was a big part of her life, and she really enjoyed the whole experience. However, she never perceived dancing as a "tool" to keep her fit and healthy. She describes it more like a holistic experience and a good job opportunity where she hadn't had to work very hard and at the same time enjoy the luxurious life of being a ballerina (make-up, nice costumes, being on stage, meeting various artists etc).* *When Beth's career ended, she never considered taking up dancing just for fun or doing any other physical activities. However, she continued going to the theatre. It took her back to the times when she was a part of that world. She also became a "Friend of Covent Garden". That is a membership, which allowed her to enjoy performances "with the crowd who understood".* *When Beth started caring for her husband, she had to stop her membership and focus mainly on her husband's needs, which she perceives as unfair. She is*

	missing the theatre, and she gave up trying to find a way to enjoy it again. Now Beth gets out of breath very quickly and cannot manage things as she did before. She engrosses herself in gardening, mainly because it makes her think of something else and keeps her away from dwelling. Beth says she would rather die in the hospital than at home.
Bob (husband, 75 years old)	*Bob grew up in Colorado. He has a past he did not want to talk about, but he revealed that he was not always a good citizen and that this is his second marriage. Bob says he was active when younger like all the rest of the kids and young adults. They played basketball and enjoyed bowling, however that was something everyone did. No one perceived it as "health investment".* *After he met his wife, he moved to London and established his life here. He was no longer participating in sports but found other activities like going to the cinema, travelling, and doing church activities with his wife. He enjoyed walking around London. Every year he travelled to America in order to see his family and friends, which meant a lot to him.* *Since Bob started caring for his wife, he gave up his activities and focus on providing care, and purchased activities his wife would enjoy. He is very clear about his priorities, and his personal wishes are not one of them. He even describes it as selfishness. The only thing he is concerned about, is that he might not be able to visit his family and friends in America this year. Bob very clearly expresses that he would require help. He would like to share his experiences with other carers, and potentially get advice and/or support on situations he struggles the most with.*
Fran (wife, 64 years old)	*Fran had a very full and active life. She was traveling a lot, and she was active in the community. Fran's husband was doing a lot of sports, whereas she described herself as being more or less an observer. Fran recently retired and she imagined her life to be different at this point. She imagined that she would be traveling with her husband, go to workshops and courses she always wanted to try and that she would be able to "slow her life down".* *Fran's husband was diagnosed with dementia in 2014 and two years later he caught sepsis, which made him dependent on Fran. She has to assist him with the simplest things, which has curtailed her life to a huge degree. Everything she does needs to be carefully planned. There is no room for spontaneity. Fran's family lives abroad and she used to visit them every year. Due to her husband's condition, she could not visit them. During that time her mother passed away. From time to time, Fran gets help with transport from her children, however they have their own families and are busy with work. Moreover, she helps them with school runs. Fran is aware that she has to take care of her own health and not merely address her husband's needs. She is attending conferences and groups for carers to attain as much information as she can. She acknowledges the fact that she has to be physically active and take breaks in order not to get overwhelmed with the situation. At the moment Fran is not receiving any professional help and can afford only short breaks. She is aware that her husband's condition will get worse and therefore she is planning to have a closer look at relevant services in the future.*
Abby (daughter, 55 years old)	*Abby's parents were very active when younger. They loved dancing and so did Abby. They never had professional training but when there was a chance to dance, they danced. As a child Abby did ballet and gymnastics, and absolutely loved it. Later she explored dance by attending different workshops and performances abroad. Even though Abby was always active, she became more "health-aware", due to a "healthy environment trend" during her work in mental health. She has been suffering from chronic fatigue since 1993.* *Abby now lives with her mother who has dementia and is her full-time carer. Abby takes time for her activities and perceives it as very important and beneficial for her health and well-being. She goes swimming, takes long walks in the park, visits her family, and friends, and goes traveling. Abby says that it is*

	important that she feels nourished otherwise she would not be able to provide good care. Also, Abby tells that her mother would want her to go and enjoy her life. Abby is in a good relationship with her sister, who helps her with the administrative part of care, orders medication etc. She is also receiving financial support.
Anne (daughter, 54 years old)	*Anne grew up in the countryside and was very active as a child. Her parents introduced her to horse riding, which she still does. She always had dogs and various other hobbies. She enjoyed spending time in nature, travelling with her partner and meeting friends. She loved her work, which required a lot of planning and organising.* *After Anne's father passed away and her mother's condition got worse, Anne moved back to her parents' house in order to take care of her mother. In that period Anne's partner died and she had to leave her job in order to become a full-time carer. Anne is aware that she has to take care of her own health in order not to resent the situation and is therefore perusing all the activities she enjoyed in the past. She still has a horse, dogs, and meets with her friends. Good planning, professional care assistance and help from her brother gives Anne time to do activities she enjoys.* *Recently, Anne met her new partner, decided to get married, sell the house, and move to the seaside. She tells that she did everything there is for her mother, however she is not getting any younger and has to think of her own life as well. Moreover, her mother is being looked after and she would want Anne to enjoy her life.*

Findings

Four major themes emerged from narrations: 'Physical activity and Well-being, 'Sacrificing time', 'Changes in Help' and 'Plans for Future'. Carers' perceptions on the themes before and after their partners' or parents' diagnosis were outlined in table 3 and discussed below.

PHYSICAL ACTIVITY AND WELL-BEING: The Impact of Physical Activity as a Youth on the Current Sense of Well Being

Table 3 Physical Activity Perceptions Before and After Diagnosis

	Before diagnosis	After diagnosis
Bob (husband, 75 years old)	-Being active meant playing basketball and bowling with friends, going to the cinema, travelling, going to church, and walking around London -Playing sports was something normal, what everyone in the community did	-Being active means providing care, going to church and dementia clubs with his wife -Do not know how to do sports anymore and it is not significant
Richard (husband, 80 years old)	-Being active meant working hard, taking care of the family, managing the house and being body aware (maintaining healthy weight) -Physical activity was not significant	-Being active means providing care, doing shopping, sudoku, helping the neighbour, managing the household and being body aware (maintaining healthy weight) -Physical activity is not significant
Beth (wife, 80 years old)	-Being active meant playing in the neighbourhood, going to the cinema and	-Being active means watching television and gardening

	theatre, and visiting public pool with friends -Being active was something ‘normal’ -Dancing ballet professionally did not mean being physically active -Not thinking about physical activity	-Not thinking about physical activity
Fran (wife, 64 years old)	-Being active meant being involved in the community, working, travelling, and supporting husband while he was participating in sports -Not being health aware	-Being active means doing chair yoga, going to the cinema and theatre, and meeting with friends. -Being physically active and doing preferred activities is extremely important for one’s health and well-being, and affects the quality of care -Being health conscious
Abby (daughter, 55 years old)	-Being active meant doing gymnastics in a school club, dancing ballet, and travelling -Was introduced to activities by parents -Became health conscious while working as a psychologist -Suffered from chronic fatigue	-Being active means walking, dancing, and travelling -Attending swimming classes arranged by carer’s centre -Being active and doing preferred activities is important for one’s health and well-being, and crucial while providing care -Being health conscious
Anne (daughter, 54 years old)	-Being active meant horse riding, walking with dogs, travelling, meeting with friends, and having hobbies -Was introduced to activities by parents -Was encouraged to be physically active by GP -Being health conscious	-Being active means going horse riding, walking with dogs, travelling, and meeting with friends -Being active and doing preferred activities is important for one’s health and well-being, and crucial while providing care -Being health conscious

In England, two major physical cultural changes affected the participants. The first happened after the Second World War, when pedagogic practice in physical education changed (Kirk, 2006) and the second happened in the 1980s, when physical activity became recognized as a part of a ‘lifestyle’ and developed into an industry. The latter shaped people’s perceptions on physical activity and what they should do (Kirk, 2006). These key social movements were reflected in the stories carers narrated.

Carers 70+ years old were born between 1935 and 1944, an age of austerity. At that time, being physically active was a part of everyday life. Carers recalled they were generally active daily as children, which was different from playing sport. Overall physical activity was considered irrelevant compared to work, socioeconomic status and taking care of the family. Even when work was dancing professionally, it was perceived as a convenient way of earning a living rather than being physically active.

Carer 60+ years old, born in 1954 has similar perceptions of physical activity before her husband's diagnosis. Being active meant working and being involved in the community.

Carers 50+ years old were born between 1963 and 1964, therefore their perceptions of physical activity were constructed when physical activity had been recognised as a "lifestyle". Their parents encouraged them to pursue various activities, such as horse riding, dancing, and gymnastics as 'exercise/sport' events, which they continued with in their adulthood.

> *"Well um… I was always a very lively child… and quite um skilful and I had a good rhythm and um… so we had this club, I mean a group at my school it was only girls and um it was a part of my school and I used to really enjoy gong for that you know and also because my parents were always active, not like sports but you know they went dancing and singing and doing different things so um I guess it was just how we were" (Abby)*

Even though carers 50+ years old were physically active in their childhood, they became truly health aware in their thirties. Due to their working environment and encouragement from health professionals.

> "*I often remember my doctor she used to say to me "oh you know often people used to come in and say: oh, I feel depressed with this and this and this can you give me some tablets?" she'd say "no, go for a walk" hehe yeah go and get a hobby or go swimming or something…" (Anne)*

In order to raise awareness and encourage UK citizens to make healthier life choices Public Health England has encouraged a range of digital technologies and media (Public Health England, 2017, Age of Fear 1986-2005). However useful this might be, older adults found new technology confusing and were less likely to use them (Vaportzis et al., 2017). Their lack of competence in using new technologies created barriers for the benefits of physical activity to reach them. Therefore, carers 70+ years old did not change their perceptions of physical activity and well-being after their partners' diagnosis. Moreover, they did not even think about it. Being active meant mainly providing care, doing sudoku, helping neighbours with shopping, and watching television. A worldview similar to the one they grew up with.

> *"I don't know how to do it anymore (sports) but I do other things… it's good to be around other people when you have dementia so it's good to go we go to church that helps I try to and then we go to another place like this where they uum we eat dinner and um lunch I mean play dominos and memo and listen to music… so I try to do everything to help" (Bob)*

Carers' 50+ and 60+ years of age had grown up with changing perceptions of physical activity and well-being. Carer 60+ years old acknowledged the benefits of physical activity and that post diagnosis she has to keep active as much as possible and not merely focus on providing care. Carers 50+ years of age shared similar perceptions. They tried to keep active as much as possible.

> *"…it's good um the carers centre organised for a course so it doesn't cost anything and that's been tremendously helpful because it just made me say "look here's the encouragement to take care of yourself!" and if I'm swimming I just swim up and down and I mean I've got to a point where I can do up to 40 lengths... I mean I don't achieve it every week because my energy is not so strong every week or maybe I've been doing other things like I've been away now… but I mean if I can mentally I am reborn Yeah…and the walking is excellent! You know um sometimes I would go for a two hour walk… A-a-ah yes lovely…" (Abby)*

and felt that they provide better care if they take care of themselves, even if they were feeling tired, they felt some movement was necessary and beneficial.

> *"you know I have my moments but then I just get on with it otherwise what's the point you know you have to look after yourself otherwise you cannot look after them… yeah who's going to look after them if you end up having a you know… nervous breakdown or feel that you can't cope…you see it's very easy to sit and "oh I can't be bothered I'm to tired" but you have to do that otherwise you just… you're just in in this place um with you and um that's it and whoever you are taking care for… so you just have to…" (Anne)*

The strongest physical activity determinant for all participants was not necessarily the dementia diagnosis, even though there were significant limitations such as time and their responsibilities for the person with dementia, but rather the age of the carer and the social perceptions of physical activity they had grown up with were more significant. The eldest had a view that exercise was part of the everyday, it was undertaking activities of daily living. The youngest had a clear sense of sport and exercise as a separate activity, no doubt general social values absorbed in youth. The middle group showed the transitionary views between the eldest and youngest.

SACRIFICING TIME: The Impact of Caring on Being Able to Take Time for Oneself

Table 4 Perceptions of Taking Time Before and After the Diagnosis

	Before diagnosis	After diagnosis
Bob (husband, 75 years old)	-Took time for activities either together with his wife or alone -Took time to go to America to visit family and friends every year	-Taking time for preferred activities is selfish and irresponsible -Only priority is providing care and doing activities together with his wife -Will not be able to go to America
Richard (husband, 80 years old)	-Took time to go for holidays with his family -Took time to visit his brother	-Only priority is providing care for his wife -Visiting friends and family is difficult, as his wife does not like to go and becomes agitated quickly

Beth (wife, 80 years old)	-Took time for activities, with or without her husband - Took time to meet with friends, attend concerts, go to the cinema and theatre - Had “Friends of Covent Garden” membership	-Experiencing the situation as loss of freedom -Preferred activities, such as going to the theatre are greatly missed and cannot be arranged -Had to give up “Friends of Covent Garden” membership
Fran (wife, 64 years old)	-Took time to travel and visit her family abroad -Took time to visit friends	-Managing and arranging free time is difficult and sometimes impossible -Cannot travel and visit family abroad -Can only take 3-4 hours away -Acknowledging that free time is extremely important for one’s health and well-being
Abby (daughter, 55 years old)	-Took time to participate in preferred activities -Took time to travel, meet with friends and family	-All activities can be arranged -Taking time to meet with friends, travel and do preferred activities -Acknowledging that free time is extremely important for one’s health and well-being -Knowing that her mother would want her to take time for herself and not merely provide care
Anne (daughter, 54 years old)	-Took time to participate in preferred activities -Took time to travel, meet with friends and family	-All activities can be arranged -Taking time to meet with friends, travel and do preferred activities -Being encouraged by partner -Acknowledging that free time is extremely important for one’s health and well-being -Knowing that her mother would want her to take time for herself and not merely provide care

According to The Health and Wellbeing of Unpaid Carers report (2015) carers found managing and planning ahead extremely challenging. This resulted in having no time for activities they wanted to do, with their main concern being the health and well-being of the person they care for. Similarly, Brodaty et al. (2009, pp220) reported that *“Caregivers tend to sacrifice their leisure pursuits and hobbies”* as well as time with family and friends.

Carers 70+ years old thought taking time off was selfish and thought they must sacrifice their needs while providing care, even if that meant they will not be able to see their family.

> *“I can’t do what I wanna do you know you’ve got… responsibilities… I’m I’m used to going… going around London you know seeking out things so I can’t be as selfish as I used to be once I’m tryin’ to help my wife” (Bob)*

Their partner dictated leisure time such as being with friends or family.

> *…when we go and see friends she can't be there for more than about an hour to an hour and a half and she gets very um fidgety even to the extent of getting up getting her coat and walking out you know then I have to chase her out and grab her out of the street you know… so um ok we go for an hour an hour and half the most… like when I go and see my brother who lives in Windsor on Thursdays and she's not that keen on going there but she goes um but normally we only stay just for over an hour as long as she can cope with… (Richard)*

Carer 60+ years old acknowledged the fact that her husband cannot always be the absolute priority and that taking time for preferred activities is extremely important for her health and well-being. However, despite acknowledging this, only very limited time could be arranged,

> *"everything is got to be very planned and I cannot go for too long because I miss um… there has to be an organised deals um to offer me assistance…you know I have to do things in chunks so really its like a 3 hour thing or a 4 hour and I have to organise someone to be around additionally…" (Fran)*

Carers 50+, on the other hand, did not change their perceptions on taking leisure time and continued with activities they pursued before their parents' diagnosis. The benefits of having free time were highly acknowledged and portrayed as a necessity in order to provide good care, not resent the situation and stay healthy. Nevertheless, the amount of planning and organisation it took to meet friends and family, have weekends away and go for holidays, they successfully managed it. Partners' support and a belief that their parents would want them to enjoy life and not merely provide care overcame feelings of guilt, often experienced by spousal carers (Farina et al., 2017).

Carer's perceptions of leisure time, again was dependent on their age and was located in the moral and social views of the society they grew up in. The eldest thought it was their duty to sacrifice themselves to their charge, the youngest believed they had a duty to look after themselves in order to be effective and the middle group fell between the other two.

CHANGES IN HELP: The Shift from Independence to Requiring Help

Table 5 Perceptions About Receiving Help Before and After the Diagnosis

	Before diagnosis	After diagnosis
Bob (husband, 75 years old)	- Did not require help	-Not receiving help -Would require help and advice in order to cope with the situation, however do not know where to find it -Family members cannot help as they live in America

Richard (husband, 80 years old)	-While providing care to his mother Richard had very bad experience with professional care/help	-Not receiving help -Would require help with managing the household -Do not know how to organise help -Would never put his wife in a day centre -Family members cannot help, as they have their own families to take care of
Beth (wife, 80 years old)	-Never thought of requiring help -Being annoyed by support groups for elderly -Reluctant to ask for help	-Not receiving help -Would require help with managing the household -Wants to move to a smaller flat, but cannot because her husband would not like it -Finds help programmes for elderly annoying
Fran (wife, 64 years old)	-Did not require help -In general, there was not a lot of care and help options in the community	-Not receiving help -Attending conferences and various groups for carers in order to attain information -Family members help with the transport but rarely, they have their own families to take care of -Noticing that there is more help and information available now than in the past -Noticing that not many older carers look for help, as they believe they can manage the situation
Abby (daughter, 55 years old)	-Did not require help	-Receiving financial support, help from professional carers and her sister -Receiving help is paramount in order to get free time
Anne (daughter, 54 years old)	-Did not require help	-Receiving help from professional carers, admiral nurses and her brother -Noticing that older carers are left alone without additional support -Receiving help is paramount in order to get free time

Receiving help and support while providing care is paramount in order to get free time and participate in preferred activities. Even though there are currently many initiatives offering help and support for carers of people with dementia, research findings continuously report that caregivers feel unsupported (Farina et al., 2017; The Health and Wellbeing of Unpaid Carers report, 2015). This was evident in the stories carers 70+ years old narrated. They expressed that they would require additional support but did not know how to arrange it and lacked awareness of programmes currently available. Even if they left their partner in a day centre for few hours it was simply not enough.

> *"so it would be it would be helpful if they'd have somethin' like 12 steps move (support groups for people with addiction) where people like carers could come and share their experience to help them cope…*
> *It would be helpful you know… to be around other carers and share people share what we… khm… they are going through and it would help cos they might they might know ways to to help… they probably have some but I have no a-a-a nobody has mentioned carers' anonymous I have to do some research… cos you know GPs don't really um help…" (Bob)*

Bad experiences with health care in the past is a reason making this group of carers more reluctant to get help and support even after care services became more person centred, advanced and available (Godfrey et al., 2000). The outcome is they do not want to put their partner in a day centre.

> *"I don't want to put her in a-a… I-I'd probably destroy her in the day centre… she'd spend the day with the nurse… spend the day looking for me… it's there's nothing else I-I could do anyway… so um It's it's how it is…" (Richard)*

Interestingly carer 60+ years old confirmed that older carers believe they can manage the situation, however due to their age they struggle. On the other hand, even though carer 60+ years old was not receiving help, she welcomed all new developments regarding dementia and care and confirmed that the quality and availability of information to support carers of people with dementia has changed in the past few years and became more broadly available. However, it was perceived as irrelevant if the carers could not access the information.

> *"which unless you look for it… I think what I have with um… people quietly at home just getting on and not realising that there is some help um information… because information is cue really in order to… at least if you know… you can remember and get a bit of advice, that's useful… I've been to several conferences which really focused on the carers which was very helpful… very helpful… and people had no idea because they are just quietly waiting for the word of mouth from their friends to come along and tell what these conferences are really about" (Fran)*

Even though both, carers 60+ and 70+ years old had adult children they did not want to ask for support, nor they were expecting it. In contrast all carers 50+ years old were receiving support such as financial, from day centres, admiral nurses and professional carers.

They reported they had to be very organised and ask for help themselves. Moreover, offspring carers were getting additional help from their siblings.

> *"um my sister's very good and she comes to help and she'll do some things like order the medication or admin stuff as well because there is a lot of admin…" (Abby)*

The three age groups showed significant differences in their perceptions of support and help. The eldest knew they needed support but were unable to find and access it, whereas the youngest knew of a reasonable range of support on offer and also how to obtain it. The 60+ carer again fell in the middle of these two world views. This supports the research findings by Victor (2009).

Overall, carers 50+ and 60+ years of age *"were more assertive, confident and knowledgeable about their rights and support as well as were more likely than others to receive the support they wanted."* (Victor, 2009, pp. 39). The younger the carer, the more likely they were to co-opt family help to care for the person with dementia.

PLANS FOR FUTURE: The Value of Living for the Moment Versus a Focus on the Future

Table 6 Perceptions of the Future Before and After the Diagnosis

	Before diagnosis	After diagnosis
Bob (husband, 75 years old)	-Had a past that he did not want to reveal -Never thought that he will have to provide care	-Not thinking about the future as the worry would make him go crazy -Hoping that dementia cure will be discovered
Richard (husband, 80 years old)	-Main concern was to provide for the family and to achieve better socioeconomic status -Never thought that he will have to take care of his wife	-Main concern is not to die before his wife, as no one would be able to look after her
Beth (wife, 80 years old)	-Main thoughts were to live life connected to the theatre as much as possible and to continue with preferred activities - Never thought that she will have to care for her husband	-Being frightened of her husband's deterioration -Thinking of where and how she would like to die -Not looking forward to many things
Fran (wife, 64 years old)	-Thought she would have more time for herself, do courses she always wanted to try and enjoy travelling with her husband -Never thought that she will have to care for her husband	-Acknowledging the fact that her husband condition can only deteriorate and that she will have to maintain healthy and strong in order to provide care for him as long as possible, as no one else would be able to care for him -Looking to arrange more professional help in order to get more free time for herself
Abby (daughter, 55 years old)	-Had various plans for the future, such as travelling and just enjoying life -Never thought she will have to take care of her mother and move back to her parent's house	-Planning to go for more art and dance classes and travel
Anne (daughter, 54 years old)	-Had various plans with her previous partner before he died -Never thought she will have to take care of her mother and move back to her parent's house	-Acknowledging the fact that she is not getting any younger and made big decisions for future such as, moving together with her new partner, getting married and selling the house

		-Once her caring role is over, she will have her life back -Have something to look forward to in the future -Feeling sorry for older carers

It has been reported that positive health assets, such as positive emotions, life satisfaction, optimism and life meaning and purpose can lower the risk of sedentary lifestyle, which can otherwise lead to poorer psychological and physical health (Park et al, 2016). Research showed that older carers 70+ years of age tend to feel anxious and not hopeful for their future (Greenwood et.al., 2019[1]; Greenwood et.al., 2019; The Health and Wellbeing of Unpaid Carers report, 2015). Their main concern was not to die before their partner, as no one would be able to take care of them.

> *I mean If I wasn't there she'd go in a home there's no two way about it you know I don't think neither of my daughters could look after her I think because um… my um… youngest daughter as I said is a teacher and she's got her sons to look after and the house and everything else…" (Richard)*

Some were frightened of their partners' future deterioration and changes they might have to make as well as thinking about their own death.

> *"It's going to be worse… you know you got to be realistic and um it's going to get worse and I'm… Oh what is this "going to get worse look like" is he going to have to get a stair lift in the house? I mean that really is the pits… we actually talked about this quite a few years ago when they wanted to put horrible plastic white handles all over everything and we decided that no we're not going to mark up the house and then it will look like some sort of an old nursing home…" (Beth)*

Others felt that they rather not think about the future and live in the hope that the cure for dementia will be found.

> *"I take it one day at a time otherwise you'd just go crazy if you'd be sitting there and thinking about how it's gonna get worse… you gotta just take it for today what's happening today..." (Bob)*

Or what life might be like without their partner,

> *"some people… once that person dies their whole life was with that one person… how are they going to create new life again… you know that's what I think I can see and there's a lot of older people you know they are in their 70s, 80s you know… the person they are looking after, they've been probably married for like 40, 50 years or something you know so they're the ones I feel really sorry for" (Anne)*

In contrast, carer’s 60+ years of age plans for the future involved arranging more help and get more free time for herself as well as to be fit and healthy as long as possible, otherwise no one else would be able to take care of her husband.

> *“And above all I have to keep fit and healthy as much as possible… because if my health goes then we would have to change things totally, it would be long term care for him and you know all would change… so I’m hoping, I’m hoping hehe to keep going for few more years hehe…”(Fran)*

The view of younger carers 50+ years of age, was that in the future, when their role as a carer came to an end, they would have their life back.

> *“if nothing happens to me then I’ll have my life back… you know because um my life is um to a certain degree has been put on hold…” (Anne)*

They acknowledged the fact that they are not getting any younger and made big decisions for the future such as, selling the house, getting married and moving.

> *“you know I’ve decided to sell the house I’ve decided to move down to Cornwell I’ve decided that we’re going to get married… cos otherwise you know I’d just be sitting limbo… and I hehe so I can’t do that…” (Anne)*

This ability to make decisions or envisage a future, gave them something to look forward to.

> *I have something to look forward to… If you don’t you can’t see there’s a light at the end of a tunnel I suppose…” (Anne)*

The eldest carers had a negative view of the future with visions of their spouses’ demise, being without their spouse or their own death in contrast to the youngest who had a strong vision of their futures. It may be the youngest had a sense that they still had enough years left to build another life after the demise of their relative. The middle group this time had optimism and wanted to stay healthy for the present but did not have the long-term view of the youngest.

Discussion

Taking into account the accumulation of the underlying social, behavioural, and biological processes that drove the impact of the life course on carers’ health, findings here suggest that there are three distinct groups of carers: partners 70+ years old, partners 60+ years old and offspring 50+ years old and they show differences in the way they perceive physical activity, taking time for themselves, acquiring help and their perceptions of the future.

Table 7 summarises four main themes found from the stories narrated:

Table 7 Themes

Theme	Carers 70+	Carers 60+	Carers 50+
PHYSICAL ACTIVITY AND WELL-BEING: the impact of physical activity as a youth on the current sense of well being	-Generally active as children (playing outside, meeting with friends, working in farms…) -After becoming a carer exercise is still seen as a part of the everyday. It undertakes ADLs -Providing care is more important than participating in preferred activities	-Generally active as a child -Becoming health aware after husband's diagnosis - A clear sense of sport and exercise as a separate activity and its importance for health	-Participating in various exercise programmes -Being encouraged by parents and by a GP in their adulthood -A clear sense of sport and exercise as a separate activity and its importance for health
SACRIFICING TIME: The Impact Of Being Able To Take Time For Oneself	-Sense of a duty to sacrifice themselves to their charge.	-Sense of duty to look after themselves, however unable to take time.	-Sense of a duty to look after themselves -Taking time to look after themselves
CHANGES IN HELP: The Shift From Independence To Requiring Help	Acknowledging they need support but were unable to find and access it. -None/very little support from other family members. -Having bad experience with care services in the past.	-Knowledgeable of some support on offer, and at the same time facing difficulties in attaining it -positive difference between the amount of care options/services in the past and after her husband's diagnosis -None/very little support from other family members.	-Knowledgeable of a reasonable range of support on offer and also how to obtain it. -Support from siblings and/or partners.
PLANS FOR FUTURE: The Value Of Living For The Moment Versus A Focus On The Future	-Having a negative view of the future with visions of their spouses' demise, being without their spouse or their own eventual death	-Want to stay healthy for the present but do not have the long term view of the future.	-Having a strong vision of their futures and a sense that they still have enough years left to build another life after the demise of their relative.

Carers 70+ years old were very active as children and young adults, however they did not intentionally participate in any specific physical activity programme solely for the health benefits. Working, in order to achieve better socioeconomic status, taking care of their family and household was always a priority. As informal caregivers, they had similar perceptions. Being active meant taking care of their spouse with dementia, playing Sudoku, going shopping, and maintaining the household. Even though being active was considered vital while providing care, exercise was not. Interestingly carers 60+ had similar perceptions as carers 70+ in their youth, however that changed when they started providing care. In contrast the youngest carers always had a very clear understanding of exercise as a separate activity, were participating in various activities as children and thought it was crucial for their health while providing care.

In the last couple of decades perceptions of physical activity have changed profoundly. All the industrial and health campaigns, products, programmes, research findings and new mediums, especially Internet, have expanded the knowledge of physical activity and its health benefits. However, even though overall awareness increased people older than 70 years got excluded. Recent studies showed that this group is the least active on the internet (Boekel et al., 2017; Klimova et al., 2018) and is more likely to attain health related information from a health care provider (Turner et al., 2018), who on the other hand lack confidence and knowledge to promote physical activity (Brooks et al., 2016). Moreover, it has been reported that elderly are less likely to shift well-known strategies for new ones even when they realise the benefits (Lemaire, 2010) and are more engrained in a habitual processing approach (Hertzog et al., 2011; Spieler et al. 2006), which might partly explain why they insisted with the same perceptions and methods they have learned as young adults.

In order to participate in any physical activity having free time is paramount. In many cases of caregiving for people with dementia this means that having assistance and/or help is crucial. It has been reported that partner caregivers, in contrast to offspring felt reluctant towards putting their spouse in a day centre as well as receiving help from any support services (Tatangelo et al., 2018), which correlated with findings from the current study. Moreover, offspring carers normally received help from other family members such as siblings and partners, whereas partner caregivers did not, nor they were asking for it. Previous research suggested that partners perceived their caring role as their natural duty, which must be fulfilled without assistance (Conde-Sala et al., 2010) and believed that "*self-sacrifice and self-neglect are necessary within their role as a caregiver*" (Tatangelo et al., 2018, pp 12). According to Lang et al. (2019) deep attachment style, shared identity and shared history highly determined the devotion and the paramountcy of the loved one's welfare in one-sidedness of dementia caregiving. It was perceived as a continuing expression of a loving relationship, which might partly explain why partners felt reluctant towards taking free time for themselves while their partner is in need. The other part might be the underlying social values deeply rooted in each era carers 70+, 60+ and 50+ years old were born in, bad experiences with care services and traumatic incidents from childhood.

The eldest carers narrated stories regarding evacuation to farms outside of London during-World War II and being separated from their families. Various studies looked at long-term effects of children evacuees in Britain and their adult mental health. They reported that as adults these people had a greater risk of anxiety and presented high levels of dependency (Rusby et al., 2009). Moreover, present health care services and what was available few decades ago are almost incomparable. Carers 70+ years old shared stories describing bad experiences with health care services while taking care of their parents and were very clear that they will not put their spouse in a day care centre. On the other hand, carer 60+ acknowledged the fact that health care services were nothing like they used to be and that there is a lot of information available if you search for it. Even though carer 60+ did not use any of the services or help, she was willing to explore the options for future. Tatangelo et al. (2018) reported that offspring carers did not acknowledge the importance of free time, had a lack in knowledge of support options and were deprived of social life. In contrast offspring carers from current study acknowledged that they cannot stop their life just for the sake of providing care. They used various care services and were receiving financial support in order to get time to socialize, travel and do preferred activities. Interestingly they said their parents would want them to continue with their lives, be happy and not merely provide care.

Another factor in order to participate in physical activity is having positive health assets, such as positive emotions, life satisfaction, optimism and life meaning and purpose (Park et al, 2016).
Offspring carers perceived taking care of their physical fitness and overall well-being as an investment for future. Acknowledging the fact that they are not getting any younger and in order to potentially avoid chronic conditions associated with older age they felt strongly motivated to preserve their health. Moreover, they believed that once their caring role would be over, they will have their life back, which in a way gave them something to look forward. Carer 60+ accepted the fact that her partner can only deteriorate and that if her health weakens there will be no one to take care of him. Therefore, she found regular physical activity as an important factor in her role, however the time constraints barred her from regular participation. And lastly the eldest carers had no further plans for future, felt there is no use in changing their lifestyle and wished only not to demise before their partner.

Conclusion

There is strong evidence that family carers of people with dementia experience high burden of care (Aldeman et al., 2014; Pinquart et al., 2003) despite positive outcomes reported (Roth et al., 2015) and that they would highly benefit from a regular physical activity (Castro et al., 2002; Connell et al., 2009; King et al., 2002; Farran et al., 2016). However, even though family carers might be providing care to people with the same diagnosis, they greatly differ from one another. Studies reported dissimilarities in health needs between younger and older carers (Greenwood et al., 2019), as well as offspring and partners (Tatangelo et al., 2018; McCabe et al., 2016). However, understanding why these differences are there is scarce.

Humans are ageing and living longer and not in any other time in the history so many generations had to live together and face similar challenges, such as taking care of their parent or spouse with dementia. The age difference between the oldest and the youngest carers, who are seen as a coherent group could be as much as 35 years, which is in the world that is constantly changing and evolving a great amount.

Using Narrative Inquiry and Alwin's five principle stance on life course to investigate peoples' temporal experiences and stories in this study, adds a novel view on the complexity of lives of those who provide care for family members with dementia and their perceptions of physical activity and well-being. The results support previous studies reporting differences between carers and at the same time add a greater depth into understanding why these differences might be there.

Farina et al. (2017) stated that caring for a family member extends beyond the hands-on care, therefore cleverly designed interventions taking into account individual life-course might find a way for carers to change their behaviours regarding physical activity and build upon a health-promoting lifestyle. This could help them to meet caregiving demands as well as look after themselves and positively affect their health-related quality of life and quality-adjusted life-years.

Strengths and limitations

Even though according to Fraser (2004) and Morse (2000) studies with a small sample size and narrative inquiry as a method can result in numerous stories and offer rich data, a larger sample size should be considered in order to explore whether the themes found in this study could be applied to a larger population of informal carers of people with dementia.

CHAPTER FIVE

This chapter describes the cross-national approach contextualised to two countries and cultural contexts and provides the rationale for the comparison between the informal carers in the UK and Slovenia in the third study. The first section contextualises the influence Covid-19 pandemic had on the course of this PhD research and the challenges informal carers of people with dementia faced during this time. This is followed by the theoretical underpinning of the cross-national and cross-cultural research, and cultural differences between the North and South of Europe in relation to informal care.

Covid-19 Pandemic

In March 2020 the World faced a coronavirus pandemic, which had devastating, global implications for the society (Bailey et al., 2022) and significantly affected the course of this PhD.

Coronavirus disease or Covid-19 is an infectious, respiratory disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) (Hao et al., 2022). The disease was first discovered in Wuhan, a city in China in 2019 and spread worldwide (Hao et al., 2022). Due to high infectivity and pathogenicity of the virus the World Health Organization (WHO) declared Covid-19 a global pandemic in 2020 (Khalifa et al., 2021). In order to minimize the spread of the disease, governments and agencies around the world posed strict rules such as, social distancing, limited travel, compulsory quarantines and shut down of schools/universities, places of work and public places (i.e. theatres) (Khalifa et al., 2021). People were advised to stay at home and minimize contacts outside of their households. Though stay-at-home orders were beneficial in limiting the spread of the virus, not being able to see family members/friends and take part in activities in the community negatively affected peoples' psychological and physical health (Akwa et al., 2023; Khalifa et al., 2021; Violant-Holz et al., 2020). Frail Individuals living with various chronic conditions and elderly were especially at risk of deconditioning and losing their independence (Bailey et al., 2021).

The uprise in Covid-19 cases also put an immense pressure on healthcare services. A sudden rise in acute Covid-19 cases revealed scarcity of resources and outdated infrastructure of the public health institutions worldwide (Kooli, 2021). Furthermore, healthcare sectors faced various ethical dilemmas such as, '*provision and withdrawal of intensive care units and life-supports and also regarding family visits and quality of care provided*' (Kooli, 2021, pp.2), which resulted in significant psychological strain on healthcare professionals (Tsamakis et al., 2020). Nurses and doctors working in hospitals during

Covid-19 pandemic reported feeling helpless when dealing with patients who were critically ill due to limited number of intensive care beds and resources available (Tsamakis et al., 2020).

Covid-19 pandemic also impacted scientific research. On one side a significant amount of financial resources was allocated to support research areas related to Covid-19 emergency, such as developing a vaccine, however on the other side fields of research not directly related to Covid-19 were displaced (Riccaboni & Verginer, 2022). According to Bartels et al. (2022) early career dementia researchers faced, alongside the overall health consequences of the Covid-19, significant research delays, more project adjustments, and higher financial costs. Sharma et al. (2022) agreed with Bartels et al. (2022) and showed that qualitative researchers whose research involved older adults faced further challenges with reaching, engaging, and recruiting participants.

At first, the overall aim of this PhD thesis was to explore physical activity and well-being perceptions of informal carers of people with dementia residing solely in the UK. However, due to the Covid-19 outbreak the researcher had to travel back to her home country, Slovenia. The researcher reflected on the past experiences and beliefs and followed the underlining pragmatic paradigm of this PhD. Therefore, a part of data collection for the second study was conducted in Slovenia. The third study therefore took a cross-cultural approach in order to explore if different age groups defined in the first and second study were present cross-culturally, and to see whether there are differences between informal carers in the UK and Slovenia.

Informal carers during Covid-19

There is emerging evidence that the Covid-19 outbreak had and continues to have a significant effect on informal carers of people with dementia (Giebel et al., 2022; Greaney et al., 2021). During the pandemic services such as professional paid home care, daycare centers, professional health care, respite care and social support (i.e. peer support groups, counselling, activities for people with dementia and their carers) had to abide by the pandemic-related restrictions and reduce their services or even close their premises (Giebel et al., 2022). Considering the increased susceptibility of older adults, especially those already living with chronic conditions to the virus negatively affected people with dementia and even more so their carers (Eurofound, 2022). Suddenly the support the informal carers might have been receiving substantially reduced and thus even further increased the already high level of care they were providing prior to the pandemic (Giebel et al., 2021). In the light of the restrictions and advice given by the national health services worldwide people had no other option but to stay within the sanctuary of their own home and practice social distancing. In order to stay connected during this time the use of technology significantly increased, even amongst the elderly

(Elimelech et al., 2022). Though the benefits of online services for older adults such a grocery shopping, banking, online video calls, online physical activity programmes etc. can be of great use, the correlation between the age and technology use remains contradictory (Vaportzis et al., 2017). Apart from the fact that some people aged 65+ became first time internet and smart phone users during the pandemic (Kung & Steptoe, 2023), there seemed to be other challenges involved with technology use. These include sufficient financial funds to buy technology as well as broadband services required, knowledge or skills to use the technology (Vaportzis et al., 2017) and living with conditions, thereby restricting its use (i.e. being visually impaired). Informal carers are already struggling with high costs of care, age related health conditions and the burden of care, which together with the fact that the world is entering a digital era where some of the services are no longer operated by a human employee and can be only accessed online, it is important that older adults, especially the ones with additional responsibilities such as informal carers are not at risk of exclusion (Kung & Steptoe, 2023).

Cross-national

Cross-national studies explore particular issues or phenomena in two or more countries '*with the express intention of comparing their manifestations in different socio-cultural settings using the same research instruments'* (Hantrais & Mangen, 1996, p.1). There are many advantages that can be obtained through cross-national research. Hantras & Mangen (1996) argue that it can lead to a deeper and more comprehensive understanding of phenomena and issues that are of central concern in various countries, as well as facilitating the testing theories across diverse contexts. Cross-national research can also identify patterns and variations that may not be apparent within a single country (Mahoney & Thelen, 2010). By comparing similar phenomena across different countries, researchers can uncover systematic differences that highlight the impact on national contexts such as governance, culture, or policy frameworks. This comparative approach enables researchers to discern the factors that drive variations in outcomes and to identify best practices (Mahoney & Thelen, 2010). Facilitating theoretical innovation and opening new direction for future research about which the researchers may not have been previously aware is also one of the advantages of cross-national research (Mahoney & Thelen, 2010). By examining how theories apply across multiple countries, researchers can refine or expand existing models to account for cross-national differences (Gharawi et al., 2009). Another advantage is the ability to address concerns about external validity. Studies that are confined to a single country may be limited in their applicability to other nations due to differing contexts. By broadening the scope to include multiple countries, cross-national researchers can explore whether the findings are robust across diverse settings, thereby improving external validity of their conclusions

(Mahoney & Thelen, 2010). And lastly employing a cross-national methodology can lead to the identification of gaps in knowledge (Gharawi et al., 2009).

However, despite all the advantages cross-national research methodology can be complex, as it requires a deep understanding of the different national contexts and how these might affect the phenomena being studied (Mahoney & Thelen, 2010). A key challenge is conceptual equivalence, that is making sure that the phenomena being studied are comparable across countries. This involves defining terms and constructs in ways that are contextually relevant to each country involved, as meaning and interpretations can vary culturally and socially (Hantrais, 2009). Case selection is a vital step in cross-national research. Researchers need to choose countries that are appropriate for the research question while also considering issues of comparability and generalisability (Sartori, 1991). For instance, choosing to compare countries that are similar in some respect (i.e. economic development) but differ in others (i.e. political systems) to explore relationships (Sartori, 1991). Contextualisation of findings can also present as a challenge in cross-national research. What works in one country might not be applicable to another due to differences in historical, cultural, political, or economic contexts. Researchers must account for these differences and avoid making overly simplistic generalisations (Geertz, 1973). And lastly, another challenge in cross-national research, besides data comparability, availability and cultural bias is an ethical concern related to cross-cultural validity and ensuring that the research respects the values and norms of the countries studied (Parker & Tritter, 2006).

There are three sampling procedures applied in cross-national studies: convenience sampling, systematic sampling, and random sampling (van de Vijver & Leung, 1997). For the purposes of this PhD, convenience sampling was used in the second and third study. And the countries chosen to be compared were the UK and Slovenia. Though the countries differ in geographical location, cultural differences, and historical political regimes, they share many similarities such as being recognised as developed countries, having almost universal healthcare coverage, recognising dementia as an epidemic, acknowledging the need to support informal carers and recognising the health benefits of regular physical activity. The researcher has lived in the UK for the past eight years and is Slovenian by birth and nationality, therefore informal carers of people with dementia residing in the UK (London) and Slovenia (Ljubljana) were chosen to be compared (van de Vijver & Leung, 1997).

Cultural Aspect

Culture can be described as a '*shared way of life of a group of people that includes beliefs, values, ideas, language, communication, norms and visibly expressed forms such as customs, art, music, clothing and etiquette'* (Papadopoulos, 2018; 2006), which is normally transferred from one generation to the next (Shiraev & Levy, 2010). Cultural norms can have a significant effect on psychology and consequentially behaviour and actions of individuals living in a specific culture (Shiraev & Levy, 2010). However, even though culture can be shared within one ethnic group or nation no society is culturally homogenous. Certain level of dissimilarities, variations and inconsistencies within the same cultural clusters are always present (Shiraev & Levy, 2010). When comparing different cultures, cross-cultural researchers '*establish and conceptualize the main culture's features in terms of cultural dichotomies*' such as, collectivism versus individualism and seek to establish psychological universals common to individuals in several, many, or all cultures (Shiraev & Levy, 2010, pp.24).

When conducting cross-national and cultural research, it is vital that the researchers challenge their own beliefs and values and understand how their cultural background interrelates with the respondents (becoming culturally aware). Being in contact with individuals from different cultural backgrounds and acquiring knowledge about similarities, differences and health inequalities is as equally important, and can lead to avoidance of stereotyping, prejudice, and discrimination (attaining cultural knowledge) (Papadopoulos & Lees, 2001). Challenging the power relationship between the researcher and participants and offering choices in line with the participant's cultural identity (as well as considering their gender and socio-economic status) is another practice that can result in rich and more accurate data collection (considering cultural sensitivity). And lastly, it is crucial to be aware of and challenge any form of discrimination, racism and ethnocentricity throughout the research design, data collection and analysis, discussion of findings and its dissemination (being culturally competent) (Papadopoulos & Lees, 2001).

Methods used in order to collect data in cross-national and cultural research must be given an extensive consideration, especially when cultures compared greatly differ in language proficiency, cultural norms and values, and having access to technology (i.e. phones, computers, internet) (Broesch et al., 2020). Though surveys are one of the most common and financially affordable data collection methods, there are a few points that need to be considered before employing the method (Shiraev & Levy, 2010).

- **Translation** - It is necessary that translation of the questionnaire is verified by legal translators or professionals with an equivalent knowledge of the language. Moreover, it is helpful to involve several people in the translation, so there are multiple versions of the questionnaire which can then be compared and merged into one (Shiraev & Levy, 2010). Piloting the questionnaire on 2-3 individuals participating in the study allows the researcher to see whether the translated questions are understood correctly by the participants (Shiraev & Levy, 2010; Broesch et al., 2020).

- **Formal response scales** - Familiarization with formal response scales included in questionnaires might also pose a challenge, especially if there are higher levels of illiteracy amongst the communities studied (Shiraev & Levy, 2010). In this case the researcher can consider utilisation of non-complex visual aids, in order to ensure the scales measure what the researcher is intending (Broesch et al., 2020).
- **Honesty** - Not being able to identify participants who are not being honest in their responses might be another challenge faced by cross-cultural researchers. When exploring topics that could be perceived sensitive, inappropriate, and shameful, there is a higher chance participants will answer with socially acceptable answers and not what they truly think (Shiraev & Levy, 2010).
- **Self-perception** – How people perceive themselves can also vary amongst different cultures. For instance, Schmitt et al. (2007) reported that North Americans perceived themselves as a hardworking and conscientious individuals (working longer hours than other nations). Consequentially, American economy continues to be one of the most productive economies in the world. In contrast, individuals from China, Korea and Japan evaluated themselves as the least hardworking, even though all three countries are productive and economically successful nations (Schmitt et al., 2007). This suggests that peoples' perceptions of self might be influenced by different, culturally derived factors and must be interpreted with caution (Shiraev & Levy, 2010).
- **Political regimes** - Conducting surveys in countries under authoritarian regime can also pose many challenges. Individuals in such countries are often discouraged or prohibited from providing any information regarding topics that could damage the government's reputation or they provide socially acceptable answers to avoid potential conflicts with the authorities.

Informal Care and Culture

Individuals from different cultures and ethnic groups can differ in the way they perceive and provide care (Papadopoulos, 2018; 2006). For instance, people with individualistic values, common to some of the Western cultures might view caring for an older family member, partner, or a friend as another role to fulfil, and are thus more likely to report high burden of care and seek external help with their caring responsibilities (Santoro et al., 2015). In contrast, people sharing collectivistic views '*place substantial value on the welfare of one's family members'* and perceive caregiving as a duty shared within the family unit (Santoro et al., 2015, pp.665). Collectivistic values, however, can differ between cultures (Schwartz et al., 2010). The sub-forms of collectivism are communalism, which endorses the relationships between family members and relatives in daily life and decision making (Santoro et al., 2015). Familism, which emphasizes the importance of honouring, respecting, and maintaining a sense of obligation to family members, as well as placing family's needs before one's own (Valdes, 2008). And lastly, filial piety, which describes the virtue of respect, obedience, and care for an older family member demonstrated by a younger member of the family. For cultures practicing filial piety placing an older family member into a care home or include professional carers to assist with care would be perceived as shameful, since it is the offspring's duty to provide care (Santoro et al., 2015).

However, it is important to note that even within a particular cultural group and value systems there is a likely variability in how individuals express their (cultural) reasons for providing care (Dilworth-Anderson et al., 2005). Characteristics, such as gender and age together with personal experiences can significantly impact and influence cultural beliefs and values about caregiving (Dilworth-Anderson et al., 2005). Moreover, external factors such as the environment and the country-level factors, like the welfare, social and healthcare regulations, and the societal perceptions play an equally significant role (Shaji & Reddy, 2012). For example, if providing care is undervalued, and perceived negatively or as a burden in the society, informal caregiver's physical and psychological health might worsen, and consequentially affect the quality of care provided to the person in need (Ng & Indran, 2021).

Informal Care in the North and South of Europe

How dementia care is organised, delivered, and funded varies between different European countries (Jönsson et al., 2023). However, according to numerous studies there have been particular cultural and institutional differences observed between the north (N) and south (S) European countries (Jönsson et al., 2023; Verbakel, 2018; Herlofson et al., 2011; Dykstra & Fokkema, 2011; Gustavsson et al., 2010). Familialistic values in combination with fragmented and inconsistent policies considering informal carers (Hvalič-Touzery et al., 2022) led to informal care being more prominent in the southern than in the northern Europe (Herlofson et al., 2011). Certain practices, such as intergenerational co-residence (i.e. elderly parents with adult children, which is the highest in the Mediterranean countries) in combination with specific norms and expectations in the south led to the family care being assumed but not adequately supported by policies (Dykstra & Fokkema, 2011). Consequentially, informal carers' living in southern Europe reported poorer physical and mental health in comparison to the informal carers residing in the north, who perceive the care for dependent elderly is mainly the governments' and social networks' responsibility (Bom & Stöckel, 2021; Hoefman et al., 2017; Solé-Auró & Crimmins, 2014). Though the likely variably in the endorsement of filial responsibility and other factors, such as personal financial security, age, gender, cultural diversity (within individual countries), infrastructure and the urban-rural difference in both the north and the south of Europe can influence individual perceptions of informal care provision (Herlofson et al., 2011). While there might be character differences in intergenerational solidarity between the north and south (Daatland & Lowenstein, 2005) the balance between how much support should be provided by informal carers vs the health and social care services, together with the eligibility for support in order to midgait the informal care burden remains a debate worldwide (Verbakel, 2018; Perdrix & Roquebert, 2022; Plöthner et al., 2019).

Findings from the second study confirmed the fact that different age groups of informal carers experience their roles, health, and physical activity differently. Considering the potential differences described between the N and S European countries, the third study of this PhD compared age groups of informal carers and their characteristics between the UK and Slovenia. The importance of this is to firstly confirm the fact that the 3 distinct groups of carers exist cross-nationally and to explore if there are any differences between them. This could point out potential weaknesses in the healthcare and support system, cultural differences, and influence of the environment informal carers of people with dementia live in.

CHAPTER SIX

Study 2

Differences in physical activity and well-being: perceptions of family carers of people with dementia

Abstract

Background: It has been well established that the informal carers, such as family members, relatives, and friends are a vital part of care provision for people with dementia. Without the informal care contribution, the already high burden and financial strain on healthcare and social care services would increase even further. Therefore, it is important that informal carers of people with dementia stay healthy and feel supported in their roles. Regular physical activity participation has proven to have positive effects on one's physical and mental health and increases overall well-being, however informal carers of people with dementia often do not meet the recommended 150 minutes of moderate physical activity per week. Study 1 suggested there are three distinct groups of informal carers of people with dementia and how they perceive physical activity (including the barriers and facilitators that prevent or encourage exercise participation). These groups are carers 50-60, 60-70 and 70+ years of age. This study explored whether the findings could be applied to a larger number of informal carers of people with dementia.

Methods: The carers were asked to complete a standardised questionnaire – entitled 'Differences in Physical Activity and Well-Being Questionnaire' consisting of 25 questions aiming to attain carers' quality of life, relationship style with the care recipient and physical activity perceptions. Eligible participants were non-paid caregivers (either family members, relatives, or friends), 50 years of age or more and providing care for an individual diagnosed with dementia at least 5 hours per day. The carers were recruited in the UK (London) and Slovenia (Ljubljana).

Results: Overall, 166 informal carers completed the questionnaire (50% were from the UK and 44.6% from Slovenia). Carers aged 50-60 years presented the largest group (38.9%), followed by carers 60-70 years of age (31.7%). Elderly carers 70+ years of age represented the smallest age group (29.3%). One-way ANOVA revealed significant differences between the age groups of carers and their role as carers, information and advice availability, relationship style, current physical activity participation, beliefs and knowledge of exercise, and actions taken to stay healthy. The analysis showed no

significant results in support & needs and physical activity levels during the school/University, however.

Conclusion: Numbers of people living with dementia and consequentially their family members/friends providing care is increasing worldwide. Therefore, future research identifying the three age groups of informal caregivers of those with dementia cross-nationally is needed. Thus far none of the programmes targeting informal carers of people with dementia considered the differences between the generations and how they perceive PA, make decisions about their health and what is preventing them from utilising the support offered. This research confirmed the differences between different generations of carers and how they perceive their roles, make decisions about their health and what barriers they face while caring for their loved ones with dementia. These findings are novel and contribute to the existing literature and could help reform current systems and physical activity programmes offered to informal caregivers. In turn, this might result in a better outreach and increase the utilisation of the support aimed at carers of people with dementia, and consequentially improve caregivers' exercise adherence and overall well-being.

Introduction

Study 1 found that informal carers of people with dementia born in different periods perceived physical activity and their overall well-being, taking free time to take part in activities, asking for assistance while providing care and thinking of their future differently. By utilising Alwin's (2012) five principle stance on life-course (life-span development, agency, time and place, timing and linked lives) and incorporating Heikkinen's (2011) 'Accumulation model' (which suggests that life events compound or accumulate and modify agency) a more wholesome view of the complex lives of informal carers of people with dementia was explored.

Conclusions from study 1 might play a crucial role in designing and implementing new or amending existing programmes and initiatives to best support and meet the needs of different groups of informal carers of people with dementia. Study 2, therefore aimed to explore whether the themes found in Study 1 could be applied to a larger population of family carers of people with dementia.

The main aim and objectives were:

- To explore whether the findings from study 1 could be applied to a larger population.
- To examine the differences among the three age groups (50-60, 60-70, 70+) of caregivers and their perceptions of physical activity and well-being, sacrificing time, changes in help and plans for the future.

The research question was: are physical activity and well-being perceptions of family carers of people with dementia different between offspring carers 50-60 years old, spouse carers 60-70 years old, and 70+ years old?

Hypothesis: Physical activity and well-being perceptions of family carers of people with dementia differ between offspring carers 50-60 years old, spouse carers 60-70 years old and spouse carers 70 or more years old.

Methodology

Study 2 utilised a quantitative approach to explore differences in physical activity and well-being, sacrificing time, changes in help and plans for the future amongst the different age groups of informal carers of people with dementia (50-60 years of age, 60-70 years of age and 70 + years of age). Informal carers who consented to participate in the study were asked to complete a questionnaire, which was constructed of a validated Carer Well-being and Support Questionnaire (CWS) designed specifically for carers of people with a mental health problem or dementia, The Relationship Questionnaire, and questions about exercise history and health behaviour (AARP, 2002). The CWS consists of different parts aiming to attain carers' aspects on their general well-being (Part A: Well-being), their satisfaction with the support they may receive (Part B: Support), their need for support (Part C: Your Needs) and their personal characteristics (Part D: Background Information). The questionnaire has strong positive rating of internal consistency, content validity, structural validity, and moderate positive rating of reliability (Quirk et al., 2012). It has been recognised as the most appropriate instrument to assess the quality of life of informal carers of people with dementia (Dow et al., 2018). Findings from the first study suggested there might be differences in relationship styles between different age groups of informal carers and how they perceive their role as carers and consequentially provide care for their loved ones with dementia. Therefore, a well-established, 4-item self-report Relationship Questionnaire was added to measure adult attachment style (Bartholomew & Horowitz, 1991; Morales-Vives et al., 2021). The questions about the exercise history asked the informal carers to rate their exercise level for each age range (from 15 to 81+ years of age), inquired about their current and past physical activity participation, and the potential influence of an exercise programme on their caring role. They also had to answer questions about their exercise knowledge (i.e. how often do you think a person your age needs to exercise to be healthy?), to what level do they agree with statements about exercise (i.e. It is hard for me to fit exercise into my life), rate how important they think exercise is to their overall health, what types of additional support they would like to receive, name anything else they would like help with or would like to change in order to maintain their health and well-being while providing care, and were given an opportunity to state specific types of support, describe any negative experiences with physical activity, and name the physical activities they are currently involved in. This approach had the advantage of replication comparison of results, testing a hypothesis and using a larger number of participants.

Sample

Eligible participants were either male or female, primary, non-paid caregivers (spouse, partners, or adult children), 50 years of age or more (because this is the population at higher risk form suffering from age related impairments and disease) and currently providing care for an individual diagnosed with dementia at least 5 hours per day. Participants were recruited through websites targeted to this specific population and in person, from carer support groups, dementia cafes and carer centres across London and Ljubljana. Based on the confidence level of 80% and margin of error of 5% a sample size of 164 participants was required to find statistical significance. Which means that the probability of the population mean value being between -1.28 and 1.28 z-scores if the sample mean is 80% (Kiang, 2018).

In order to calculate the sample size, this study used a free online software OpenEpi which has been recommended by Martinez-Mesa et al. (2014) who explored sample size estimations in health research. The population size has been estimated at 1 million though the number of informal carers of people with dementia is estimated to be higher (the sample size did not vary much for population larger than the estimation used). Hypothesized percentage frequency of outcome factor in the population (*p*) was set to 50% +/-5 and confidence limits as percentage of 100 (*d*) was 5%. Consequentially for the confidence level of 95% a sample size of 384 informal carers would have to be considered which was estimated to be expensive for the researcher as well as unrealistic to achieve at the time of data collection. The data collection took place during Covid-19 pandemic, which made the recruitment of a sufficiently large and representative sample size extremely challenging. The recruitment challenges were also observed by other researchers studying the population of informal caregivers of people with dementia (Joshi et al., 2023; Malm et al., 2021; Leslie et al., 2019; Szabo et al., 2018). Similarly, Lenth (2001) points out that the simple size challenges are context dependent and that the size of the sample "*is not always the main issue; it is only one aspect of the quality of a study design"* (Lenth, 2001, pp.192).

Ethics

This study was a subject of ethical approval of the London Sports Institute ethics sub-committee. Prior to the start of the study, the Participation Information Sheet and Consent forms were either handed out to people interested in participating in the study or were accessible online on Qualtrics (an online platform used to create and distribute online surveys) before participants were able to proceed-with the questionnaire. Questionnaires were anonymous, and participants were able to opt out from the study at any point during the data collection period without providing any reason and were informed their participation was voluntary. All the documents, including paper files (which were scanned and shredded) were stored in a password protected computer with only the researcher having access. The questionnaires were translated from English to Slovene when handed to Slovenian participants to address potential language barriers, however overall, the study was conducted in English. The questionnaire was translated by the researcher and confirmed by the procurator from a translating agency to ensure accuracy. Translated questionnaire was piloted on 2 participants to ensure they understood it clearly.

Data collection

After attaining consent forms, participants were asked to complete the questionnaire consisting of 24 questions regarding their perceptions and experiences with care, health and well-being, relationship style and physical activity. The questionnaire took approximately 15 minutes to complete and was available on websites targeted at informal carers of people with dementia and sent to the participants interested in taking part via their email address in a form of a link to the questionnaire on Qualtrics. The paper versions of the questionnaire were handed out in person at carers support groups and dementia cafes across London and Ljubljana before the Covid-19 outbreak. During the lockdown, the questionnaire was available on websites and online support groups targeted to caregivers of people with dementia. After, all the data collected was used in data analysis. See full questionnaire at Appendix D.

Data analysis

Data from 166 fully completed questionnaires was transported to an Excel spreadsheet, where it was appropriately 'cleaned up' and then imported into the IBM SPSS Statistics Version 27 software. There the nominal and ordinal data were re-coded in order to be analysed and the significance level was set to $p < 0.05$. Then the descriptive statistics (mean, standard deviation) was calculated. In order to see, whether there are differences between the mean scores of the three age groups of informal carers of people with dementia (identified in study 1), one-way analysis of variance (ANOVA) was used. The test is applied to compare the variability in scores (variance) '*between the different groups (believed to be due to the independent variable) with the variance within each of the groups (believed to be due to chance)'* (Pallant, 2020, pp.262). The analysis of variance uses the F-ratio test to represent '*the variance between the groups divided by the variance within the groups'* (Pallant, 2020, pp.262). The value computed determines if the variances are equal or different. In cases when the F-ratio is close or equals 1 it can be concluded that the variances are equal, and the null hypothesis is accepted. However, the further the F-ratio deviates from 1, the higher the likelihood that the underlying variances differ between groups. '*A significant F-test indicates that we can reject the null hypothesis'* (Pallant, 2020, pp.262) and make an assumption that '*the probability that the observed group means would have appeared by chance is less than 5%'* (Brown, 2005, pp.90). The test, however, cannot portray which of the groups differ. In order to obtain that information a post-hoc test was conducted for each of the group means.

Post-hoc tests or posteriori are used to explore whether there are significant differences between each of the groups in a study (Pallant, 2020). Though there are different kinds of post-hoc tests, which vary in nature and strictness, they share a commonality. They all aim '*to help the researcher gain insight into the pattern of means'* and explain why the ANOVA null hypothesis was rejected (Homack, 2001, pp.9). The post-hoc tests also guard against the possibility of an increased Type I error (which defines falsely rejected null hypothesis – false negative) (Pallant, 2020). The analysis of the pattern of difference between means in post-hoc tests is achieved by specific comparisons most commonly referred to as pairwise comparisons (Williams & Abdi, 2010). The most common post-hoc tests are described below:

Fisher's LSD test - The least significant difference or LSD test was the first pairwise comparison developed by Fisher and can be used if the ANOVA F value is significant ($p < 0.05$) (Brown, 2005). The test aims *to 'compute the smallest significant difference between two means as if these had been the only means to be compared and to declare significant any difference larger than the LSD'* (Williams & Abdi, 2010, pp.1). The test has more power in comparison to other post-hoc tests '*because the* α *level for each comparison is not corrected for multiple comparisons'* (Williams & Abdi, 2010, pp.3). Consequently, this can increase the Type I error (finding a difference when it does not actually exist) (Williams & Abdi, 2010). As a result, Fisher's LSD test has been recommended only for comparing maximum three groups, since the Type I error increases exponentially with the number of groups (Brown, 2005).

Tukey's HSD test - The honestly significant difference or HSD test was developed by John Tukey and is considered as one of the most conservative post-hoc test, due to employing considerable control over the Type I error (Homack, 2001). The HSD test explores whether the means of two groups are the same and '*is designed to make all pairwise or simple comparisons while maintaining the experiment wise error rate at the pre-established* α *level*' (Brown, 2005, pp.91). Initially the Tukey's test was used solely for the groups with an equal number of participants/observations and was later modified by Kramer to be suitable for unequal group sizes (Lee & Lee, 2018).

Scheffé's post-hoc test – Developed by Henry Scheffé, the post-hoc method compares the means based on the F distribution and includes all possible contrasts not only paired comparisons (Kim, 2015). The test can be used only if the null hypothesis has been rejected as a result of the ANOVA test. Then the Scheffé's post-hoc method will compute *'all possible contrasts between means and the Type I error at most* α *for any of the possible combinations'* (Brown, 2005, pp.92). If the Scheffé's test statistic is larger than the critical value, the null hypothesis is rejected. The test is considered appropriate when the researcher is interested in a broad range of complex tests as it results in a high Type II error correction, and '*is not recommended when only pairwise comparisons are of interest'* (Kim, 2015, pp.175).

Dunnett's test – Developed by Charles Dunnett, is a very powerful post-hoc method and can detect relatively small yet significant differences while comparing the mean of one group to the mean of the other groups (Brown, 2005; Lee & Lee, 2018). Dunnett's test is recommended for studies where a specific group, such as the control group is compared with each of the other groups (Ruxton & Beauchamp, 2008). However, the test can only be applied in a situation where one group is compared to others and cannot compare the groups between each other. Another property of the Dunnett's test is that it can be used for one-tailed or two-tailed testing (Lee & Lee, 2018). This can be particularly useful in studies exploring the effects of a new drug versus the effects of the known drug (two-tailed) and comparing the new drug to a control group (Lee & Lee, 2018).

Bonferroni's post-hoc test – Developed by Bonferroni, the post-hoc test is used to control the spurious significant differences, which are observed when evaluating multiple pairwise means and increasing the number of comparisons. The Bonferroni post-hoc test '*compensates for the multiple comparisons by dividing'* the probability by the number of comparisons made (Etymologia: Bonferroni correction, 2015, pp.289). For example, if a study would test five comparisons with a significance level set at .05, '*there would be up to a 25% likelihood that any one of them would show a significant difference by chance'* (Etymologia: Bonferroni correction, 2015, pp.289). By using the Bonferroni test the significance level would be adjusted to .01 (significance level divided by the number of tests) (Etymologia: Bonferroni correction, 2015). Though the test can reduce the chance of Type I error, it can increase the Type II error (which defines falsely accepted null hypothesis – false positive) due to its stringent nature (Armstrong, 2014).

The second study utilised the LSD post-hoc test to compare the means of the three age groups whenever the ANOVA F value proved significant. Though the LSD post-hoc test is not the most popular option amongst the researchers (Meier, 2006; Kim, 2015), the HSD and Bonferroni as well as the Sheffe's post-hoc tests appeared to be too strict for the purposes of this study and are more frequently used in biomedical research and clinical trials (Meier, 2006). Similarly, the Dunnett's post-hoc test was not considered as it is only applied in situations where various groups are being compared to one particular group (i.e. treatment groups to one control group).

Findings

The analysis revealed that the alternative hypothesis set in this study was confirmed showing differences in physical activity and well-being perceptions of family carers of people with dementia between offspring carers 50-60 years old, spouse carers 60-70 years old and spouse carers 70 or more years old.

Table 8 shows baseline characteristic of the participants. Amongst the 166 informal carers of people with dementia who completed questionnaires 89 were female, 76 male and 1 gender not specified. Most of the informal carers were 50-60 years of age (38.9%), followed by carers 60-70 years of age (31.7%). Elderly carers 70+ years of age represented the smallest age group (29.3%). More than 50% were from the UK (19.3% White British, 13.9% Asian or Asian British, 15.1% Black or Black British and 7.2% of other ethnic backgrounds) and 44.6% were from Slovenia (ethnicity is presented in Figure 1). The carers were mainly providing care for their partner/spouse (53%), followed by the carers caring for their parents (34.9%), and finally carers providing care for other individual (7.2%) and their brother/sister (4.8%).

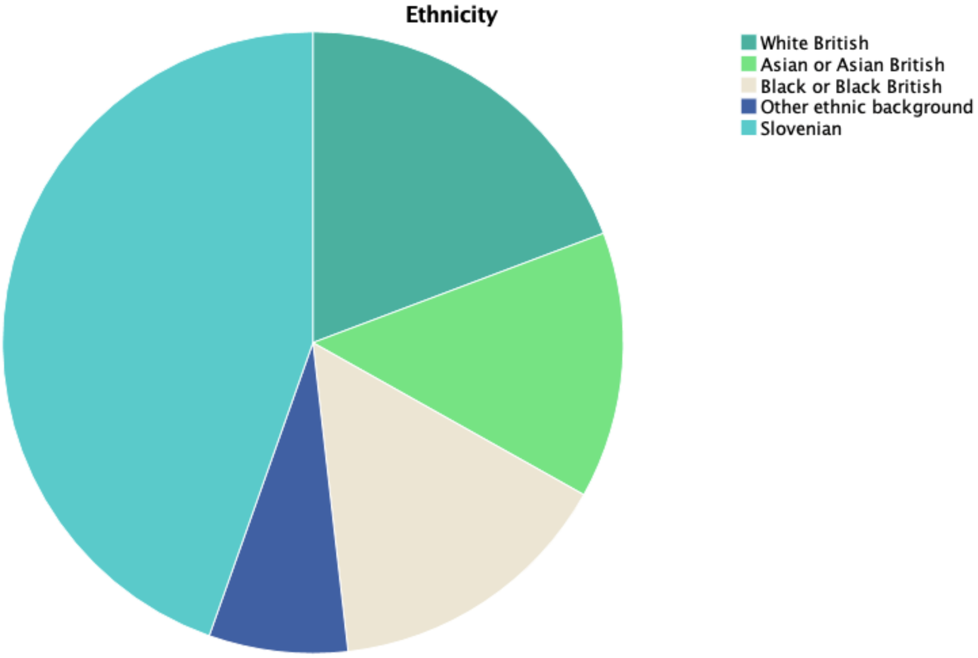


Figure 1 Ethnicity

Table 8 Baseline Characteristics

Informal Caregivers	**Number of Participants**	**Percent**
Age group		
50-60	65	38.9
60-70	53	31.7
70+	48	29.3
Total	166	
Gender		
Female	89	53.3
Male	76	45.5
Not specified	1	1.2
Ethnicity		
White British	32	19.3
Asian or Asian British	23	13.9
Black or Black British	25	15.1
Slovenian	74	44.6
Other Ethnic Background	12	7.2
Caring for		
My partner/spouse	88	53
My brother/sister	8	4.8
My parents	58	34.9
Other	12	7.2

Role as a Carer

When carers were asked to rate the concerns, such as not being able to take a break and not being able to plan for the future, analysis revealed significant differences between the age groups. One way ANOVA, with age, as an independent variable and role as a carer as dependent variable showed, F (2.163), MSe = 0.29, $p < 0.001$ (Table 9). Post-hoc comparisons of the means using LSD showed significant differences between all three age groups with 50-60 vs 60-70, $p < 0.002$, 50-60 vs 70+, $p < 0.001$ and 60-70+ vs 70+, $p < 0.001$ (Table 10).

Table 9 Differences between the age groups and Role as a carer

				50-60	**60-70**	**70+**
	F	MSe	p	*M (SD)*	*M (SD)*	*M (SD)*
Role as carer	2.163	0.29	<0.001	2.84 (0.62)	2.52 (0.49)	3.51 (0.46)

Table 10 LSD Multiple comparison by age

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	< 0.002	0.319	0.099	0.1231	0.5168
50-60 vs 70+	< 0.001	-0.675	0.102	-0.8780	-0.4731
60-70 vs 70+	< 0.001	-0.995	0.107	-1.2075	-0.7836

*. The mean difference is significant at the 0.05 level.

Information & Advice for Carers

Satisfaction with the information and advice for informal carers and knowing where to find it differed between the age groups. One way ANOVA, with age, as an independent variable and Information & advice for carers as dependent variable showed, F (2.163), MSe = 0.28, p < 0.001 (Table 11). Post-hoc comparisons of the means using LSD showed significant differences between 50-60 vs 70+ and 60-70 vs 70+ age groups with 50-60 vs 70+, p < 0.001 and 60-70 vs 70+, p < 0.001. Age group 50-60 vs 60-70 showed no significant differences (Table 12).

Table 11 Differences between the age groups and Information & Advice

				50-60	**60-70**	**70+**
	F	MSe	p	*M (SD)*	*M (SD)*	*M (SD)*
Information & Advice	2.163	0.28	<0.001	2.09 (0.65)	2.13 (0.49)	3.64 (0.37)

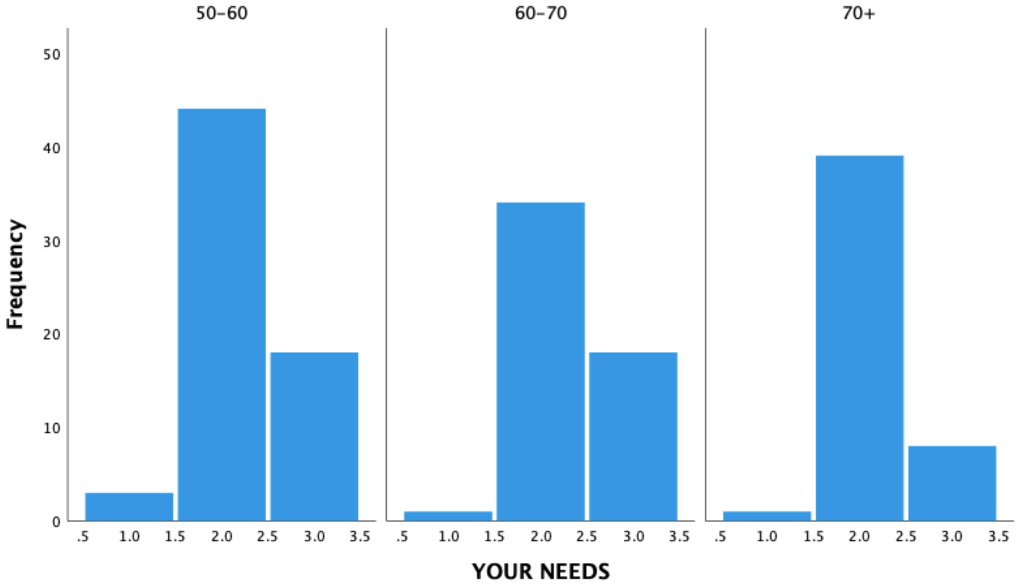
Table 12 LSD Multiple comparison by age

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.686	-0.398	0.098	-0.2337	0.1541
50-60 vs 70+	< 0.001	-1.543	0.100	-1.7425	-1.3437
60-70 vs 70+	< 0.001	-1.503	0.106	-1.7121	-1.2946

*. The mean difference is significant at the 0.05 level

Support & Needs

All the age groups expressed a high need for a little support as carers. However, in contrast to the oldest group of carers (70+ years of age), the youngest group (50-60 years of age) and the carers aged 60-70 years expressed higher need for a lot of support in their roles (Figure 2).



* 1 = No, not at all, 2 = Yes, a little, 3 = Yes, a lot

Figure 2 Support in your role as a carer

One way ANOVA, with age, as an independent variable and support needs as dependent variable showed no significant differences between the age groups, F (2.163), MSe = 0.24, p = 0.203

Table 13 Differences between the age groups and Support & Needs

				50-60	60-70	70+
	F	MSe	p	*M (SD)*	*M (SD)*	*M (SD)*
Support & Needs	2.163	0.24	0.203	2.23 (0.52)	2.32 (0.51)	2.15 (0.41)

The highest demand for additional support amongst the youngest age group of informal carers (50-60 years of age) was financial (58%), followed by support from a professional carer or a daycare centre (52.5%), counselling/emotional support (44.4%) and taking free time or go on holidays (42.9%). This group needed very little support with the transport/travel (9.5%) and household/garden/cooking and shopping (2.6%). The youngest carers expressed occasional need for the support from the community/supported activities for people with dementia (36.4%) and assistance with providing personal hygiene/manual handling (23.8%). The carers aged 60-70 years showed higher need for help with transport/travel (47.6%), support from the community/supported activities for people with dementia (45.5%), support from a professional carer or a daycare centre (45%), taking free time or go on holidays (42.9%) and help with medication/doctors' appointments (40%). This group of carers needed some support with Information on disease/care/nutrition and communication (35.3%) and assistance with providing personal hygiene/manual handling (33.3%). The oldest group of carers 70+ years of age showed the highest demand for assistance with household/garden/cooking/shopping (71.1%), followed by a general advice on their role as carers (66.7%), help with medication/doctor's appointments (50%), support with Information on disease/care/nutrition and communication (47.1%), counselling/emotional support (44.4%), personal hygiene/manual handling (42.9%) and help with transport/travel (24.9%). They expressed very little demand for support from a professional carer or a daycare centre (2.5%) (Table 14).

Table 14 Demand for additional support

Support	50-60	60-70	70+
Help with the household/garden/cooking/shopping	2.6%	26.3%	71.1%
Help with transport/travel	9.5%	47.6%	42.9%
Daycare/stay-in-carer/paid carer	52.5%	45.0%	2.5%
Financial	58.0%	28.0%	14.0%
Free time/a break/ day off/ holidays	42.9%	42.9%	14.3%
Personal hygiene/ manual handling	23.8%	33.3%	42.9%
General advice/information for employed informal carers	16.7%	16.7%	66.7%
Information on disease/care/nutrition/communication	17.6%	35.3%	47.1%
PPE/help with medication/doctor’s appointments	10.0%	40.0%	50.0%
Support from the community/supported activities for people with dementia	36.4%	45.5%	18.2%
Counselling/emotional support	44.4%	11.1%	44.4%

*PPE: Personal Protective Equipment

In order to take a break from caring the youngest group of carers received support from family members or friends (71.9%), had paid carers coming into their home (74.4%) or had paid carers providing care for the person with dementia outside of their home (43.1%). Some younger carers used supported activities for people with dementia outside of their home (30%) and almost half (42.9%) said they do not need support to take a break from caring. On the other hand, the majority (70.0%) of carers aged 60-70 years used supported activities for the person they cared for outside of their homes and some used paid carers providing care away from their home (36.2%). More than half of the carers 60-70 years of age (66.7%) said they are unable to take a break from caring. In contrast, the highest percentage (87.0%) of the eldest carers 70+ years of age said they do not need to take a break from caring and were, opposed to the youngest group of carers, receiving the least support from other family members or friends (3.1%) and paid carers providing care in their home (2.6%). Interestingly, almost the same proportion of carers aged 60-70 years and 70+ (28.6% and 28% respectively) said they do not need support to take a break from caring (Table 15).

Table 15 Break used by carers

Support used	50-60	60-70	70+
Friend/family providing temporary care	71.9%	25.0%	3.1%
Paid carers coming into the home	74.4%	23.1%	2.6%
Paid carers providing care away from the home	43.1%	36.2%	20.7%
Supported activities out of the home, for the person you care for	30.0%	70.0%	/
I am unable to take a break from caring	16.7%	66.7%	16.7%
I do not need support to take a break from caring	42.9%	28.6%	28.0%
I do not need to take a break from caring	4.3%	8.7%	87.0%
Other	21.4%	28.6%	50.0%

Relationship Style

When carers were asked to describe their relationship style analysis showed significant differences between the age groups. One way ANOVA, with age, as an independent variable and Relationship style as a dependent variable showed, F (2.163), MSe = 1.37, p < 0.001 (Table 16). Post-hoc comparisons of the means using LSD showed significant differences between 50-60 vs 70+ and 60-70 vs 70+ age groups with 50-60 vs 70+, p < 0.001 and 60-70 vs 70+, p < 0.007. Age groups 50-60 vs 60-70 showed no significant differences (Table 17).

Table 16 Differences between the age groups and Relationship Style

				50-60	**60-70**	**70+**
	F	MSe	p	*M (SD)*	*M (SD)*	*M (SD)*
Relationship Style	2.163	1.37	<0.001	2.68 (1.26)	2.91 (1.20)	3.54 (0.99)

Table 17 LSD Multiple comparison by age

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.292	-0.229	0.216	-0.66	0.20
50-60 vs 70+	< 0.001	-0.865	0.222	-1.30	-0.43
60-70 vs 70+	0.007	-0.636	0.233	-1.10	-0.186

*. The mean difference is significant at the 0.05 level.

Figure 3 demonstrates a representation of different relationship styles amongst the informal carers by age group. Dismissing relationship style was a predominant style amongst all the groups, however it had the highest representation amongst the eldest group of informal carers.

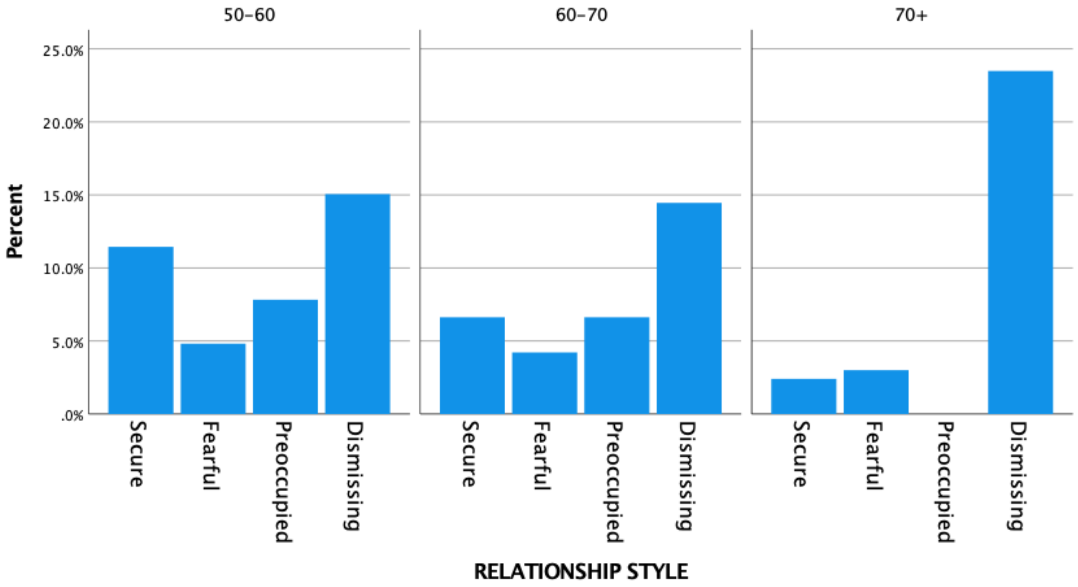


Figure 3 Relationship Style

Being Active During School/University

The analysis showed no significant differences between the age groups and their activity levels during school/university. One way ANOVA, with age, as an independent variable and being active in School/University as dependent variable showed, F (2.163), MSe = 0.24, p = 0.409 (Table 18).

Table 18 Differences between the age groups and being active during School/University

				50-60	**60-70**	**70+**
	F	MSe	p	*M (SD)*	*M (SD)*	*M (SD)*
Being Active in School/University	2.163	0.24	0.409	1.32 (0.47)	1.42 (0.50)	1.44 (0.50)

Figure 4 demonstrates a representation of physical activity participation during school/university amongst the informal carers by age group. The age group 50-60 showed the highest physical activity participation during school/university in comparison to other two groups.

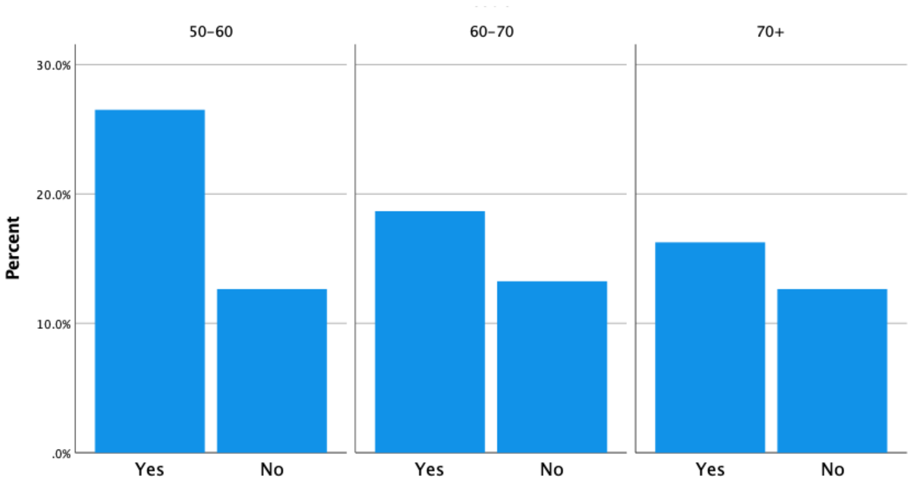


Figure 4 Being active in School/University

Current Physical Activity Participation

However, when carers were asked about their current levels of physical activity the analysis showed significant differences between the age groups. One way ANOVA, with age, as an independent variable and current physical activity participation as dependent variable showed, F (2.163), MSe = 0.21, p < 0.001 (Table 19). Post-hoc comparisons of the means using LSD showed significant differences between all three age groups with 50-60 vs 60-70, p = 0.008, 50-60 vs 70+, p < 0.001 and 60-70 vs 70+, p = 0.004 (Table 20).

Table 19 Differences between the age groups and current physical activity participation

				50-60	**60-70**	**70+**
	F	MSe	p	*M (SD)*	*M (SD)*	*M (SD)*
Currently Physically Active	2.163	0.21	<0.001	1.34 (0.47)	1.57 (0.50)	1.83 (0.38)

Table 20 LSD Multiple comparison by age

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.008	-0.228	0.085	-0.40	-0.06
50-60 vs 70+	< 0.001	-0.495	0.087	-0.67	-0.32
60-70 vs 70+	0.004	-0.267	0.091	-0.45	-0.09

*. The mean difference is significant at the 0.05 level.

Figure 5 demonstrates a representation of current physical activity participation amongst the informal carers of people with dementia by age group. The youngest group of informal carers aged 50-60 years showed the highest current physical activity participation in comparison to other two groups and the oldest group of carers (70+ years of age) showed the lowest current physcial activity participation.

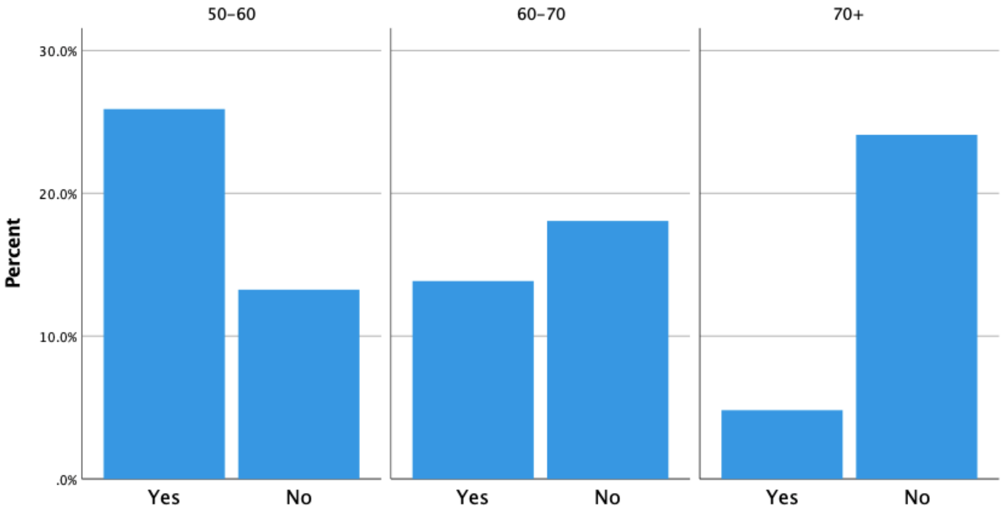


Figure 5 Current PA participation

Beliefs About Exercise Programme

Whether participants thought an exercise programme would interfere with their caring role significantly differed between the age groups. One way ANOVA, with age, as an independent variable and exercise & caring as dependent variable showed, F (2.162), MSe = 0.18, p < 0.001 (Table 21). When they were asked whether they think an exercise programme would benefit their caring role was also significantly different between the age groups. One way ANOVA, with age, as an independent variable and exercise & caring benefits as dependent variable showed, F (2.163), MSe = 0.10, p < 0.001 (Table 21). Post-hoc comparisons of the means using LSD showed significant differences between all three age groups for exercise & caring with 50-60 vs 60-70, p = 0.001, 50-60 vs 70+, p < 0.001 and 60-70 vs 70+, p < 0.001 and for exercise & caring benefits with 50-60 vs 70+, p < 0.001 and 60-70 vs 70+, p < 0.001. There were no significant differences between the 50-60 vs 60-70, p = 0.822 (Table 22).

Table 21 Differences between the age groups, exercise & caring role

				50-60	**60-70**	**70+**
	F	MSe	p	*M (SD)*	*M (SD)*	*M (SD)*
Exercise & Caring	2.162	0.18	<0.001	1.72 (0.45)	1.45 (0.50)	1.08 (0.28)
Exercise & Caring Benefits	2.163	0.10	<0.001	1.11 (0.31)	1.09 (0.30)	1.85 (0.36)

Table 22 LSD Multiple comparison by age

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
Exercise & Caring					
50-60 vs 60-70	0.001	0.266	0.080	0.11	0.42
50-60 vs 70+	< 0.001	0.635	0.082	0.47	0.80
60-70 vs 70+	< 0.001	0.369	0.085	0.20	0.54
Exercise & Caring Benefits					
50-60 vs 60-70	0.822	0.013	0.059	-0.10	0.13
50-60 vs 70+	< 0.001	-0.746	0.061	-0.87	-0.63
60-70 vs 70+	< 0.001	-0.760	0.064	-0.89	-0.63

*. The mean difference is significant at the 0.05 level.

Perceptions and Knowledge of Exercise

When carers were asked how strongly do they agree/disagree with statements regarding exercise participation such as ‘It’s hard for me to fit exercise into my life, I do not exercise because I do not know what kind of exercise to do, I cannot exercise because of health problems, I exercise because it is good for my health, I exercise because my doctor instructed me to do so, exercising gives me more energy and relives stress for me, I’m too out of shape to exercise’ and others the analysis showed significant differences between the age groups. One way ANOVA, with age, as an independent variable and exercise participation as dependent variable showed, F (2.163), MSe = 0.12, p < 0.001 (Table 23). The difference between the age groups was also significant when the carers were asked how often a person their age should exercise to be healthy. One way ANOVA, with age, as an independent variable and exercise frequency as dependent variable showed, F (2.163), MSe = 0.12, p < 0.001 (Table 23). And lastly when participants were asked how long each exercise session should be, the analysis showed significant differences between the age groups. One way ANOVA, with age, as an independent variable and exercise duration as dependent variable showed, F (2.160), MSe = 1.25, p < 0.001 (Table 23). Post-hoc comparisons of the means using LSD showed significant differences between all three age groups for exercise participation with 50-60 vs 60-70, p = 0.001, 50-60 vs 70+, p < 0.001 and 60-70 vs 70+, p < 0.001. Differences between age groups for exercise frequency and exercise duration were significant only for 50-60 vs 70+ and 60-70 vs 70+ age groups with p < 0.001 (Table 24).

Table 23 Differences between the age groups and perceptions and knowledge of exercise

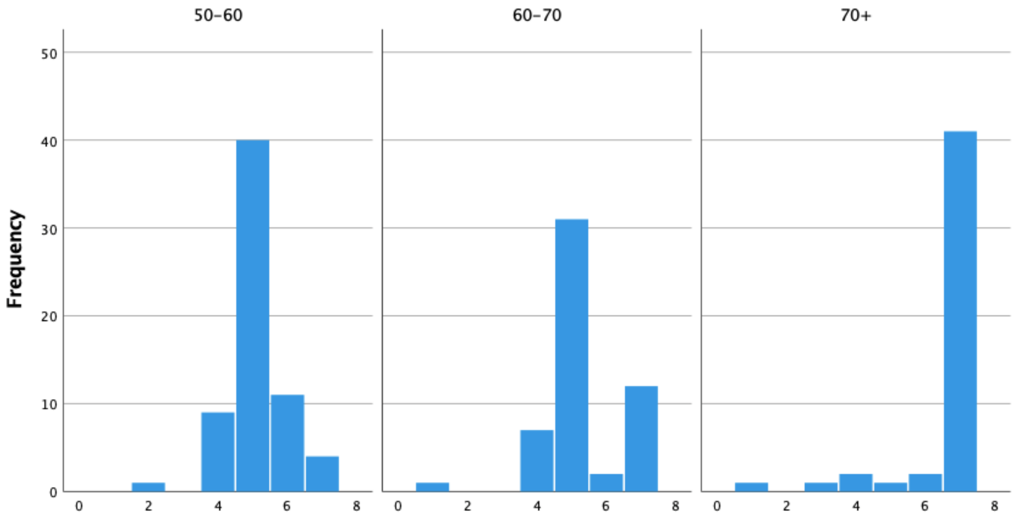
				50-60	60-70	70+
	F	MSe	p	*M (SD)*	*M (SD)*	*M (SD)*
Exercise Participation	2.163	0.12	< 0.001	2.73 (0.39)	2.52 (0.36)	2.09 (0.25)
Exercise Frequency	2.163	1.11	< 0.001	5.11 (0.83)	5.28 (1.15)	6.58 (1.20)
Exercise Duration	2.160	1.25	< 0.001	3.72 (0.76)	3.78 (1.14)	5.02 (1.47)

Table 24 LSD Multiple comparison by age

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
Exercise Participation					
50-60 vs 60-70	0.001	0.214	0.064	0.09	0.34
50-60 vs 70+	< 0.001	0.637	0.066	0.51	0.77
60-70 vs 70+	< 0.001	0.423	0.069	0.29	0.56
Exercise Frequency					
50-60 vs 60-70	0.370	-0.175	0.195	-0.56	0.21
50-60 vs 70+	< 0.001	-1.476	0.200	-1.87	-1.08
60-70 vs 70+	< 0.001	-1.300	0.210	-1.71	-0.89
Exercise Duration					
50-60 vs 60-70	0.770	-0.061	0.209	-0.47	0.35
50-60 vs 70+	< 0.001	-1.298	0.214	-1.72	-0.87
60-70 vs 70+	< 0.001	-1.237	0.226	-1.68	-0.79

*. The mean difference is significant at the 0.05 level.

Figure 6 demonstrates a representation of informal carers' knowledge of exercise frequency needed for health benefits. The youngest group of carers (50-60 years of age) and the group 60-70 years of age thought exercising three times a week would have the most health benefits. In contrast the oldest group of carers (70+ years of age) did not know which frequency would bring the most health benefits. In terms of exercise duration, the carers 50-60 and 60-70 years of age mainly thought the exercise session should last for 30 minutes or 45 minutes and more whereas carers 70+ largely did not know how long the session should last.



* 1= not at all, 2= less than 1x a month, 3= 1-2x a month, 4= 1x a week, 5= 3x a week, 6= 5x + a week, 7 = I don't know

Figure 6 Exercise frequency per age group

Staying Healthy

When participants were asked about the importance of factors to stay healthy (SH), such as reducing stress, eating right, getting enough exercise etc. the analysis showed significant differences between the age groups. One way ANOVA, with age, as an independent variable and important factors to stay healthy as dependent variable showed, F (2.162), MSe = 0.13, p < 0.001 (Table 25). There were no significant differences found amongst the age groups and how important carers thought exercise is to stay healthy (Table 25).

Post-hoc comparisons of the means using LSD for important factors to SH showed significant differences between 50-60 vs 70+ and 60-70 vs 70+ age groups with 50-60 vs 70+, p < 0.001 and 60-70 vs 70+, p < 0.001. Age group 50-60 vs 60-70 showed no significant differences (Table 26).

Table 25 Differences between the age groups and staying healthy (SH)

				50-60	**60-70**	**70+**
	F	MSe	p	*M (SD)*	*M (SD)*	*M (SD)*
Important Factors to SH	2.162	0.13	< 0.001	1.53 (0.31)	1.62 (0.47)	2.06 (0.25)
Exercise & Stay Healthy	2.161	0.79	0.382	2.13 (0.42)	2.28 (0.69)	2.35 (1.39)

Table 26 LSD Multiple comparison by age

Important Factors to SH	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.197	-0.085	0.066	-0.22	0.04
50-60 vs 70+	< 0.001	-0.530	0.068	-0.66	-0.40
60-70 vs 70+	< 0.001	-0.444	0.071	-0.58	-0.30

*. The mean difference is significant at the 0.05 level.

Discussion

The second study has confirmed the differences between the three age groups of informal carers providing care to people with dementia from study 1 and how they perceived their well-being and physical activity. These age groups are informal carers aged 50-60, 60-70 and 70+.

Even though numerous studies reported about the carer burden and challenges informal carers of people with dementia experience while providing care (Aldeman et al., 2014; Pinquart et al., 2003), this study suggests that, while all informal carers experienced challenges these differed between the three age groups of carers. The oldest carers experienced less burden while providing care than the youngest carers, while the carers aged 60-70 experienced the highest burden. The latter group reported higher concerns over not having enough time for themselves, not being able to take a break from caring and not being able to plan for the future.

The youngest carers and carers 60-70 expressed they were somewhat satisfied with the amount of advice and information available to support their role, as well as where to go in order to get it. In contrast the oldest carers expressed high dissatisfaction regarding the amount of information and advice available as well as not knowing where to find it.

Being able to locate and receive help and support while providing care is paramount in order to get free time and participate in preferred activities. Even though there are currently many initiatives offering help and support for carers of people with dementia, research findings continuously report that caregivers feel unsupported (Farina et al., 2017; The Health and Wellbeing of Unpaid Carers report, 2015). This study, however showed that overall, the youngest group of carers used more means of support in order to get a break from caring than the other two age groups. The support used included paid carers coming into their homes or providing care outside the home, as well as having family support. Carers aged 60-70 manly used supported activities outside their home, which in general last no more than 2 hours giving this group a very limited amount of time for preferred activities. In contrast, the eldest carers showed more reluctance towards receiving help and support especially from paid carers coming to their house.

Even though the youngest carers reported the highest level of PA participation during school/University, all carers reported being active in that period. However, there were significant differences between the age groups and current PA participation. The oldest group of carers reported being the least active whereas the youngest age group of carers reported being the most active. The 70+ group also believed that exercise would interfere with their caring role and would not benefit the caring. Whereas the other two age groups recognised that a PA programme would benefit them as carers and the quality of the care they provide. Similarly, an understanding of the duration and frequency of an exercise programme differed between the age groups. The eldest carers showed poorer knowledge of frequency and duration of each exercise session in comparison to the other two age groups of carers. This might be due to the fact that perceptions and knowledge of physical activity have changed profoundly in the last couple of decades. All the industrial and health campaigns, products, programmes, research findings and new mediums, especially Internet, expanded the knowledge of physical activity and its health benefits. However, even though overall awareness increased people older than 70 years got excluded. Recent studies showed that this group is the least active on the internet (Boekel et al., 2017; Klimova et al., 2018) and is more likely to attain health related information from a health care provider (Turner et al., 2018), who on the other hand lack confidence and knowledge to promote physical activity (Brooks et al., 2016).

Interestingly, there is a number of studies that acknowledged that carers differ by age, gender, culture and their relationship with the care receiver, which can affect how they experience their role as carers and consequentially make decisions (Rigby et al., 2019; Francis & Hanna, 2022; Larkin et al., 2022; Lorini et al., 2022). Rigby et al. (2019) found that offspring carers saw the care recipient less than the spouses or partners, reported lower quality of life/more caregiver burden, and were receiving more support than the spousal caregivers and experienced less grief when the disease of the care receiver progressed. In parallel, Francis & Hanna (2022) found that informal carers of people with dementia from different cultural backgrounds differed based on how they perceived and searched for help. Furthermore, Larking et al. (2022) reported that older carers often did not self-identify as carers, due to their relationship and co-residency with the care receiver. They also struggled with obtaining support and did not receive any information until the person they cared for got admitted to the hospital (Larkin et al., 2022). Similarly, Lorini et al. (2022) found that the percentage of inadequate health literacy amongst spousal caregivers was higher than amongst the offspring cares. Moreover, not meeting the unique needs of informal carers of people with dementia and acknowledging their past experiences and views can result in higher rejection of support services. Zwingmann et al. (2020) reported that carers rejection rate concerning social integration, for example joining caregiver support groups was high mainly due to personal views of caregivers and service factors. Higher rejection was specifically associated with a higher cognitive functioning of the person with dementia (Zwingmann et al., 2020). This study however did not explore if there are any age differences among the informal carers of people with dementia in the context of social services rejection rate. None of the differences observed in the studies above were looked through a physical activity perspective and how these differences might affect caregivers exercise participation and adherence.

Conclusion

People all over the world are ageing and living longer and not in any other time in the history so many generations had to live together and face similar challenges, such as taking care of their parent or spouse with dementia. The age difference between the oldest and the youngest carers, who are seen as a coherent group could be as much as 35 years, which is in the world that is constantly changing and evolving a significant amount. This study offers a novel understanding of how age differences and views about health care and physical activity carers grew up with affect their current understanding of physical activity and decisions they make regarding their health.

Dementia has been recognised as a worldwide concern, with numbers of people living with the condition and their family members/friends providing care increasing with each year. Therefore, future research focusing in identifying the three age groups of informal carers cross-nationally is needed. This might help to reform current support systems and physical activity programmes resulting in a better outreach and potentially form new interventions taking into account the characteristics of each age group rather than being drawn from a generalised support model.

CHAPTER SEVEN

Study 3

Differences in PA and well-being: perceptions of family carers of people with dementia – a cross-national study with cultural aspects

Abstract

Background: Though most of the countries that lie in the continent of Europe share strong economic partnerships, similar healthcare and social care regulations and have about equal living standards they differ culturally. Cultural diversity is especially prominent between the Northern/Western and Central/Southern European countries, such as the UK vs Slovenia. While informal carers of people with dementia have been recognised as a cornerstone of the long-term care plans in both countries, this study investigated potential national and cultural differences between the UK and Slovenia in connection to the three age groups recognised in Study 1 and 2, and carers' physical activity and well-being perceptions.

Methods: The third study used data collected during the second study and therefore applied the same methods of data collection. Participants completed a standardised questionnaire consisting of questions about carers' quality of life, relationship style with the care recipient and physical activity perceptions. Eligible participants were non-paid caregivers (either family members, relatives, or friends), living in the UK or Slovenia, 50 years of age or more and providing care for an individual diagnosed with dementia at least 5 hours per day.

Results: Overall, 166 informal carers completed the questionnaire, 92 were from the UK (22.9% of carers were 50-60 years of age, 19.9% were 60-70 years of age and 12.6% were 70+ years of age) and 74 were from Slovenia (16.2% of carers were 50-60 years of age, 12.0% were 60-70 years of age and 16.4% were 70+ years of age). Two-way ANOVA revealed no interaction effects between age groups, nationality, and role as a carer, however there were separate significant main effects for age groups and nationality. Similarly, there was no interaction effect between age, nationality, and information/advice availability, but significant main effects for both age groups and nationality. Interaction effect for age and nationality was also not significant for relationship style, with significant main effect for age groups and none for nationality. Being active during school/University showed no interaction effects between the age groups and nationality, and no main effects for both variables. No

interaction effect was found between the age groups and nationality, and current physical activity participation, however main effects were significant for both, age groups and nationality. The analysis showed no interaction effect between the age groups and nationality, and whether the exercise would interfere with the carers' role, with significant main effect for age groups and no significant main effect for nationality. Likewise, the interaction effect between the age groups and nationality, and whether carers believed the exercise would benefit their role as carers was found not significant, with significant main effect for age groups and none for nationality. Reasons for or against exercise participation, exercise frequency and duration all showed non-significant interaction effects between the age groups and nationality, and significant main effects for age groups and none for nationality. And lastly, factors for staying healthy showed no interaction effect between age groups and nationality, and no main effects for both age groups and nationality.

Conclusion: While informal caregivers of people with dementia in Slovenia differed from the carers in the UK in the level of perceived burden, information and advice offered, current physical activity participation and the types of preferred activities suggesting potential national and cultural differences, there were no differences found in relationship style, exercise perceptions and knowledge. Additionally, three distinct groups of informal carers 50-60, 60-70 and 70+ years of age were present cross-nationally. These findings offer a novel perspective on how culture, age and nationality might affect actions and perceptions caregivers have regarding their health, physical activity and how they perceive their role. Future researchers and policy makers should take into account the complexity of informal caregivers and not portray them as a homogenous group when implementing and designing new programmes/initiatives/policies.

Introduction

Conclusions from study 2 confirmed initial findings from study 1 and showed how they were generalised across a wider population. The findings revealed significant differences between the age groups of informal carers of people with dementia and how they perceived their roles as carers, burden associated with care provision, satisfaction with information and advice availability, relationship style and physical activity. Data was collected in two countries the UK (London) and Slovenia (Ljubljana), which in spite of strong bilateral relations and shared similarities such as almost universal healthcare coverage, recognising dementia as an epidemic, acknowledging the need to support informal carers and recognising the health benefits of regular physical activity, the countries share many differences. Amongst the obvious such as the geographical location and cultural differences the countries also differ in historical political regimes, which significantly affected how informal care and physical activity is currently perceived, the healthcare infrastructure, the range, access, and support offered to informal carers of people with dementia, and the funds available to support the initiatives and programmes for this population.

Study 3 therefore focused solely on exploring cross-national and cultural differences between the informal carers of people with dementia in the UK and Slovenia. This might play a crucial role in designing and implementing new or amending existing physical activity programmes and/or other initiatives (i.e. physical activity awareness programmes) which might help different groups of informal carers of people with dementia to reach the recommended daily physical activity levels. The findings could also lead to collaboration and knowledge exchange amongst the countries and a dissemination of the practices that work well.

The main aim and objectives were:

- To explore whether there are differences between the various age groups of British and Slovenian informal carers (50-60, 60-70 and70+) and their perceptions of physical activity and well-being.
- To examine national and cultural differences among the Slovenian and British informal carers and how they perceive their roles as carers, burden associated with care provision, satisfaction with information and advice availability, relationship style and physical activity.

The research question was: are physical activity and well-being perceptions of family carers of those with dementia different between the three groups: offspring carers aged 50-60, spouse carers aged 60-70, and spouse carers aged 70+ between the UK and Slovenia?

Hypothesis: Physical activity and well-being perceptions of family carers of people with dementia differ between offspring carers 50-60 years old, spouse carers 60-70 years old and spouse carers 70+ between the UK and Slovenia.

Methodology

Study 3 statistically compared the data collected from study 2, therefore the information regarding the methodology, sample, data collection and ethics has been provided earlier and can be found on pages 72-74. A few changes were made to the data analysis process.

Data analysis

To explore the differences between the three groups of informal carers of people with dementia from the UK and Slovenia, two-way between-groups analysis of variance (ANOVA) was used. The test allows the researchers to *"assess the individual and joint effects of two independent variables on one dependent variable"* (Pallant, 2020, pp.281). In this study the researcher used 3 X 2 factorial design. Age groups and nationality were considered as independent variables and role as a carer, information & advice, relationship style, physical activity participation during school/University, current physical activity participation, beliefs about exercise programme, perceptions & knowledge of exercise, and actions informal carers took to stay healthy as dependent variables. The advantage of using the two-way ANOVA is *"that we can test the main effect for each independent variable and also explore the possibility of an interaction effect"* which is not possible with one-way analysis of variance (Pallant, 2020, pp.281).

The independent variables in factorial experimental designs are commonly called factors and the groups of these variables are typically called levels (Parke, 2010). The two-way ANOVA calculation considers two fixed factors (i.e. factor A and factor B) and their levels (i.e. a levels for factor A, b levels for factor B and ab levels for a combination of factor A and B) (Larson, 2008). The effect where one of the independent variables has an effect on the dependent variable and ignore the effects of all other independent variables is called a "main effect" (Pallant, 2020). *"Tests of main effects are tests of one factor averaged over levels of the other factors"* (Larson, 2008, pp.118). Hence, in cases where there is no interaction between the two factors, the effect of one factor is the same across all levels of the other factor (Larson, 2008). In contrast, the interaction effects represent the combined effect of independent variables on the dependent measure, meaning that the impact of one factor depends on the level of the other. An interaction exists when the difference between the levels of the first independent variable changes throughout the levels of the second independent variable (Pallant, 2020).

Partial eta squared was used as an index to determine the interaction effect size in the two-way ANOVA calculation. The value for partial eta square normally varies between 0 and 1. The closer the values come to 1 the larger the effect size and the closer the values are to 0, the smaller the effect size (0.01 – small effect size, 0.06 – medium effect size, 0.14 or more – large effect size) (Richardson, 2011; Cohen, 2013). Additional characteristics of partial eta square are that *"it can be applied to all research designs, it can be calculated from inferential statistics in published research reports and is widely used in educational research"* (Richardson, 2011, pp.144).

In cases where the main or interaction effects are significant ($p<0.05$), another test has to be conducted in order to see where the significant differences are. Most common approaches to obtain more detailed information on where the differences are located are one-way ANOVA, post-hoc tests, simple effects tests and planned comparisons (Garofalo et al., 2022). This study utilised the LSD post-hoc test, which is described in more detail on page 68.

Data was analysed using IBM SPSS Version 27 software and the statistical significance was set at $p<0.05$. First the frequencies for age groups, gender and who the informal carers of people with dementia were caring for were separated by nationality. Then the two-way ANOVA was used in order to see whether there are differences between the three age groups and Slovenian and British nationalities.

Findings

The analysis revealed that the alternative hypothesis set in this study was confirmed showing differences in physical activity and well-being perceptions of family carers of people with dementia between offspring carers 50-60 years old, spouse carers 60-70 years old and spouse carers 70 or more years old in Slovenia and the UK.

Table 27 shows baseline characteristic of the participants. Overall, 166 informal carers completed the questionnaire of which 92 were from the UK (38 or 22.9% of carers were 50-60 years of age, 33 or 19.9% of carers were 60-70 years of age and 21 or 12.6% of carers were 70+ years of age) and 74 were from Slovenia (27 or 16.2% of carers were 50-60 years of age, 20 or 12.0% of carers were 60-70 years of age and 27 or 16.4% of carers were 70+ years of age). The oldest carers represented the smallest group amongst the British citizens. On the contrary the carers 60-70 years of age represented the smallest group amongst the Slovenian carers. Among the British carers 50 (30.1%) were female, 41 (24.7%) were male and 1 (0.6%) was not specified. There were 39 (23.5%) female carers amongst the Slovenian population, 35 (21.1%) male carers and none were not specified. The British informal carers were mainly providing care for their partner/spouse (27.1%) followed by the carers caring for their parents (21.1%), then carers providing care for other individuals (5.4%) and finally the smallest group of carers were providing care to their brother/sister (1.8%). Similarly Slovenian carers were mainly caring for their partner/spouse (25.9%), followed by carers providing care to their elderly parents (13.9%). The smallest percentage of Slovenian informal carers were providing care to their brother/sister (3.0%) and other individuals (1.8%).

Table 27 Baseline Characteristics

Age groups by nationality	**Frequency**	**Percent**
British		
50-60	38	22.9
60-70	33	19.9
70+	21	12.6
Total	92	55.4
Slovenian		
50-60	27	16.2
60-70	20	12.0
70+	27	16.4
Total	74	44.6
Gender by nationality		
British		
Female	50	30.1
Male	41	24.7
Not specified	1	0.6
Slovenian		
Female	39	23.5
Male	35	21.1
Not specified	0	0
Caring for by nationality		
British		
My partner/spouse	45	27.1
My brother/sister	3	1.8
My parents	35	21.1
Other	9	5.4
Slovenian		
My partner/spouse	43	25.9
My brother/sister	5	3.0
My parents	23	13.9
Other	3	1.8

Role as a Carer

A two-way between groups analysis of variance was conducted to explore the impact of nationality and age groups on role as a carer as measured by the questionnaire used in the second study. Informal carers were divided into three groups according to their age (50-60, 60-70 and 70+). The interaction effect between nationality and age group was not statistically significant, F (2, 160), p = 0.388. However, there was a statistically significant main effect for age groups, F (2, 160), p = < 0.001 and nationality, F (1, 160), p = < 0.001; with the effect size being large for both variables (partial eta squared = 0.34 and 0.11 respectively) (Table 28). Post-hoc comparisons of the means using LSD showed significant differences between all three age groups with 50-60 vs 60-70, p < 0.001, 50-60 vs 70+, p < 0.001 and 60-70+ vs 70+, p < 0.001 (Table 29).

Table 28 Test of Between-Subjects Effects

				50-60		**60-70**		**70+**	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality * Age groups	2,160	0.25	0.388	2.73 (0.59)	2.99 (0.65)	2.41 (0.49)	2.70 (0.44)	3.22 (0.39)	3.74 (0.38)
Age groups	2,160	10.81	<0.001						
Nationality	1,160	5.13	<0.001						

*GB: British nationality, SLO: Slovenian nationality

Table 29 Multiple Comparisons

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	< 0.001	0.319	0.095	0.1329	0.5070
50-60 vs 70+	< 0.001	-0.675	0.097	-0.8679	-0.4833
60-70 vs 70+	< 0.001	-0.995	0.102	-1.1969	-0.7942

*. The mean difference is significant at the 0.05 level.

Information & Advice for Carers

A two-way between groups analysis of variance looking at the impact of nationality and age groups on information & advice for carers showed that the interaction effect between nationality and age group was not statistically significant, F (2, 160), p = 0.542. However, there was a statistically significant main effect for age groups, F (2, 160), p = < 0.001 and nationality, F (1, 160), p = < 0.001; with the effect size being large for age groups (partial eta squared = 0.64) and medium for nationality (partial eta squared = 0.09) (Table 30). Post-hoc comparisons of the means using LSD showed significant differences between the age groups with 50-60 vs 70+, p < 0.001 and 60-70+ vs 70+, p < 0.001. There were no significant differences between 50-60 vs 60-70 group (Table 31).

Table 30 Test of Between-Subjects Effects

				50-60		**60-70**		**70+**	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality * Age groups	2,160	0.16	0.542	1.92	2.33	2.00	2.35	3.52	3.72
				(0.62)	(0.62)	(0.35)	(0.61)	(0.33)	(0.38)
Age groups	2,160	36.26	<0.001						
Nationality	1,160	4.04	<0.001						

*GB: British nationality, SLO: Slovenian nationality

Table 31 Multiple Comparisons

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.673	-0.039	0.093	-0.2253	0.1457
50-60 vs 70+	< 0.001	-1.543	0.097	-1.7339	-1.3523
60-70 vs 70+	< 0.001	-1.503	0.101	-1.7031	-1.3036

*. The mean difference is significant at the 0.05 level.

Relationship Style

When carers were asked to describe their relationship style a two-way between groups analysis of variance showed that the interaction effect between nationality and age group was not statistically significant, F (2, 160), p = 0.246, however, there was a statistically significant main effect for age groups, F (2, 160), p = < 0.001 with medium effect size (partial eta squared = 0.10). There was no statistically significant effect on nationality, F (1, 160), p = 0.182 with small effect size (partial eta squared = 0.01) (Table 32). Post-hoc comparisons of the means using LSD showed significant differences between two age groups with 50-60 vs 70+, p < 0.001 and 60-70+ vs 70+, p < 0.007. There were no significant differences between 50-60 vs 60-70 group (Table 33).

Table 32 Test of Between-Subjects Effects

				50-60		60-70		70+	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality * Age groups	2,160	1.91	0.246	2.92 (1.26)	2.33 (1.21)	2.85 (1.18)	3.00 (1.26)	3.71 (0.72)	3.41 (1.15)
Age groups	2,160	11.96	<0.001						
Nationality	1,160	2.42	0.182						

*GB: British nationality, SLO: Slovenian nationality

Table 33 Multiple Comparison

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.289	-0.23	0.215	-0.65	0.20
50-60 vs 70+	< 0.001	-0.86	0.221	-1.30	-0.43
60-70 vs 70+	0.007	-0.64	0.231	-1.09	-0.18

*. The mean difference is significant at the 0.05 level.

Being Active During School/University

Two-way between groups analysis of variance looking at the impact of nationality and age groups on physical activity participation during school/University showed that the interaction effect between nationality and age group was not statistically significant, F (2, 160), p = 0.562 (Table 34). Post-hoc comparisons of the means using LSD showed no significant differences between the age groups.

Table 34 Test of Between-Subjects Effects

				50-60		60-70		70+	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality * Age groups	2,160	0.138	0.562	1.32 (0.47)	1.33 (0.48)	1.33 (0.48)	1.55 (0.51)	1.38 (0.50)	1.48 (0.51)
Age groups	2,160	0.241	0.366						
Nationality	1,160	0.491	0.154						

*GB: British nationality, SLO: Slovenian nationality

Current Physical Activity Participation

A two-way between groups analysis of variance looking at the impact of nationality and age groups on current physical activity participation showed that the interaction effect between nationality and age group was not statistically significant, F (2, 160), p = 0.913. However, there was a statistically significant main effect for age groups, F (2, 160), p = < 0.001 and nationality, F (1, 160), p = 0.019; with the effect size being large for age groups (partial eta squared = 0.181) and small for nationality (partial eta squared = 0.034) (Table 35). Post-hoc comparisons of the means using LSD showed significant differences between the age groups with 50-60 vs 60-70, p = 0.008, 50-60 vs 70+, p < 0.001 and 60-70+ vs 70+, p = 0.004 (Table 36).

Table 35 Test of Between-Subjects Effects

				50-60		**60-70**		**70+**	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality * Age groups	2,160	0.019	0.913	1.42 (0.50)	1.22 (0.42)	1.64 (0.49)	1.45 (0.51)	1.90 (0.30)	1.78 (0.42)
Age groups	2,160	3.649	<0.001						
Nationality	1,160	1.149	0.019						

*GB: British nationality, SLO: Slovenian nationality

Table 36 Multiple Comparison

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.008	-0.23	0.084	-0.39	-0.06
50-60 vs 70+	< 0.001	-0.49	0.086	-0.67	-0.32
60-70 vs 70+	0.004	-0.27	0.090	-0.045	-0.09

*. The mean difference is significant at the 0.05 level.

Figure 7 demonstrates that most of the carers aged 50-60 years participated in activities such as skiing, running, cycling, swimming and team sports. Participation in Yoga, Pilates, dancing, group exercise classes and going to a gym were also popular options. Informal carers aged 60-70 years mainly reported walking and hiking as their main choice of activities. Some carers from this age group also participated in group exercise classes or chose to go to the gym. The eldest group of informal carers 70+ years of age reported gardening and walking or hiking as their main option.

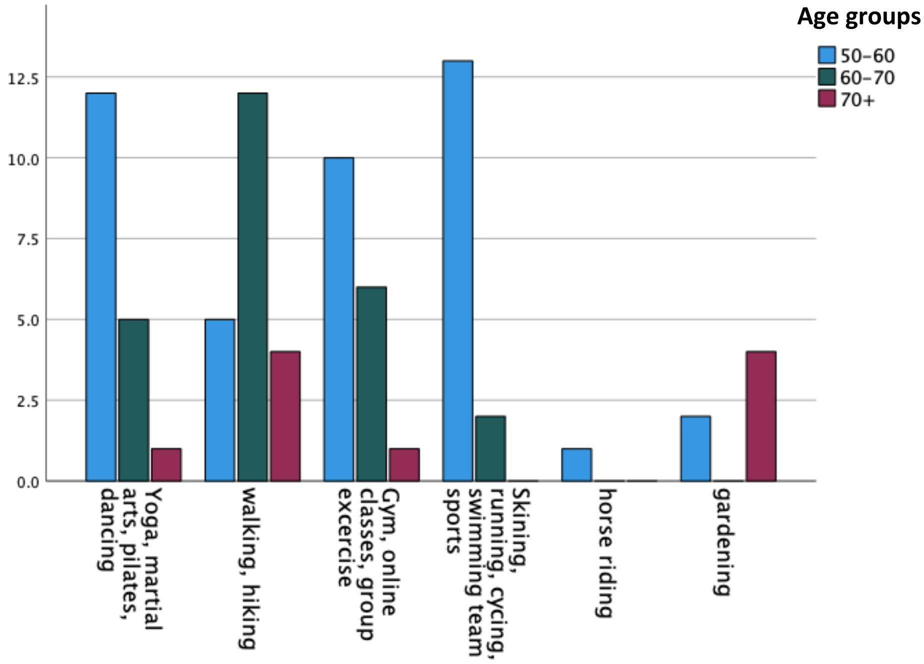


Figure 7 Current PA participation by age groups

Nationality wise Slovenian informal caregivers largely preferred outdoor activities such as walking and hiking, group exercise classes or going to a gym. Gardening was also a quite popular choice among the Slovenian citizens. Informal carers in the UK mainly participated in Yoga, martial arts, Pilates, and dancing classes. Many British carers reported running, cycling, swimming, and participating in team sports as their main choice. Group exercise classes and going to a gym was also somewhat a popular choice among the informal carers in the UK (Figure 8).

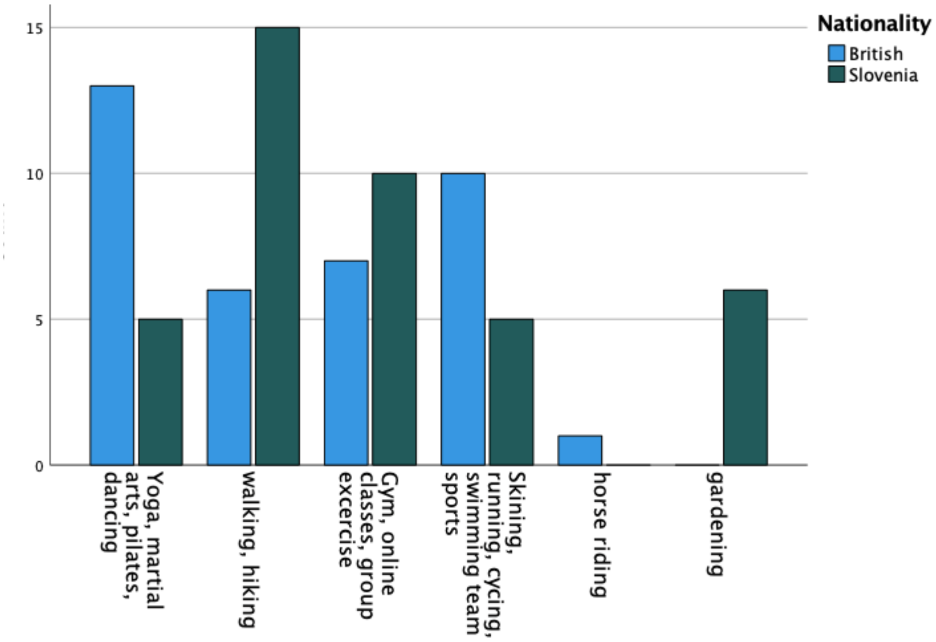


Figure 8 Current PA participation by nationality

Beliefs about Exercise Programme

A two-way between groups analysis of variance looking at the impact of nationality and age groups on whether participants thought an exercise programme would interfere with their caring role showed that the interaction effect between nationality and age group was not statistically significant, F (2, 160), p = 0.646. There was a statistically significant main effect for age groups, F (2, 160), p = < 0.001, however, the main effect for nationality was not statistically significant, F (1, 160), p = 0.174. The effect size was large for age groups (partial eta squared = 0.259) and small for nationality (partial eta squared = 0.012) (Table 37). Post-hoc comparisons of the means using LSD showed significant differences between all the age groups with 50-60 vs 60-70, p = 0.001, 50-60 vs 70+, p < 0.001 and 60-70+ vs 70+, p < 0.001 (Table 38).

Table 37 Test of Between-Subjects Effects

				50-60		**60-70**		**70+**	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality * Age groups	2,160	0.080	0.646	1.79 (0.41)	1.62 (0.50)	1.48 (0.51)	1.40 (0.50)	1.10 (0.30)	1.07 (0.27)
Age groups	2,160	5.109	<0.001						
Nationality	1,160	0.342	0.174						

*GB: British nationality, SLO: Slovenian nationality

Table 38 Multiple Comparison

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.001	0.27	0.080	0.11	0.42
50-60 vs 70+	< 0.001	0.64	0.082	0.47	0.80
60-70 vs 70+	< 0.001	0.37	0.085	0.20	0.54

*. The mean difference is significant at the 0.05 level.

When looking at the impact of nationality and age groups on whether carers thought an exercise programme would benefit their caring role showed that the interaction effect between nationality and age group was not statistically significant, F (2, 160), p = 0.332. There was a statistically significant main effect for age groups, F (2, 160), p = < 0.001, however, the main effect for nationality was not significant, F (1, 160), p = 0.706. The effect size was large for age groups (partial eta squared = 0.536) and small for nationality (partial eta squared = 0.001) (Table 39). Post-hoc comparisons of the means using LSD showed significant differences between two age groups with 50-60 vs 70+, p < 0.001 and 60-70+ vs 70+, p < 0.001. Age group 50-60 vs 60-70 showed no significant differences (Table 40).

Table 39 Test of Between-Subjects Effects

				50-60		60-70		70+	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality *	2,160	0.114	0.332	1.13	1.07	1.06	1.15	1.90	1.81
Age groups				(0.34)	(0.27)	(0.24)	(0.37)	(0.30)	(0.40)
Age groups	2,160	9.517	<0.001						
Nationality	1,160	0.015	0.706						

*GB: British nationality, SLO: Slovenian nationality

Table 40 Multiple Comparison

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.823	0.27	0.080	0.11	0.42
50-60 vs 70+	< 0.001	0.64	0.082	0.47	0.80
60-70 vs 70+	< 0.001	0.37	0.085	0.20	0.54

*. The mean difference is significant at the 0.05 level.

Perceptions and Knowledge of Exercise

When looking at the impact of nationality and age groups on the reasons for or against exercise participation the analysis showed that the interaction effect between nationality and age group was not statistically significant, F (2, 160), p = 0.652. There was a statistically significant main effect for age groups, F (2, 160), p = < 0.001, however, the main effect for nationality was not significant, F (1, 160), p = 0.449. The effect size was large for age groups (partial eta squared = 0.362) and small for nationality (partial eta squared = 0.004) (Table 41). Post-hoc comparisons of the means using LSD showed significant differences between all age groups with 50-60 vs 60-70, p = 0.001, 50-60 vs 70+, p < 0.001 and 60-70+ vs 70+, p < 0.001 (Table 42).

Table 41 Test of Between-Subjects Effects

				50-60		60-70		70+	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality * Age groups	2,160	0.051	0.652	2.76 (0.41)	2.68 (0.36)	2.55 (0.36)	2.47 (0.36)	2.08 (0.23)	2.11 (0.26)
Age groups	2,160	5.444	<0.001						
Nationality	1,160	0.069	0.449						

*GB: British nationality, SLO: Slovenian nationality

Table 42 Multiple Comparison

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.001	0.21	0.064	0.09	0.34
50-60 vs 70+	< 0.001	0.64	0.066	0.51	0.77
60-70 vs 70+	< 0.001	0.42	0.069	0.29	0.56

*. The mean difference is significant at the 0.05 level.

When carers were asked how often a person their age should exercise to be healthy a two-way between groups analysis of variance showed that the interaction effect between nationality and age group was not statistically significant, F (2, 160), p = 0.807. There was a statistically significant main effect for age groups, F (2, 160), p = < 0.001, however, the main effect for nationality was not significant, F (1, 160), p = 0.753. The effect size was large for age groups (partial eta squared = 0.266) and small for nationality (partial eta squared = 0.001) (Table 43). Post-hoc comparisons of the means using LSD showed significant differences between all age groups with 50-60 vs 60-70, p = 0.001, 50-60 vs 70+, p < 0.001 and 60-70+ vs 70+, p < 0.001 (Table 44).

Table 43 Test of Between-Subjects Effects

				50-60		**60-70**		**70+**	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality *	2,160	0.242	0.807	5.03	5.22	5.27	5.30	6.62	6.56
Age groups				(0.89)	(0.75)	(1.01)	(1.38)	(1.07)	(1.31)
Age groups	2,160	32.620	<0.001						
Nationality	1,160	0.112	0.753						

*GB: British nationality, SLO: Slovenian nationality

Table 44 Multiple Comparison

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.373	-0.18	0.196	-0.56	0.21
50-60 vs 70+	< 0.001	-1.48	0.202	-1.87	-1.08
60-70 vs 70+	< 0.001	-1.30	0.211	-1.72	-0.88

*. The mean difference is significant at the 0.05 level.

When carers were asked how long each exercise session should last a two-way between groups analysis of variance showed that the interaction effect between nationality and age group was not statistically significant, F (2, 157), p = 0.807, as well as the main effect for nationality, F (1, 157), p = 0.753. The main effect for age groups was statistically significant, F (1, 157), p < 0.001. The effect size was large for age groups (partial eta squared = 0.202) and medium for nationality (partial eta squared = 0.076) (Table 45). Post-hoc comparisons of the means using LSD showed significant differences between two age groups with, 50-60 vs 70+, p < 0.001 and 60-70+ vs 70+, p < 0.001. Age group 50-60 vs 60-70 showed no significant differences (Table 46).

Table 45 Test of Between-Subjects Effects

				50-60		60-70		70+	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality * Age groups	2,157	4.935	0.807	5.03 (0.89)	5.22 (0.75)	5.27 (1.01)	5.30 (1.38)	6.62 (1.07)	6.56 (1.31)
Age groups	2,157	22.539	<0.001						
Nationality	1,157	14.778	0.753						

*GB: British nationality, SLO: Slovenian nationality

Table 46 Multiple Comparison

	p	Mean Difference	Std. Error	Lower Bound	Upper Bound
50-60 vs 60-70	0.373	-0.18	0.196	-0.56	0.21
50-60 vs 70+	< 0.001	-1.48	0.202	-1.87	-1.08
60-70 vs 70+	< 0.001	-1.30	0.211	-1.72	-0.88

*. The mean difference is significant at the 0.05 level.

Staying Healthy

When participants were asked about the importance of factors to stay healthy, such as reducing stress, eating right, getting enough exercise etc. a two-way between groups analysis of variance showed that the interaction effect between nationality and age group was not statistically significant, F (2, 158), p = 0.809. Similarly, the main effect for nationality, F (1, 158), p = 0.828 and age groups F (1, 158), p = 358 did not show statistical significance (Table 47). Post-hoc comparisons of the means using LSD showed no significant differences between the age groups.

Table 47 Test of Between-Subjects Effects

				50-60		**60-70**		**70+**	
				GB	*SLO*	*GB*	*SLO*	*GB*	*SLO*
	F	MSe	p	*M (SD)*		*M (SD)*		*M (SD)*	
Nationality * Age groups	2,158	0.170	0.809	2.19 (0.47)	2.04 (0.34)	2.27 (0.52)	2.30 (0.92)	2.33 (1.39)	2.37 (1.42)
Age groups	2,158	0.826	0.358						
Nationality	1,158	0.038	0.828						

*GB: British nationality, SLO: Slovenian nationality

Discussion

Though both Slovenian and informal carers in the UK aged 70+ reported less burden while providing care than informal carers aged 50-60 and 60-70, they expressed higher concern about not being able to continue caring for their loved ones with dementia due to reasons beyond their control such as poor health. This correlates with the narrative review exploring experiences of caregivers 75+ years of age of multiple ethnic backgrounds in comparison to the younger carers (Greenwood & Smith, 2016). Greenwood & Smith (2016) reported that with age carers might find caregiving less burdensome and more rewarding. This study and a number of others (Braun et al., 2019; Greenwood et al., 2019; Greenwood & Smith, 2016) found this information slightly contradictory as older informal caregivers' health might also be declining making various caregiving tasks, especially the physical ones, more challenging (Greenwood et al., 2019). In parallel to this study, it has also been reported that older carers expressed a need for more support and at the same time shared a belief that they should not ask for help and showed a resistance towards outside support for the care recipient (i.e. paid carers) (Greenwood et al., 2019). It might be that the often expressed motivators for caring among spousal carers such as commitment to partnership/marriage, shared identity, reciprocity, love, responsibility and duty (Greenwood & Smith, 2016; Lang & Fowers, 2018) in combination with the values carers 70+ years old were brought up with, their past experiences and perceptions of social care services shaped their views regarding attaining professional support.

Even though the act of caring is universally present, some cultures differ in how much certain norms and values, such as filial piety are being appraised by the individuals from a particular cultural group. This study found that in contrast to the informal carers from the UK, Slovenian informal carers were generally less concerned about not having enough time for themselves, reported less concern about putting the needs of the care recipient ahead of their own needs, and were less worried about not being able to take a break. Slovenia is a country with a strong familial care regime and widely accepted and frequently present intergenerational cohabitation (Euro Carers, 2023). Though the assumption that the family should be the main care provider might shape Slovenian carers' perceptions of care and explain reduced concerns, it might be the practicality of cohabiting in a multigenerational household that could potentially result in shared responsibilities among the family members and offer some respite to the informal carers.

There were no differences found in the relationship style (defined by attachment style) and nationality of the informal carers of people with dementia, however there were significant differences observed between the age groups 50-60 vs 70+ and 60-70 vs 70+. Overall, the dismissing attachment style was a predominant style among all the age groups no matter the nationality, however to some extent carers aged 50-60 and 60-70 years also had a secure and preoccupied attachment styles present. Attachment styles, which are formed in early childhood and evolve/shift in connection to the relationships in adulthood '*describe how we seek out closeness and how secure we feel in a close relationship'* (Shalev et al., 2022, pp.10). Dismissive and preoccupied attachment styles are a subclassification of an insecure attachment and are characterised by a feeling of being overwhelmed by a close relationship (dismissive) and anxiety when there is distance in a relationship (preoccupied) (Shalev et al., 2022). In contrast, securely attached individuals '*find comfort in both close and distant relationships'* (Shalev et al., 2022, pp.10). Besides the fact that attachment styles are important for individuals' mental health and emotion regulation, they offer '*a context to understanding how people deal with chronic illness and increased independency, experiences of giving and receiving care, and adjustment to ageing and well-being in old age'* (Nelis at al., 2014, p.748). In connection to caregiving, it has been reported that carers with secure attachment style are more likely to be comforting and supporting and consequentially experience less burden associated with providing care (Nelis at al., 2014). On the other hand, carers with unsecured attachment styles experience more burden and depressive disorders (Nelis at al., 2014). This is contradictory to the findings of this study where older carers with predominantly dismissing attachment style reported less caregiver burden. It has been noted, however, that the attachment style can change over time in response to new experiences or be exacerbated during stressful situations '*especially those that threaten the stability or quality of their current relationships'* (Simpson & Steven Rholes, 2017).

Study 3 found significant differences between the age groups, nationality, and the level of satisfaction with the amount of advice available to the carers (i.e. from the healthcare workers), as well as how and where to attain help if required. This study found significant differences in the satisfaction level between the carers aged 50-60 vs 70+ and 60-70 vs 70+ years of age. The oldest group of carers (70+ years of age) reported high dissatisfaction with the amount of advice available to them as well as how and where to find it. In contrast the carers aged 50-60 and 60-70 years were somewhat satisfied with the amount of advice available and where/how to attain it. Nationality wise, Slovenian informal carers, in contrast to the carers from the UK reported higher overall dissatisfaction with the amount of advice available to them as well as how and where to get it.

Informal carers have been recognised as a vital part of the LTC provision for people with dementia in the UK and Slovenia, and in the light of that many advances have been made in both countries in order to support informal carers of people with dementia. Such as establishing Alzheimer and dementia cafes, supporting dementia awareness programmes, improving dementia diagnosis, developing activities and peer support groups exclusively for informal carers of people with dementia, advocating for dementia friendly cities and offering financial support. However, in spite of that, various studies report caregivers of those with dementia continue to feel unsupported (Britton & Zimmermann, 2022; Farina et al., 2017; Francis & Hana, 2022; Peters et al., 2020). Greenwood & Smith (2016) observed that older carers 75+ years of age might be less likely to access services as they might not be aware of their existence and the type of support they offer. Taking into account that nowadays the majority of the services operate online the oldest group of carers might struggle to attain information. Despite the increase in technology use during Covid-19 pandemic amongst the elderly (Elimelech et al., 2022; Mace et al., 2022) they continue to be an underrepresented group in relation to technology use. Moreover, Wojcik et al. (2021) found that computer use was negatively related to age among the informal caregivers of people with dementia (the higher the age the lower the computer use rate).

Higher dissatisfaction with the advice provided to informal carers of people with dementia in Slovenia and how and where to get information required might differ between the countries due to the pathways established to support the caregivers. The countries significantly differ in the total sum of the residents (2.066.880 in Slovenia in 2018 (Alzheimer Europe, 2019) vs 67.0 million in the UK in 2021 (Office for National Statistics, 2021)) and accordingly the number of informal carers of people with dementia. Which affects the number and variety of the services available to support informal carers as well as funding allocated to maintain those services. Moreover, the evaluation of the services/programmes/initiatives in Slovenia for informal carers is scarce in comparison to the UK, which might result in frameworks and services that only work for certain type of informal carers (i.e. older carers) and exclude other groups. Apart from the reports exploring overall satisfaction with the health care offered to Slovenian citizens, which showed high dissatisfaction with the service provision mainly due to long waiting times (OECD, 2021) there is a substantial gap in research exploring efficacy of the services aimed specifically at informal carers of people with dementia, and revealing potential barriers and facilitators this group might experience while attaining information. As a result Pavlič et al. (2021) reported that Slovenian informal carers are more or less left to themselves to acquire information and knowledge about providing and organising care for their loved ones. If they are able, they look for information online, access it via other types of media (magazines, newspapers), ask a neighbour/friend, but mostly they develop the knowledge of care based on their own personal experiences.

In order to take part in physical activity programmes, informal carers of people with dementia need to be able to take free time. Taking time away from caregiving, even just for a short while might be directly or indirectly related to the informal caregivers' age, relationship with the care recipient, knowing where to look for help and being able to arrange support for the care receiver during their time away. Perceptions of physical activity in general, and knowledge of exercise benefits for one's health might also play a significant part in exercise adherence among this population.

This study found significant differences between the three age groups of informal carers (50-60, 60-70 and 70+ years of age), nationality and current physical activity participation. The oldest group of carers (70+ years of age) had the lowest current physical activity participation rate, followed by the middle group of carers (60-70 years of age). The youngest group of caregivers (50-60 years of age) showed the highest current physical activity participation. These findings correlate with Horne et al. (2021) who reported that the barriers to physical activity among informal caregivers are increasing aging, health conditions, feeling tired, not wanting to leave the care receiver alone and finding it difficult to change the already established routines with the care receiver. Not having enough time was a barrier previously conveyed by Farina et al. (2020) and confirmed by Horne et al. (2021). Nonetheless, the carers that reported being physically active participated in a variety of activities. The youngest group of carers (aged 50-60 years) reported going skiing, running, cycling, swimming, and playing team sports as well as taking part in Yoga, Pilates, dancing, and group exercise. Going to a gym was also a popular option. Informal carers aged 60-70 years mainly reported walking and hiking as their main choice of activities. Some carers from this age group also participated in group exercise classes or chose to go to the gym. The eldest group of informal carers 70+ years of age reported gardening and walking or hiking as their main option. Given the fact that the youngest group of carers are proficient technology users, might live with less health conditions, have less restrictions with the transport options (i.e. are active drivers), utilise additional support (i.e. paid carers, day centres etc.) and share caring responsibilities with other family members (i.e. siblings) more regularly than the other two groups, can explain the vast variety of activities they take part in.

This study found that Slovenian carers were generally more active and preferred outdoor activities such as walking and hiking. Group exercise classes, going to a gym and gardening were also a quite popular choice among the Slovenian citizens. In contrast, carers from the UK mainly participated in Yoga, martial arts, Pilates, and dancing classes. A few British carers also reported running, cycling, swimming, participating in team sports and going to a gym as their main choice. It might be that a diverse Slovenian landscape with extensive and accessible green spaces (Hlebec et al., 2016) allow the carers to be more active without needing to travel long distances and using additional resources. Hiking also has a long tradition in Slovenia and is intertwined with the Slovenian national identity (Perko et al., 2020). Though there are a few physical activity programmes and nationwide initiatives aiming to increase fitness levels of senior Slovenian citizens, there are no physical activity programmes tailored specifically for informal carers of people with dementia. Conversely, in the UK there are a number of physical activity programmes, such as Yoga, Line dancing and Tai Chi for informal caregivers of people with dementia delivered by organisations such as Carers Network, Action for Carers, Age UK, Carers UK, Carers Trust, Open Age and others.

Current study also found differences between the three age groups of informal carers (50-60, 60-70 and 70+) and their perceptions and knowledge regarding physical activity. There were however no interaction effects found between the age groups and nationality, as well as no main effects for nationality. This showed that differences between the age groups were present in the UK as well as Slovenia. Caregivers aged 50-60 not only agreed that an exercise programme would not interfere with their caring role, but also reported that it might directly or indirectly benefit their role. This group also showed a greater knowledge of exercise frequency and duration for health benefits. Informal carers aged 60-70 years did not differ from the youngest group in their knowledge of exercise frequency and duration. They also thought that exercise might directly or indirectly benefit their role, however they reported that an exercise programme would interfere with their role as carers. Carers aged 60-70 years less frequently attain external help, thus finding free time in order to take part in activities might be challenging despite an overall understanding of the regular physical activity benefits. This has been confirmed by Horne et al. (2021) who found that facilitators for physical activity among informal caregivers include having free time and appreciation for the benefits of regular physical activity for one's health. In contrast carers aged 70+ years thought an exercise programme would interfere with their role as carers and were strongly convinced that exercising would not directly or indirectly benefit their role. Furthermore, the oldest group of carers portrayed very poor knowledge of exercise duration and frequency for optimum health benefits.

Conclusion

In conclusion there were some differences found between the informal carers of people with dementia in the UK and Slovenia. The carers mainly differed in relation to perceived care burden (the level of concern expressed about not having enough free time, putting the needs of the care receiver ahead of their own, and not being able to take a break from caring), satisfaction with the amount of information/advice available and where/how to attain it, current physical participation levels and the types of activities preferred suggesting the influence of culture, different healthcare regimes and political arrangements in the UK and Slovenia. Relationship style, beliefs about exercise in relation to the carer role together with the overall knowledge about exercise frequency and duration for optimum health benefits proved to be similar in both countries. Though Slovenian informal carers reported less concern regarding not having enough free time, not being able to take a break from caring and putting the needs of the person they care for ahead of their own, they also reported higher dissatisfaction with the advice provided, as well as where and how to get information when required. Taking into account that the family is considered the main care provider in Slovenia, this might suggest that the carer burden experienced by the caregivers in Slovenia may not be lesser than the burden experienced by the carers in the UK. Cultural practices such as intergenerational cohabitation frequently present in Slovenia should not be considered as a general solution, if not desired by the family itself and an excuse for the lack of support provided to Slovenian informal carers. Even though Slovenian government recently accepted new LTC Act and Dementia Management Strategy (with higher focus on informal care), some of the changes have not been implemented yet nor tested for its efficiency. The evaluation of the current programmes and initiatives aiming to support informal carers of people with dementia is also scarce. Future research is urgently needed to address these gaps in order to amend existing programmes/initiatives, if needed and form new ones to best support Slovenian informal carers of people with dementia.

This research compared carers living in greater London and carers living in Ljubljana. Though Ljubljana is a capital city it can hardly compare to the number of residents and the level of urbanisation present in greater London. Comparing informal carers from the rural areas of the UK might yield different results in regard to the level of physical activity participation as well as preferred types of activities. Although walking and hiking was expressed as a preferred activity by Slovenian caregivers and might have a cultural underpinning, it could also be a side-effect of not having enough physical activity programmes tailored specifically to informal carers of people with dementia.

The three distinct age groups of informal carers (50-60, 60-70 and 70+ years of age) and the differences in perceived care burden (the level of concern expressed about not having enough free time, putting the needs of the care receiver ahead of their own, and not being able to take a break from caring), satisfaction with the amount of information/advice available and where/how to attain it, attachment style, current physical participation levels and exercise knowledge were present cross-nationally. This suggests that informal carers of people with dementia are not a homogenous group as frequently portrayed by policy makers. Increasing physical activity adherence and overall well-being among the informal carers of people with dementia does not base solely on designing an appropriate physical activity programme but is a matter of addressing complex and multidimensional needs.

CHAPTER EIGHT

Informal caregivers of people with dementia have been recognised as a driving force of care and an important factor in the LTC provision plans worldwide. Research exploring informal caregivers' health and well-being as well as perceptions of various initiatives and physical activity programmes is not scarce, however exploring potential differences among the carers and how they affect caregivers' burden, overall well-being as well as exercise adherence is. This explains the fact that informal caregivers of people with dementia continuously report feeling unsupported and show low physical activity participation rates. It has been well established that if only a small percentage of informal carers would not be able to continue caring for their loved ones with dementia this would have catastrophic consequences on health and social care services as well as on the society as a whole. It is of the utmost importance that the programmes and initiative aimed at informal caregivers of people with dementia consider these differences and tailor their services to best meet the needs of all groups of informal carers of individuals with dementia.

The main focus of this PhD thesis was:

- To contextualize the complexity of lives of informal carers of people with dementia and to investigate how exercise and physical activity have played a part.
- To identify key motivational factors and barriers for physical activity participation and understand how caring for a person with dementia influenced a carer’s life, physical activity participation, well-being and their relationship with the care receiver.
- To investigate whether there are cross-national and cultural differences between informal caregivers of people with dementia in Slovenia and the UK, and their perceptions of physical activity, and well-being.
- To consider evidence to provide vital information in order to develop new programmes and/or pathways, to promote physical activity and improve exercise adherence amongst informal carers of those with dementia.

Key findings

The first study suggested that carers 50-60, 60-70 and 70+ years of age perceived physical activity and well-being differently based on the experiences of physical activity in their youth. The oldest group of carers described physical activity in their youth and early adulthood as working, meeting with friends and being generally active (not being sedentary). Their views did not change much after their partner/spouse was diagnosed with dementia. They described physical activity as conducting ADLs and were uniform in a belief that providing care to their spouse/partner is more important than participating in preferred activities. Carers 60-70 years of age also reported being generally active in their youth and as young adults, however they became more health aware after their spouse/partner was diagnosed with dementia. They understood that participating in physical activity is beneficial to their health. The youngest group of carers aged 50-60 years reported participating in a variety of exercise classes (such as gymnastics) in their youth and continued to do so in their adulthood. Some explained they were encouraged by their GPs. After their parent received the dementia diagnosis, the youngest group of carers (50-60 years of age) understood the importance of regular physical activity for their health. Carers also differed in their ability and willingness to take time away from caring. The oldest group of carers (70+ years of age) had a very strong sense of duty and believed they need to sacrifice themselves in order to provide care. In contrast carers 60-70 years of age showed a sense of duty to look after themselves, however, were unable to take free time. The youngest group of carers (50-60 years of age) also had a strong sense of duty to look after themselves and were taking time to do so. In terms of being able to attain support and external help, carers 70+ expressed they need more support but were unable to find and/or access it. They were also receiving very little help from the family members and shared they had bad experiences with professional help in the past (i.e. when they were caring for their parents). The middle group of carers (60-70 years of age) were aware of some support options as well as that the offer and availability significantly increased since their partners/spouses were diagnosed, however they faced difficulties in attaining support/help. This group also received very little help from family members, moreover they were often assisting their adult children with school runs and taking care of their grandchildren. Carers 50-60 years of age were knowledgeable of a reasonable range of support options and also how to obtain it. In contrast to the oldest and middle group of carers, they were receiving support from siblings and/or partners/spouses. How carers thought of their future also differed between the groups. Carers 70+ had mainly a negative view of the future with visions of their spouses' demise, being without their spouse or their own eventual death. The middle group of carers (60-70 years of age) were mainly focusing on staying healthy and able of care provision for the present, with no long-term views of the future. Carers 50-60 years of age had a strong vision of their futures and shared a sense they still have time to build another life after their caregiving role comes to an end.

The second study took these findings and looked to identify the groups in a wider population, and it was found to be so. It also identified more nuanced differences, such as that the eldest carers felt the least burden while providing care. Carers 50-60 years of age experienced some burden, and the middle group (60-70 years of age) experienced the highest burden while caring for their loved one with dementia. The oldest group of carers (70+ years of age) reported high dissatisfaction with the amount of advice available as well as where and how to attain it. In contrast the youngest group of carers (50-60 years of age) and carers 60-70 years of age were somewhat satisfied with the amount of advice available and how/where to get it if necessary. Relationship style also differed between the groups, however only between carers 50-60 vs 70+ and carers 60-70 vs 70+ years of age. Furthermore, there were differences found in current physical activity participation and beliefs as well as knowledge of the benefits of regular physical activity for health. The oldest group of carers reported being the least active and shared a belief that exercise would interfere with their caring role and would not benefit the caring. This group had a poor understanding of exercise frequency and duration for optimum health benefits and thought exercise is not important for overall health. Whereas the youngest (50-60 years of age) and middle (60-70 years of age) groups of carers shared a belief that exercise would directly or indirectly benefit their role as carers. Amongst all the groups, carers 50-60 years of age reported the highest current physical activity participation.

Study 3 took this further to see if these findings were nationally and culturally isolated to the UK or more universal by comparing the UK with Slovenia. The third study therefore compared the age groups cross-nationally and found no interaction between the age groups and nationality, however it revealed significant main effects between the age groups/nationality and role as a carer, information/advice availability, and current physical activity participation. Variables such as relationship style, beliefs and knowledge about exercise showed significant main effects for age groups and none for nationality. In addition, the study also confirmed that the three distinct groups of informal carers 50-60, 60-70 and 70+ years of age are present cross-nationally.

Overall Discussion

In the last couple of decades perceptions of physical activity have changed profoundly. All the industrial and health campaigns, products, programmes, research findings and new mediums, especially the Internet, expanded the knowledge of physical activity and its health benefits. However, even though overall awareness increased, the elderly might get excluded. Studies showed that this group is the least active on the internet (Boekel et al., 2017; Klimova et al., 2018) despite the rise in technology use during Covid-19 pandemic (Elimelech et al., 2022; Mace et al., 2022; Wojcik et al., 2021) and is more likely to attain health related information from health care providers (Turner et al., 2018), who on the other hand lack confidence and knowledge to promote physical activity (Brooks et al., 2016), have very limited time with their patients and were seen as not doing enough for carers (Peters at al., 2020). There have been attempts made in creating online based exercise programmes for informal carers which showed promising results, however the adherence of these programmes in the long term is unknown (Egan et al., 2021). Also, there is the question of the availability and use of technology in order to participate in online physical activity programmes for older carers 70+ years of age. Moreover, it has been reported that elderly are less likely to shift well-known strategies for new ones even when they realise the benefits (Lemaire, 2010) and are more engrained in a habitual processing approach (Hertzog et al., 2011; Spieler et al. 2006), which might partly explain why they insisted with the same perceptions and methods they have learned as young adults. This could justify higher physical activity participation rate among the youngest group of carers 50-60 years of age and a good understanding of the exercise benefits for their health.

In order for the informal carers of people with dementia to take part in physical activities, taking time away from caring is paramount. This correlates with the findings from all three studies showing that the offspring carers use external support more often than the middle and the oldest group of carers and consequentially get more free time. The youngest group is also more aware of the support offered and knows where and how to obtain it. Moreover, sharing caring responsibilities with their siblings and/or partners/spouses might allow carers 50-60 years of age to get more respite from the caregiving responsibilities and take part in activities of their choice. Interestingly, this group reported a higher burden of care than the oldest group 70+ years of age. Which could be because, apart from the caring responsibilities, carers 50-60 years of age have families of their own and might still be in paid employment.

Apart from sharing a belief that physical activity is not beneficial to their caring role, having poor understanding of exercise benefits for one’s health, and finding accessing information online challenging spousal carers 70+ years of age found it extremely difficult to be separated from their loved ones with dementia. Similarly, carers 60-70 years of age who mainly cared for their partner/spouse also shared the same perceptions, despite being aware of the support services, how/where to get information if necessary and being more proficient technology users. It might be that expressed motivators for caring among spousal carers such as a commitment to partnership/marriage, shared identity, reciprocity, love, responsibility, and duty (Greenwood & Smith, 2016; Lang & Fowers, 2018) shaped carers' views regarding attaining professional support.

Perceived care burden (the level of concern expressed about not having enough free time, putting the needs of the care receiver ahead of their own, and not being able to take a break from caring), satisfaction with the amount of information/advice available and where/how to obtain it, current physical participation levels and the types of activities preferred also differed cross-nationally. The landscape in Slovenia is very diverse with extensive and accessible green spaces, which offer a lot of opportunities to engage in outdoor activities without needing to travel long distances (Hlebec et al., 2016). This study found that activities such as walking and hiking were also preferred activities among the Slovenian informal carers. Hiking has a long tradition in Slovenia and is intertwined with the Slovenian national identity (Perko et al., 2020). This might explain higher physical activity participation rates among the informal Slovenian carers in comparison to the carers in the UK. Though there are a few physical activity programmes and nationwide initiatives aiming to increase fitness levels of senior Slovenian citizens, there are no physical activity programmes tailored specifically for informal carers of people with dementia. Conversely, in the UK there are a number of physical activity programmes, such as Yoga, Line dancing and Tai Chi for informal caregivers of people with dementia delivered by organisations such as Carers Network, Action for Carers, Age UK, Carers UK, Carers Trust, Open Age and others. This could explain why preferred activity choices among the British informal carers were Yoga, martial arts, Pilates, and dancing classes.

Apart from the geographical differences and consequentially the variety of activities offered to informal carers of people with dementia the countries also differ in their previous political arrangements which influenced current care regimes, beliefs, and values, such as filial piety. Slovenia is a country with a strong familial care regime, where the family is assumed as the main care provider (Rodrigues et al., 2022). According to Rodrigues et al. (2022) the form of familialism in Slovenia is described as prescribed familialism, as opposed to supported familialism. This means that the family members are obliged by law to care for an elderly family member and/or provide financial support to cover the costs of formal care provision (Rodrigues et al., 2022). However, despite that Slovenian informal carers were generally less concerned about not having enough time for themselves, reported less concern about putting the needs of the care recipient ahead of their own needs, and were less worried about not being able to take a break. It may be that the frequently present practice of intergenerational cohabitation in Slovenia (Euro Carers, 2023) could result in shared responsibilities among the family members and offer some respite to the informal carers.

Though there is a substantial gap in research exploring differences and specific traits of informal carers of people with dementia (Hengelaar et al., 2023), many studies either suggested some differences between the carers older than 70 years of age and those in their early seventies (Greenwood et al., 2019) or between partners and offspring carers (Tatangelo et al. 2018). And often suggested further investigation between the different sub-groups of carers and gaining more detailed understanding of the barriers and needs of the different groups in order to develop programmes tailored to their specific needs. Greenwood & Smith (2016) also pointed out that what is considered 'old age' is vastly changing due to people living longer, being healthier and remaining in paid employment longer. A considerable range of studies looking into older informal carers included caregivers between 50-90 years of age which could result in misleading recommendations and consequentially support informal carers with particular characteristics (Greenwood & Smith; 2016). Moreover Larkin et al. (2019) adds that much of the research is focused on caring as a set of tasks, rather than a dimension of an, often dyadic, relationship. Links between caring and carer outcomes are neither linear nor, in most cases inevitable and vary in depth and nature. Developing robust evaluative models that take into account the complexity of lives of informal carers of people with dementia is necessary in order to best support this population and increase their exercise adherence.

Even though dementia has been named as one of the six priority areas as a part of the Major Conditions Strategy in England in 2023 (Department of Health & Social Care, 2023) and Slovenian government adopted the Dementia Management Strategy until 2030 (Alzheimer Europe, 2023), post diagnostic support in both countries does not meet the needs of individuals diagnosed with dementia nor their caregivers. There are more services targeting people with dementia and their carers available in the UK than Slovenia, however both countries lack a clear local service map for post diagnostic support options for people with dementia and their carers (Future Health, 2024). Without sufficient, and as established in this PhD thesis, tailored post-diagnostic support leaves informal carers of people with dementia in great risk of losing their physical and psychological health, and reduce the ability to care. With the establishment of the ICS which aim to integrate and join the health, social care and voluntary services and provide personalised care in the local area there is an opportunity to improve the post-diagnostic support offered to British informal carers, however the initiative is still in its infancy. Unfortunately, health and social care services in Slovenia are not formed in a similar manner and besides a limited number of non-governmental organisations, Slovenian informal carers are left without adequate support.

Apart from a clear local-service map, it is important to acknowledge that informal carers of people with dementia are not a homogenous group and take into account specific characteristics and traits as well as understand why these differences might be there in order to provide appropriate and effective support, which would allow informal carers to uptake activities and improve their overall health and well-being. As found in this PhD thesis tailoring support to three age groups of informal carers 50-60, 60-70 and 70+ and taking into account their nationality might help to bridge the knowledge gap between different generations of carers, increase their awareness of the benefits of being physically active and guide the carers to access support they need and can benefit from. Figure 9 summarises the traits and perceptions of the three distinct groups of dementia caregivers uncovered in this PhD thesis and proposes a conceptual framework of support pathways that could result in higher exercise adherence among this population. A few authors worldwide have proposed theoretical frameworks concerning the nature of informal care and its effects on the health-related outcomes (Cahill et al., 2023; Cho, 2007; Hengelaar et al., 2023; Jegermalm & Joy Torgé, 2023; Kirvalidze et al., 2023) and advised that healthcare providers should assess the nature of the caregiving relationship and the caregiving itself, as well as adopt an intersectional perspective of care (Hengelaar et al., 2023) in order to provide sufficient support. Cahill et al. (2023) developed a nine-dimensional framework exploring differences, policies and how the role of caregivers is conceptualized in Sweden, Ireland and the United States. The study found that even though the countries are currently facing similar challenges regarding ageing population, long-term institutional care, and the availability as well as future sustainability of informal care, they differed in support services offered to informal carers. Authors concluded that variations could be a consequence of different welfare models, and social and cultural norms about informal caregiving and expressed a need for cross-national comparisons (Cahill et al., 2023). Jegermalm & Joy Torgé (2023) explored the general typologies of caregivers and the interconnectedness of various profiles in relation to care and support, and described three different caregiver profiles: the co-habitant family carer, persons in the care network and the helpful fellowman. Authors expressed the necessity of acknowledging the differences among informal carers in order to form new policies and provide appropriate support. However, none of the frameworks explored the complexity of informal carers and their perceptions of physical activity and well-being through a life-course approach, nor compared potential differences cross-nationally between the caregivers in Slovenia and the UK. The framework proposed in this PhD thesis (figure 9) is novel and offers a new perspective on physical activity and well-being of informal carers of people with dementia.

The framework is divided into three levels. Level three (L3) represents the groups of carers divided by age (50-60, 60-70 and 70+), level two (L2) represents four factors: cultural views, values and norms, attachment style, knowledge of dementia and physical activity, and technology use. These factors can directly or indirectly influence factors in level three (L3) which can impact exercise uptake and adherence such as: future plans and views, health and well-being, taking time, and external help. Arrows between levels and factors show potential relationships between the influencing factors. All three levels are influenced by external environment and current institutional arrangements such as policies and programmes regarding care, financial help available to informal carers of people with dementia, social prescribing and other initiatives connecting people to activities and health and social care services.

For example, a male carer 76 years of age who finds using technology challenging, has set cultural views, values and norms and a poorer understanding of the benefits of physical activity, could first be signposted to awareness programmes/workshops (i.e. physical activity awareness programme, technology use workshop etc.) offered to the same age group and if applicable ethnicity/nationality. This might increase carer's level of understanding of the benefits of regular physical activity and expand his technological skills. Technology use is directly connected to external help, being able to obtain external help is directly connected to free time, which is directly connected to physical activity participation. Being physically active affects carer's health and well-being and consequentially improves their physical and psychological health, which allows them to provide care and thus reduce burden and cost of health and social care services.

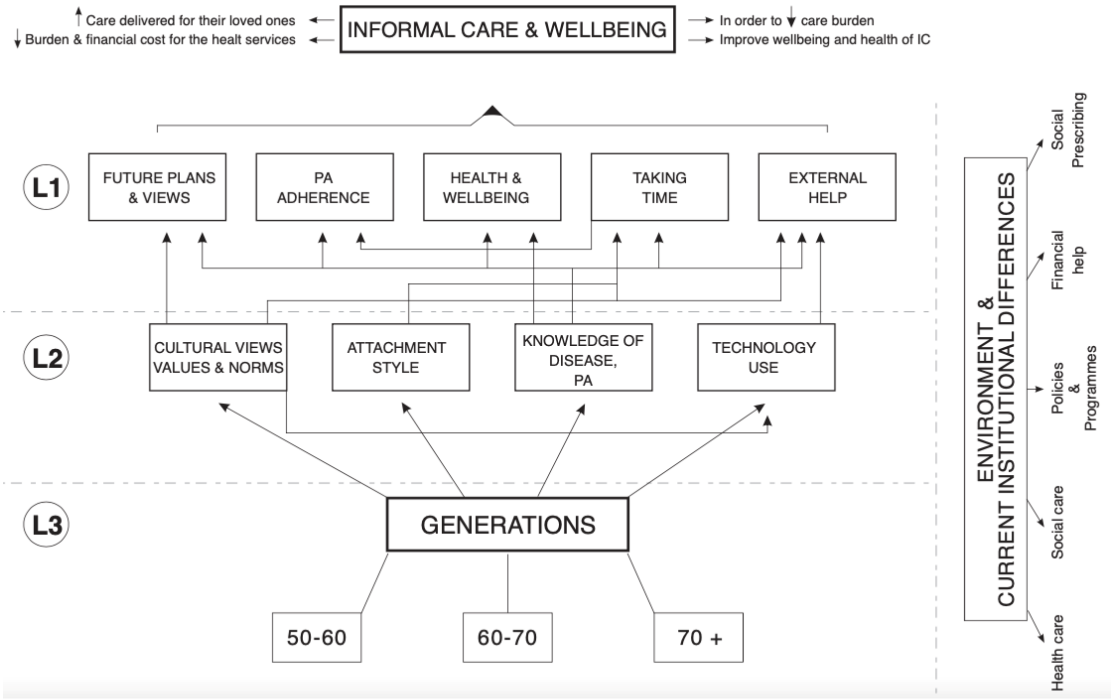


Figure 9 Levels of care in connection to age groups (by Tija Hubej)

CHAPTER NINE

Limitations & Strengths

As with all research studies, findings of this PhD thesis have some limitations.

Limitations of the Life-course approach used in this study should be noted. Even though the researcher ran a comprehensive reflective practice and prompted the carers to speak freely, she might have influenced the way stories were narrated. Another limitation is that carers who participated in the study might have biased the findings. Therefore, even though 6 participants is sufficient for this kind of study, a larger sample should be considered in the future studies. Furthermore, the limited sample size and purposive and convenient sampling method could limit the generalisability of the quantitative results. Further limitation of the sample sizes in the cross-cultural comparison should be noted. The Slovenian group of informal caregivers was smaller in comparison to the UK one, which could hinder the results. Further studies should aim to include larger sample sizes of both Slovenian and British carers in order to better represent the cultural differences. Furthermore, the age groups of carers were divided into 50-60, 60-70 and 70+ which resulted in analysis capturing double values. It would have been more appropriate to divide the groups into 50-59, 60-69 and 70+.

Moreover, the ethnic groups in Slovenia are more or less homogenous (Caucasian, Slovenian, from neighbouring countries or countries from the former Yugoslavia, predominantly Christian (Catholic, Orthodox, Protestant), with a small percentage of Muslim. The diversity in the UK however is much higher. This is especially evident in greater London where the sample for this research was collected. Future studies might consider dividing the ethnic groups in order to get a better representation and understanding of the differences in the UK first before comparing it to another country. Furthermore, even though the CWS questionnaire employed in Study 2 has been recognised as the most appropriate instrument to assess the quality of life of informal carers of people with dementia and included various characteristics such as ethnical background, gender, relationship status, it did not include other protected characteristics such as sexual orientation and religion/belief. Future studies should consider adding other protected characteristics in order to capture an even more detailed diversity of the informal carers and potential differences in how they perceive their health, physical activity and well-being.

Dementia diagnosis has drastically improved over the past years, which means that people are getting diagnosed earlier. Future research should also consider exploring younger groups of informal carers of people with dementia and their perceptions of physical activity and well-being.

However, despite the limitations, this thesis ads a novel perspective on the complexity of lives of informal carers of people with dementia and how they perceive physical activity as well as make decisions about their health. It is the first research to date employing a Life-course perspective in looking at physical activity uptake amongst informal carers of people with dementia, which uncovered novel understandings of how different generations of carers, which are normally portrayed as a homogenous group understand their roles, seek for information regarding their health and perceive physical activity. It is also the first study comparing informal carers of people with dementia and their views of physical activity cross-culturally between countries that have never been compared in this context, Slovenia and the UK.

Applications

Findings of this PhD thesis contribute to a better understanding of the complexity of lives of informal caregivers of people with dementia based on the era they were born in, their relationship with the care receiver, their perceptions and knowledge of exercise and the values and beliefs they grew up with. Increasing physical activity uptake among this population does not depend merely on quality and quantity of the physical activity programmes available to carers but ensuring that other barriers experienced by specific groups are addressed as well. Moreover, the research provides us with evidence-based findings which could contribute to formation of novel interventions, policies, pilot projects, training programmes and other services aimed at improving health and well-being of this population.

Health and social care staff such as GPs, nurses, community matrons, social workers and others working in the voluntary sector such as social prescribers could use the framework to advise the informal carers and help them access services and support tailored to their needs. Furthermore, the framework might expose the gap in service provision for certain groups of carers. For example, offering a walking group for younger, still employed carers 50-60 years of age who might not be able to attend walking groups scheduled in the morning like older, already retired carers 70+ can. Or a counselling session tailored for carers 60-70 and 70+ years of age who present with more negative future views than carers 50-60 years of age. Though digital inclusion sessions, aiming to improve digital knowledge and use among the elderly already exist, they could be tailored specifically for carers 60-70 and 70+, and teach them how to search for relevant information and services online. By acknowledging different age groups of carers and their characteristics, such as cultural values and norms, and technology proficiency, the framework could also help form new, more inclusive public health campaigns promoting physical activity engagement that could reach a larger group of informal carers of people with dementia.

Findings from this PhD also pointed out that informal carers of people with dementia not only experience their roles and perceive physical activity differently because of the generational differences but also national and cultural ones. Though the framework could be applied cross-nationally, differences in perceptions of duty, current and past political arrangements, and policies concerning informal carers should be taken into account when designing new programmes and initiatives aiming to encourage informal carers to obtain help and support. At the policy level acknowledging differences can provide insight into the usual assumptions stakeholders make about the provision of care and to rethink collaborative care networks (Hengelaar et al., 2023). Consequentially, this can encourage policy makers to create socially and culturally relevant, inclusive and effective policies.

Considering that technology has become largely integrated into the health and social care services in the UK and Slovenia with the use of IA, findings from this thesis could be applied to existing frameworks physicians and other health services, social care and the voluntary sector use during their assessments. Peters at al. (2020) noted that even though primary care, and other services, were seen as not doing enough for carers they were perceived as an integral part in identifying carers and their needs and further identified the need for pilots and experiments to develop the evidence base for such collaborations. Specific traits and challenges informal carers experience based on the era they were born in could be used as key words in softwares that are currently in use by social prescribers, well-being coaches, charity and organisation managers and GPs allowing them to identify and find support and information quickly and based on the unique needs of the carers.

Conclusion

Dementia has been recognised as a worldwide concern, with numbers of people living with the condition and their family members/friends providing care increasing with each year. The burden and challenges of care experienced by informal carers of people with dementia, despite some positive outcomes (Roth et al., 2015) are well reported (Aldeman et al., 2014; Pinquart et al., 2003). Obtaining sufficient support is vital for improving caregivers' physical and psychological health, which often worsens while caring for their loved ones with dementia ([1]Age UK, 2017). It has been established that informal carers would highly benefit from regular physical activity (Castro et al., 2002; Connell et al., 2009; King et al., 2002; Farran et al., 2016), however the physical adherence among this population, despite several studies exploring caregiving and physical activity participation, remains low (Horne et al., 2021). Findings of this PhD thesis established that informal carers of people with dementia are not a homogenous group as frequently portrayed by the researchers, policy makers and health care providers but a very diverse one, which consequentially affects their exercise adherence.

By employing Narrative Inquiry and Alwin's five principle stance on life course to investigate peoples' temporal experiences and stories, study 1 found that informal caregivers of people with dementia could be classified into three distinct groups 50-60, 60-70 and 70+ years of age. Improving physical activity adherence among informal carers of people with dementia is as complex as their role and depends on multiple factors such as the era they were born in, their relationship with the care receiver, their perceptions and knowledge of exercise and the values and beliefs they grew up with. The results support previous studies reporting differences between carers and at the same time add a greater depth into understanding why these differences might be there.

Study 2 confirmed the differences between the three age groups of informal carers established in the first study and how carers perceived physical activity and their overall well-being. The study found that the oldest carers 70+ years of age experienced less burden while providing care than the youngest carers 50-60 years of age, while carers aged 60-70 experienced the highest burden. The latter group reported higher concerns over not having enough time for themselves, not being able to take a break from caring and not being able to plan for the future. Satisfaction with the amount of advice and information available to support the caregiving role and allow the carers to attend preferred activities also differed between the age groups. The youngest carers and carers 60-70 expressed they were somewhat satisfied with the amount of advice and information available as well as where to go to obtain it. In contrast, the oldest carers expressed high dissatisfaction regarding the amount of information and advice and were unaware where and how to find it. Overall, study 2 showed that carers 50-60 years of age used more means of support to get a break from caring in contrast to the other two age groups 60-70 and 70+, which was due to the relationship and co-residency with the care receiver as well as the feeling of duty to care for a spouse. Carers also differed in their current physical activity participation rate. Besides being the least active and having poor knowledge of exercise for health benefits, the eldest group 70+ years of age also believed that exercise would interfere with their caring role and would not benefit the caring. In contrast, the youngest and middle group aged 50+ and 60-70 recognised regular physical activity as beneficial to their caring role and showed a better understanding of the duration and intensity of an exercise programme for health benefits. This might be a consequence of the health campaigns, advancements in products and physical activity programmes over the past decades, as well as new mediums, such as the internet, which helped to expand the knowledge of the benefits of being physically active. However, due to lower digital literacy, the oldest group of carers 70+ got excluded. This population is the least active on the internet and is more likely to obtain health related information from health care providers, who often lack knowledge to promote physical activity (Brooks et al., 2016).

Differences in how carers perceive and search for help also vary between caregivers of different cultural backgrounds and nationalities (Francis & Hanna, 2022). Study 3 therefore explored differences in physical activity and well-being perceptions between informal carers in Slovenia and the UK and showed that the different age groups of informal caregivers 50-60, 60-70 and 70+ are present cross-nationally. The study also found differences between Slovenian and British informal carers. The caregivers mainly differed in relation to perceived care burden (the level of concern expressed about not having enough free time, putting the needs of the care receiver ahead of their own, and not being able to take a break from caring), satisfaction with the amount of information/advice available and where/how to obtain it, current physical participation levels and the types of activities preferred. Which suggests the influence of culture, different healthcare regimes and political arraignments on physical activity and well-being perceptions among caregivers in the UK and Slovenia.

People worldwide are ageing and living longer and not in any other time in the history so many generations had to live together and face similar challenges, such as caring for a parent or spouse with dementia. The age difference between the oldest and the youngest carers, who are seen as a coherent group could be as much as 35 years, which is in the world that is constantly changing and evolving a significant amount. This PhD thesis offers a novel understanding of how age differences and views about health care and physical activity carers grew up with affect their current understanding of physical activity and decisions they make regarding their health. Increasing physical activity uptake among informal carers of people with dementia does not depend merely on the quality and quantity of the physical activity programmes and services available to this population but mainly on referring caregivers to services that will help them address and resolve barriers preventing them from participating in regular physical activity. This could help them to meet caregiving demands as well as look after themselves and positively affect their health-related quality of life and quality-adjusted life-years.

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APPENDIXES

Appendix A: Ethical Approval Letters

Middlesex University London

London Sport Institute REC

The Burroughs
Hendon
London NW4 4BT

Main Switchboard: 0208 411 5000

30/11/2017

APPLICATION NUMBER: 2708

Dear Tija Hubej

Re your application title: Perceptions of physical activity of Carers

Supervisor: Anne Elliott Rhonda Cohen

Thank you for submitting your application. I can confirm that your application has been given approval from the date of this letter by the London Sport Institute REC.

Although your application has been approved, the reviewers of your application may have made some useful comments on your application. Please look at your online application again to check whether the reviewers have added any comments for you to look at.

Also, please note the following:

1. Please ensure that you contact your supervisor/research ethics committee (REC) if any changes are made to the research project which could affect your ethics approval. There is an Amendment sub-form on MORE that can be completed and submitted to your REC for further review.

2. You must notify your supervisor/REC if there is a breach in data protection management or any issues that arise that may lead to a health and safety concern or conflict of interests.

3. If you require more time to complete your research, i.e., beyond the date specified in your application, please complete the Extension sub-form on MORE and submit it your REC for review.

4. Please quote the application number in any correspondence.

5. It is important that you retain this document as evidence of research ethics approval, as it may be required for submission to external bodies (e.g., NHS, grant awarding bodies) or as part of your research report, dissemination (e.g., journal articles) and data management plan.

6. Also, please forward any other information that would be helpful in enhancing our application form and procedures - please contact MOREsupport@mdx.ac.uk to provide feedback.

Good luck with your research.

Yours sincerely

Middlesex University London

London Sport Institute REC

The Burroughs
Hendon
London NW4 4BT

Main Switchboard: 0208 411 5000

12/07/2019

APPLICATION NUMBER: 5056

Dear Tija Hubej and all collaborators/co-investigators

Re your application title: Differences amongst Family Carers

Supervisor: Dr Anne Dr Rhonda Cohen Elliott

Co-investigators/collaborators:

Thank you for submitting your application. I can confirm that your application has been given approval from the date of this letter by the London Sport Institute REC.

Although your application has been approved, the reviewers of your application may have made some useful comments on your application. Please look at your online application again to check whether the reviewers have added any comments for you to look at.

Also, please note the following:

1. Please ensure that you contact your supervisor/research ethics committee (REC) if any changes are made to the research project which could affect your ethics approval. There is an Amendment sub-form on MORE that can be completed and submitted to your REC for further review.

2. You must notify your supervisor/REC if there is a breach in data protection management or any issues that arise that may lead to a health and safety concern or conflict of interests.

3. If you require more time to complete your research, i.e., beyond the date specified in your application, please complete the Extension sub-form on MORE and submit it your REC for review.

4. Please quote the application number in any correspondence.

5. It is important that you retain this document as evidence of research ethics approval, as it may be required for submission to external bodies (e.g., NHS, grant awarding bodies) or as part of your research report, dissemination (e.g., journal articles) and data management plan.

6. Also, please forward any other information that would be helpful in enhancing our application form and procedures - please contact MOREsupport@mdx.ac.uk to provide feedback.

Good luck with your research.

Yours sincerely

Middlesex University London

London Sport Institute REC

The Burroughs
Hendon
London NW4 4BT

Main Switchboard: 0208 411 5000

07/06/2022

APPLICATION NUMBER: 5055

Dear Tija Hubej and all collaborators/co-investigators

Re your application title: Differences amongst Family Carers

Supervisor:

Co-investigators/collaborators: Miss Tija Hubej, Dr Rhonda Cohen, Dr Anne Elliott

Thank you for submitting your application. I can confirm that your application has been given APPROVAL from the date of this letter by the London Sport Institute REC.

The following documents have been reviewed and approved as part of this research ethics application:

Document Type	File Name	Date	Version
Amendments	2.5 amendments Study3	31/05/2022	1
Amendments	(LSI) PIS	31/05/2022	1
Amendments	(LSI) Consent Form	31/05/2022	1
Amendments	Ethical Approval	31/05/2022	1
Amendments	GateKeeper letter 2019	31/05/2022	1

Although your application has been approved, the reviewers of your application may have made some useful comments on your application. Please look at your online application again to check whether the reviewers have added any comments for you to look at.

Also, please note the following:

1. Please ensure that you contact your supervisor/research ethics committee (REC) if any changes are made to the research project which could affect your ethics approval. There is an Amendment sub-form on MORE that can be completed and submitted to your REC for further review.

2. You must notify your supervisor/REC if there is a breach in data protection management or any issues that arise that may lead to a health and safety concern or conflict of interests.

3. If you require more time to complete your research, i.e., beyond the date specified in your application, please complete the Extension sub-form on MORE and submit it your REC for review.

4. Please quote the application number in any correspondence.

5. It is important that you retain this document as evidence of research ethics approval, as it may be required for submission to external bodies (e.g., NHS, grant awarding bodies) or as part of your research report, dissemination (e.g., journal articles) and data management plan.

6. Also, please forward any other information that would be helpful in enhancing our application form and procedures - please contact MOREsupport@mdx.ac.uk to provide feedback.

Good luck with your research.

Yours sincerely,

Chairs Dr Rhonda Cohen/ Dr Anne Elliott

London Sport Institute REC

Appendix B: Gatekeeper Approval Letters

Ashford
Place
Formerly Cricklewood Homeless Concern

Permission to conduct research

Tija Hubej
PHD student
Middlesex
University
Hendon

28 November 2017

Dear Tija

I am happy to give you permission to approach carers of people living with dementia at Ashford Place as part of your PHD research project.

Best wishes

Danny Maher
CEO

Ashford Place
60 Ashford Road | London | NW2 6TU
tel: 020 8208 8590 • fax: 020 8452 1373
www.ashfordplace.org.uk
Patrons: Bill Durkan, Dr Gerard O'Hare
Registered Charity: 1097475
Company Limited by Guarantee
Registered in England and Wales: 04407339

green candle
dance company

Oxford House, Derbyshire Street
Bethnal Green, London E2 6HG

Tel 020 7739 7722
Fax 020 7729 8272

Email info@greencandledance.com
Website www.greencandledance.com

Re: Research Permission - Tija Hubej

To whom it may concern,

Green Candle Dance Company consent to Tija Hubej approaching carers and companions of people with dementia, who attend our Remember to Dance in Oxford House programme.

We agree to passing the research participant information sheet and consent form on to those carers and companions in attendance at the session, whereby it will be at the discretion of the individuals if they wish to partake in the research and contact Tija Hubej in order to do so.

Kind regards

Vicki Busfield

Community and Education Manager
Green Candle Dance Company

Artistic Director: FERGUS EARLY OBE, D.Arts (hc)
Green Candle is a member of ITC
Green Candle Ltd registered in England
Registration number 2266864
Registered Charity No. 801774

LJS
ק״ק לב חדש

THE LIBERAL JEWISH SYNAGOGUE
28 St John's Wood Road, London, NW8 7HA
website: www.ljs.org

Singing for the Mind

Tel: 020 7286 5181
E-mail: sfm@ljs.org

11/Jan/18

Tija Hubej
Middlesex University.
<tija.hubej@gmail.com>

Dear Tija,

I was pleased to have the chance to meet you today at Singing for the Mind at the Liberal Jewish Synagogue

I have been in touch with Danielle Fluer and she has given me permission to pass on to you her details for your research project.

Danielle was the sole carer for her Mum who passed away recently.

Her Details are:

Danielle Fluer

Email: daniellefluer@gmail.com

Mobile: 07956-830-132

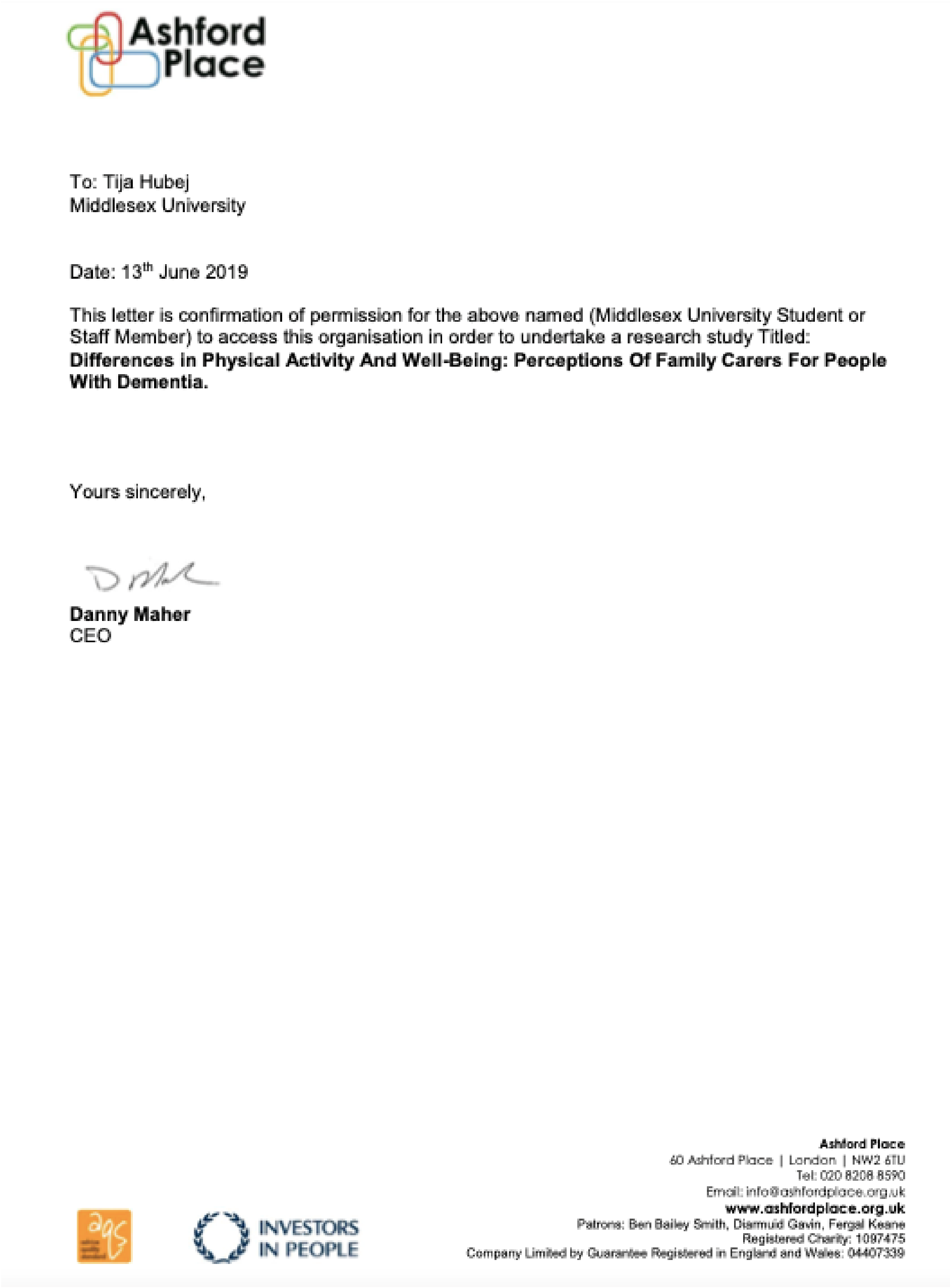
We hope this is of help to you.

regards

Judith Diamond
Co-organiser
Singing for the Mind
LJS

Generously sponsored by the Ernest Hecht Charitable Foundation, the Coward Endowment Trust and The Liberal Jewish Synagogue

The Liberal Jewish Synagogue is a company limited by guarantee (Company No. 9113305)
and a registered charity in England and Wales (Charity No. 1159292).
Registered office: 28 St John's Wood Road, London, NW8 7HA



Ashford
Place

To: Tija Hubej
Middlesex University

Date: 13th June 2019

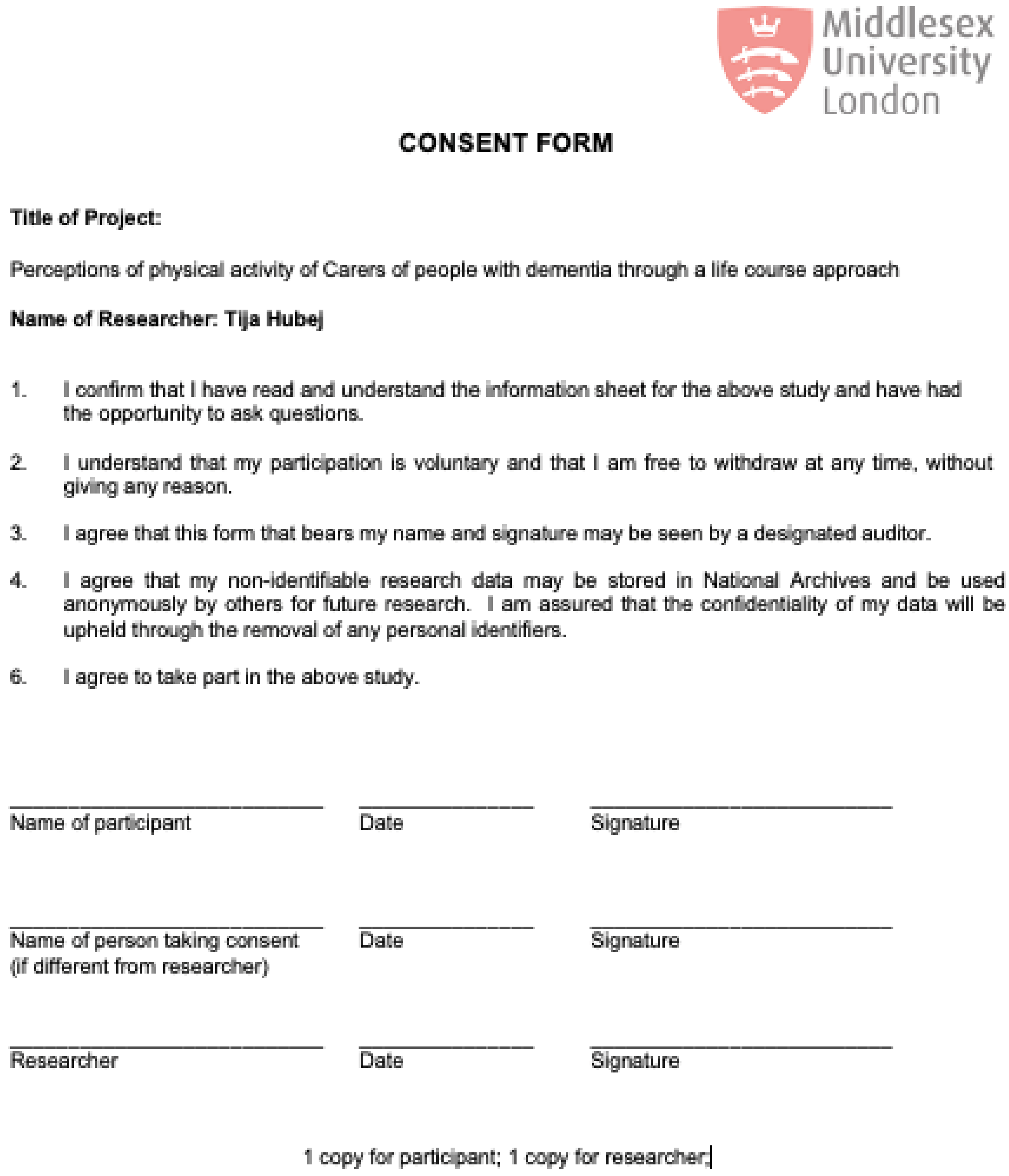
This letter is confirmation of permission for the above named (Middlesex University Student or Staff Member) to access this organisation in order to undertake a research study Titled: **Differences In Physical Activity And Well-Being: Perceptions Of Family Carers For People With Dementia.**

Yours sincerely,

Danny Maher
CEO

Ashford Place
60 Ashford Place | London | NW2 6TU
Tel: 020 8208 8590
Email: info@ashfordplace.org.uk
www.ashfordplace.org.uk
Patrons: Ben Bailey Smith, Diarmuid Gavin, Fergal Keane
Registered Charity: 1097475
Company Limited by Guarantee Registered in England and Wales: 04407339

Appendix C: Consent forms and Participant Information Sheets with Translation



Middlesex University London

CONSENT FORM

Title of Project:

Perceptions of physical activity of Carers of people with dementia through a life course approach

Name of Researcher: Tija Hubej

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I agree that this form that bears my name and signature may be seen by a designated auditor.
4. I agree that my non-identifiable research data may be stored in National Archives and be used anonymously by others for future research. I am assured that the confidentiality of my data will be upheld through the removal of any personal identifiers.
6. I agree to take part in the above study.

Name of participant	Date	Signature
Name of person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

1 copy for participant; 1 copy for researcher;

MIDDLESEX UNIVERSITY

PARTICIPANT SHEET (PIS)

Participant ID Code:…………………………………………….

1. Study title:

Perceptions of physical activity of Carers of people with dementia through a life course approach

2. Invitation paragraph

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

To contextualize the complexity of lives of informal carers of people living with dementia and to understand how has becoming a carer of a person with dementia influenced carer's life, physical activity, and their relationship.

4. Why have I been chosen?

It is important that we interview as many participants as possible, and you have indicated that you are interested in taking part in this study. Inclusion criteria is being a non-paid caregiver (either family member, relative or a friend) 50 years of age or more and currently providing care for an individual diagnosed with dementia at least 5 hours per day.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you do decide to withdraw from the study then please inform the researcher as soon as possible, and they will facilitate your withdrawal. If, for any reason, you wish to withdraw your data please contact the researcher within a month of your participation. After this period it may not be possible to withdraw your individual data as the results may have already been published. However, as all data are anonymised, your individual data will not be identifiable in any way.

6. What will I have to do?

- The interview will last approximately for an hour and will be conducted in a quiet space at the company, public space (i.e. cafe, park) or, with your permission at your home
- Person living with dementia can be present
- You will be asked to participate in a narrative interview, which is a conversational type of an interview
- You will be asked to talk about your experiences as a carer and how it has affected different aspects of your life
- The interview will be audio recorded

Please note that in order to ensure quality assurance and equity this project may be selected for audit by a designated member of the committee. This means that the designated member can request to see signed consent forms. However, if this is the case your signed consent form will only be accessed by the designated auditor or member of the audit team.

7. Will I have to provide any bodily samples (i.e. blood/saliva/urine)?
No.

8. What are the possible disadvantages and risks of taking part?
There is no known risk in participating in this project.

Appropriate risk assessments for all procedures have been conducted, and will be followed throughout the duration of the study.

9. What are the possible benefits of taking part?
We hope that participating in the study will help you. However, this cannot be guaranteed. The information we get from this study may help us to develop the programme further in order to improve the balance and quality of life of the carers of people living with dementia.

9. Will my taking part in this study be kept confidential?
The research team has put a number of procedures in place to protect the confidentiality of participants. You will be allocated a pseudonym that will always be used to identify any data you provide. Your name or other personal details will not be associated with your data, for example, the consent form that you sign will be kept separate from your data. All paper records will be stored in a locked filing cabinet, accessible only to the research team, and all electronic data will be stored on a password protected computer. All information you provide will be treated in accordance with the UK Data Protection Act.

10. What will happen to the results of the research study?
The results of the research study will be used as part of a PhD research. The results may also be presented at conferences or in journal articles. However, the data will only be used by members of the research team. At the beginning of the study you will be given a pseudonym and at no point will your personal information or data be revealed.

11. Who has reviewed the study?
The study has received full ethical clearance from the research ethics sub-committee who reviewed the study. The sub-committee is the Faculty of Science and Technology Middlesex University.

12. Contact for further information
If you require further information, have any questions or would like to withdraw your data then please contact:

Tija Hubej, TH536@live.mdx.ac.uk

Director of Studies: Dr. Rhonda Cohen, r.x.cohen@mdx.ac.uk

Supervisor: Dr. Anne Elliott, a.elliott@mdx.ac.uk

Supervisor: Prof. Trish Hafford-Letchfield

Thank you for taking part in this study. You should keep this participant information sheet as it contains your participant code, important information and the research teams contact details.

Middlesex
University
London

Participant Identification Number:

CONSENT FORM

Title of Project:

Differences in Physical Activity and Well-Being: Perceptions Of Family Carers For People With Dementia

Name of Researcher: Tija Hubej

Please initial box

1. I confirm that I have read and understand the information sheet dated ....for the above study and have had the opportunity to ask questions. ☐ 1

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without penalty . ☐ 2

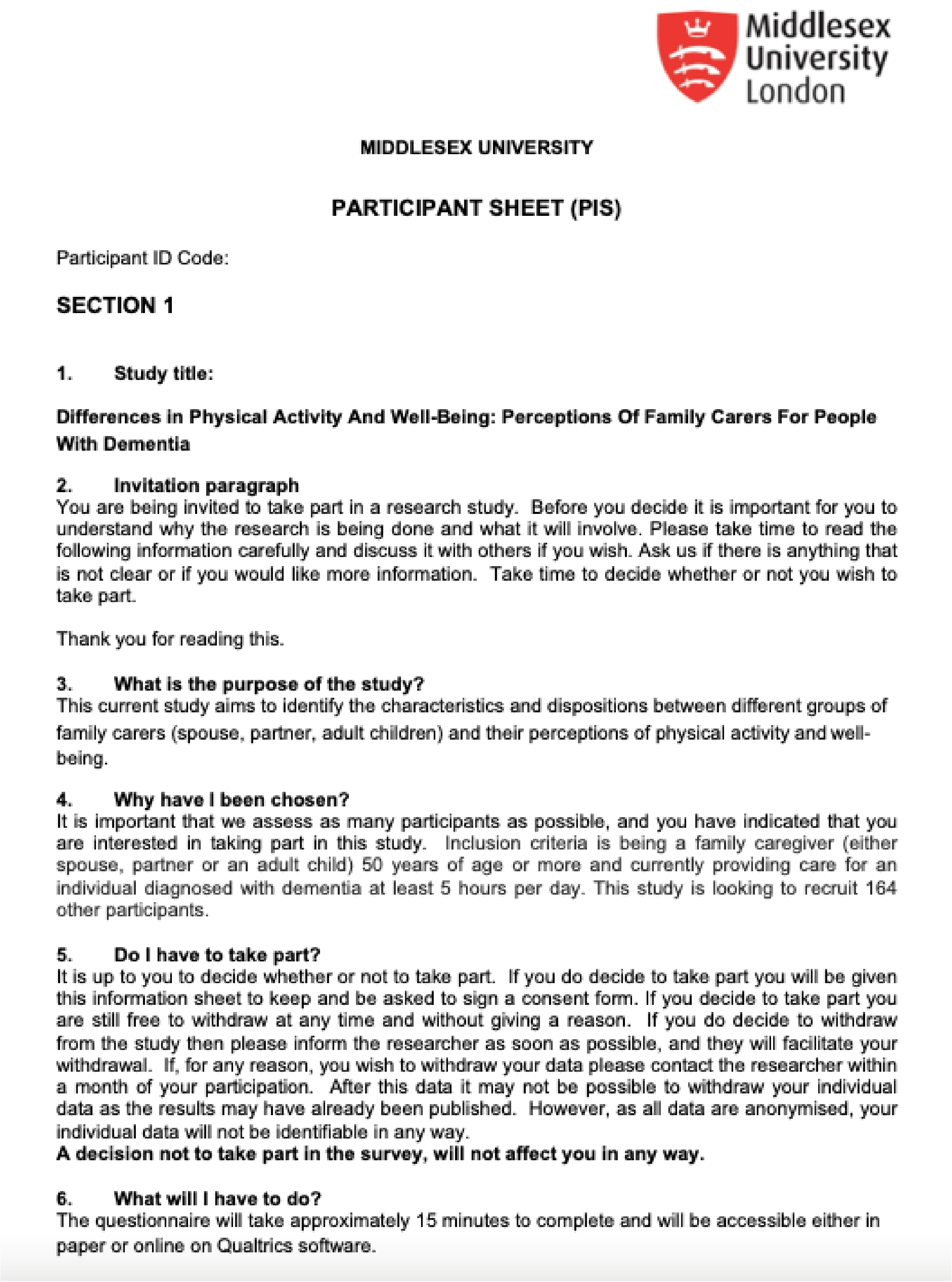
3. I agree that this form that bears my name and signature may be seen by a designated auditor. ☐ 3

4. I agree that my non-identifiable research data may be stored in National Archives and be used anonymously by others for future research. I am assured that the confidentiality of my data will be upheld through the removal of any personal identifiers. ☐ 4

7. I agree to take part in the above study. ☐ 7

______________________________	________________	______________________________
Name of participant	Date	Signature
______________________________	________________	______________________________
Name of person taking consent (if different from researcher)	Date	Signature
______________________________	________________	______________________________
Researcher	Date	Signature

1 copy for participant; 1 copy for researcher;



MIDDLESEX UNIVERSITY

PARTICIPANT SHEET (PIS)

Participant ID Code:

SECTION 1

1. Study title:

Differences in Physical Activity And Well-Being: Perceptions Of Family Carers For People With Dementia

2. Invitation paragraph

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

This current study aims to identify the characteristics and dispositions between different groups of family carers (spouse, partner, adult children) and their perceptions of physical activity and well-being.

4. Why have I been chosen?

It is important that we assess as many participants as possible, and you have indicated that you are interested in taking part in this study. Inclusion criteria is being a family caregiver (either spouse, partner or an adult child) 50 years of age or more and currently providing care for an individual diagnosed with dementia at least 5 hours per day. This study is looking to recruit 164 other participants.

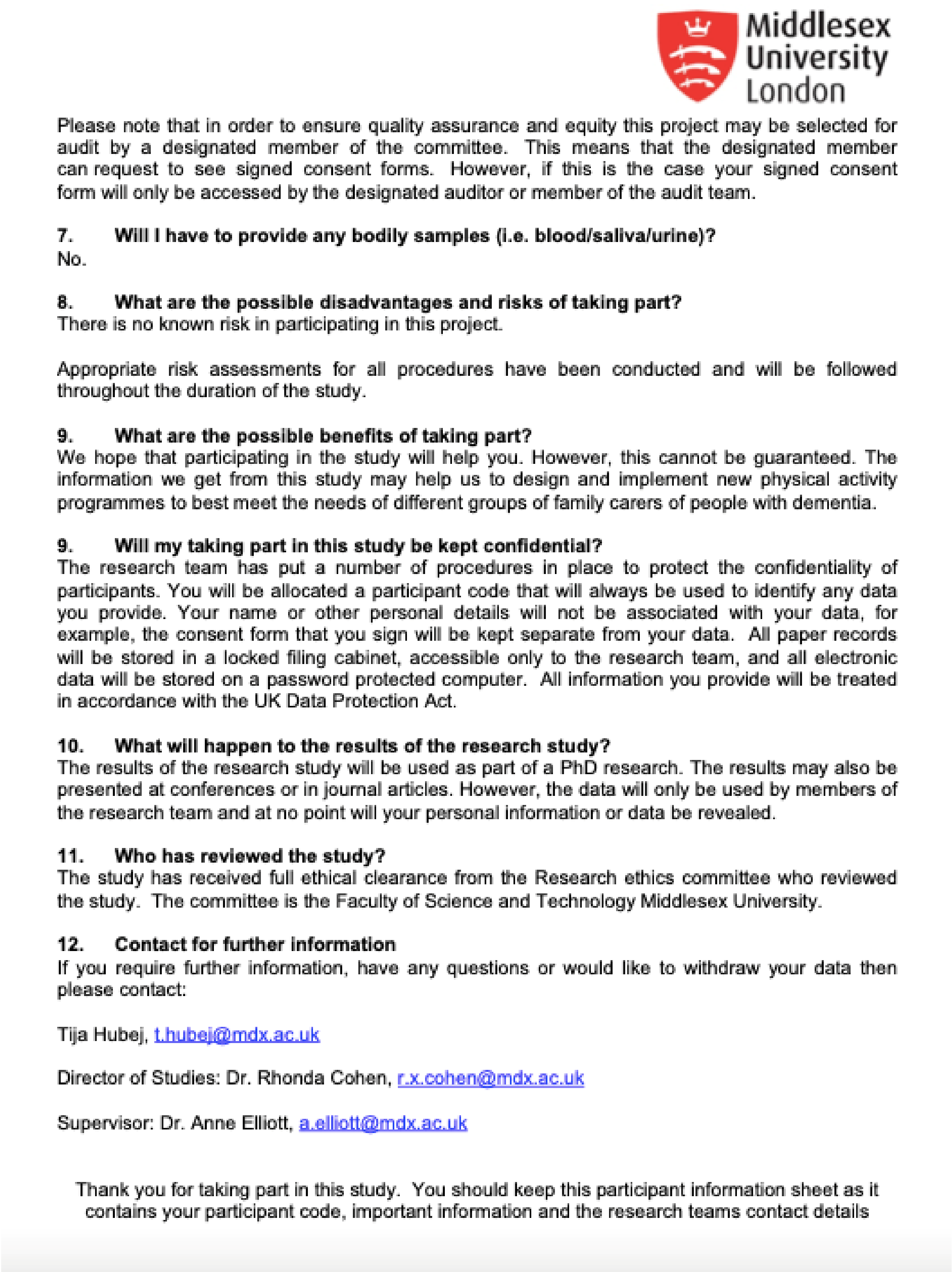
5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you do decide to withdraw from the study then please inform the researcher as soon as possible, and they will facilitate your withdrawal. If, for any reason, you wish to withdraw your data please contact the researcher within a month of your participation. After this data it may not be possible to withdraw your individual data as the results may have already been published. However, as all data are anonymised, your individual data will not be identifiable in any way.

A decision not to take part in the survey, will not affect you in any way.

6. What will I have to do?

The questionnaire will take approximately 15 minutes to complete and will be accessible either in paper or online on Qualtrics software.



Please note that in order to ensure quality assurance and equity this project may be selected for audit by a designated member of the committee. This means that the designated member can request to see signed consent forms. However, if this is the case your signed consent form will only be accessed by the designated auditor or member of the audit team.

7. Will I have to provide any bodily samples (i.e. blood/saliva/urine)?

No.

8. What are the possible disadvantages and risks of taking part?

There is no known risk in participating in this project.

Appropriate risk assessments for all procedures have been conducted and will be followed throughout the duration of the study.

9. What are the possible benefits of taking part?

We hope that participating in the study will help you. However, this cannot be guaranteed. The information we get from this study may help us to design and implement new physical activity programmes to best meet the needs of different groups of family carers of people with dementia.

9. Will my taking part in this study be kept confidential?

The research team has put a number of procedures in place to protect the confidentiality of participants. You will be allocated a participant code that will always be used to identify any data you provide. Your name or other personal details will not be associated with your data, for example, the consent form that you sign will be kept separate from your data. All paper records will be stored in a locked filing cabinet, accessible only to the research team, and all electronic data will be stored on a password protected computer. All information you provide will be treated in accordance with the UK Data Protection Act.

10. What will happen to the results of the research study?

The results of the research study will be used as part of a PhD research. The results may also be presented at conferences or in journal articles. However, the data will only be used by members of the research team and at no point will your personal information or data be revealed.

11. Who has reviewed the study?

The study has received full ethical clearance from the Research ethics committee who reviewed the study. The committee is the Faculty of Science and Technology Middlesex University.

12. Contact for further information

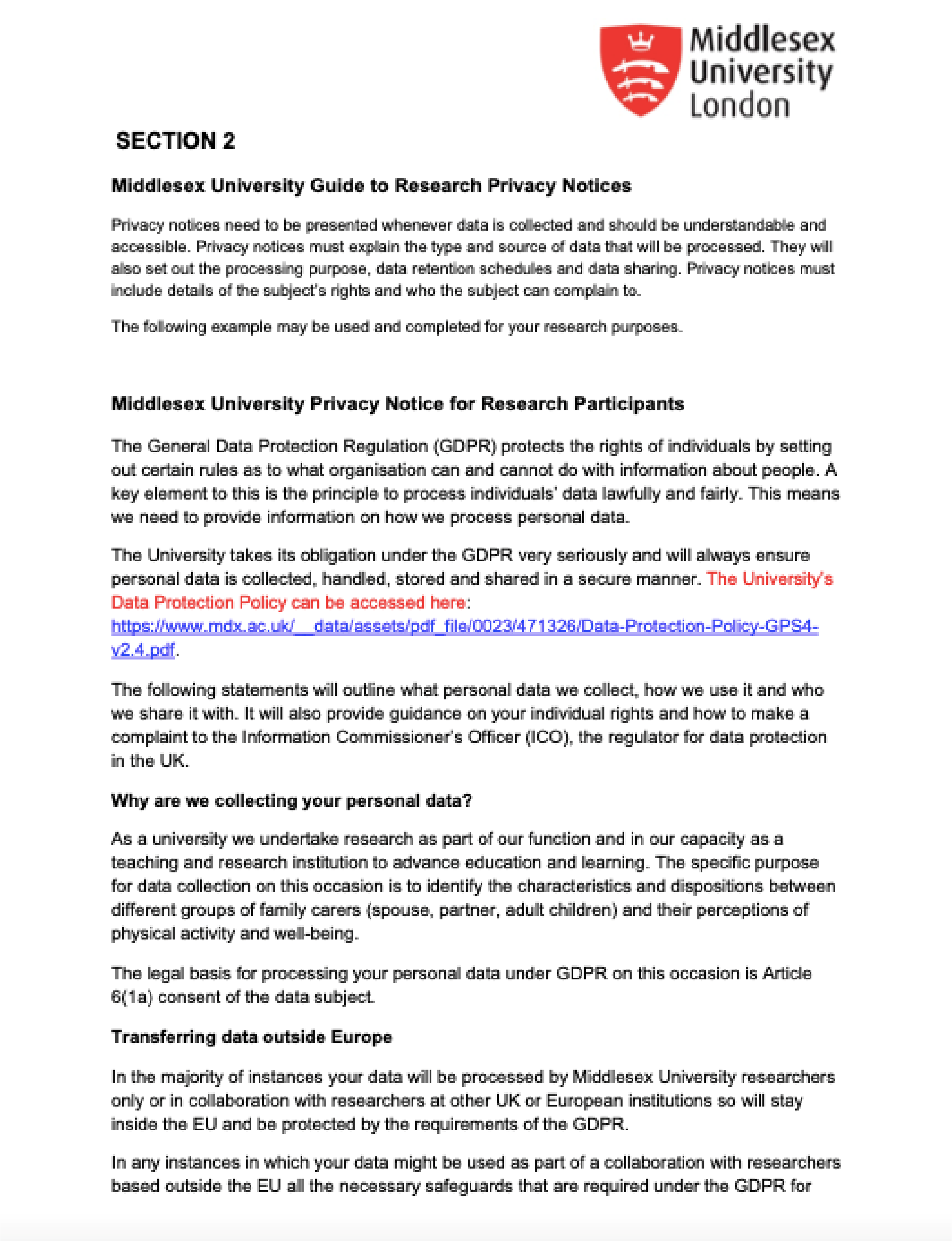
If you require further information, have any questions or would like to withdraw your data then please contact:

Tija Hubej, t.hubej@mdx.ac.uk

Director of Studies: Dr. Rhonda Cohen, r.x.cohen@mdx.ac.uk

Supervisor: Dr. Anne Elliott, a.elliott@mdx.ac.uk

Thank you for taking part in this study. You should keep this participant information sheet as it contains your participant code, important information and the research teams contact details



Middlesex
University
London

SECTION 2

Middlesex University Guide to Research Privacy Notices

Privacy notices need to be presented whenever data is collected and should be understandable and accessible. Privacy notices must explain the type and source of data that will be processed. They will also set out the processing purpose, data retention schedules and data sharing. Privacy notices must include details of the subject's rights and who the subject can complain to.

The following example may be used and completed for your research purposes.

Middlesex University Privacy Notice for Research Participants

The General Data Protection Regulation (GDPR) protects the rights of individuals by setting out certain rules as to what organisation can and cannot do with information about people. A key element to this is the principle to process individuals' data lawfully and fairly. This means we need to provide information on how we process personal data.

The University takes its obligation under the GDPR very seriously and will always ensure personal data is collected, handled, stored and shared in a secure manner. The University's Data Protection Policy can be accessed here: https://www.mdx.ac.uk/__data/assets/pdf_file/0023/471326/Data-Protection-Policy-GPS4-v2.4.pdf.

The following statements will outline what personal data we collect, how we use it and who we share it with. It will also provide guidance on your individual rights and how to make a complaint to the Information Commissioner's Officer (ICO), the regulator for data protection in the UK.

Why are we collecting your personal data?

As a university we undertake research as part of our function and in our capacity as a teaching and research institution to advance education and learning. The specific purpose for data collection on this occasion is to identify the characteristics and dispositions between different groups of family carers (spouse, partner, adult children) and their perceptions of physical activity and well-being.

The legal basis for processing your personal data under GDPR on this occasion is Article 6(1a) consent of the data subject.

Transferring data outside Europe

In the majority of instances your data will be processed by Middlesex University researchers only or in collaboration with researchers at other UK or European institutions so will stay inside the EU and be protected by the requirements of the GDPR.

In any instances in which your data might be used as part of a collaboration with researchers based outside the EU all the necessary safeguards that are required under the GDPR for transferring data outside of the EU will be put in place. You will be informed if this is relevant for the specific study you are a participant of.

Your rights under data protection

Under the GDPR and the DPA you have the following rights:

- to obtain access to, and copies of, the personal data that we hold about you;
- to require that we cease processing your personal data if the processing is causing you damage or distress;
- to require us to correct the personal data we hold about you if it is incorrect;
- to require us to erase your personal data;
- to require us to restrict our data processing activities;
- to receive from us the personal data we hold about you which you have provided to us, in a reasonable format specified by you, including for the purpose of you transmitting that personal data to another data controller;
- to object, on grounds relating to your particular situation, to any of our particular processing activities where you feel this has a disproportionate impact on your rights.

Where Personal Information is processed as part of a research project, the extent to which these rights apply varies under the GDPR and the DPA. In particular, your rights to access, change, or move your information may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we may not be able to remove the information that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. The Participant Information Sheet will detail up to what point in the study data can be withdrawn.

If you submit a data protection rights request to the University, you will be informed of the decision within one month. If it is considered necessary to refuse to comply with any of your data protection rights, you also have the right to complain about our decision to the UK supervisory authority for data protection, the Information Commissioner's Office.

None of the above precludes your right to withdraw consent from participating in the research study at any time.

Collecting and using personal data

You will be asked to complete a 24-question survey. A paper survey will be either handed out to you or will be available online on Qualtrics software.

Data sharing

Your information will usually be shared within the research team conducting the project you are participating in, mainly so that they can identify you as a participant and contact you about the research project.

Responsible members of the University may also be given access to personal data used in a research project for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your records. All of these people have a duty to keep your information, as a research participant, strictly confidential.

If we are working with other organisations and information is shared about you, we will inform you in the Participant Information Sheet. Information shared will be on a 'need to know' basis relative to achieving the research project's objectives, and with all appropriate safeguards in place to ensure the security of your information.

Storage and security

The University takes a robust approach to protecting the information it holds with dedicated storage areas for research data with controlled access.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of University information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Training is provided to new staff joining the University and existing staff have training and expert advice available if needed.

Retention

Under the GDPR and DPA personal data collected for research purposes can be kept indefinitely, providing there is no impact to you outside the parameters of the study you have consented to take part in.

Having stated the above, the length of time for which we keep your data will depend on a number of factors including the importance of the data, the funding requirements, the nature of the study, and the requirements of the publisher. Details will be given in the information sheet for each project.

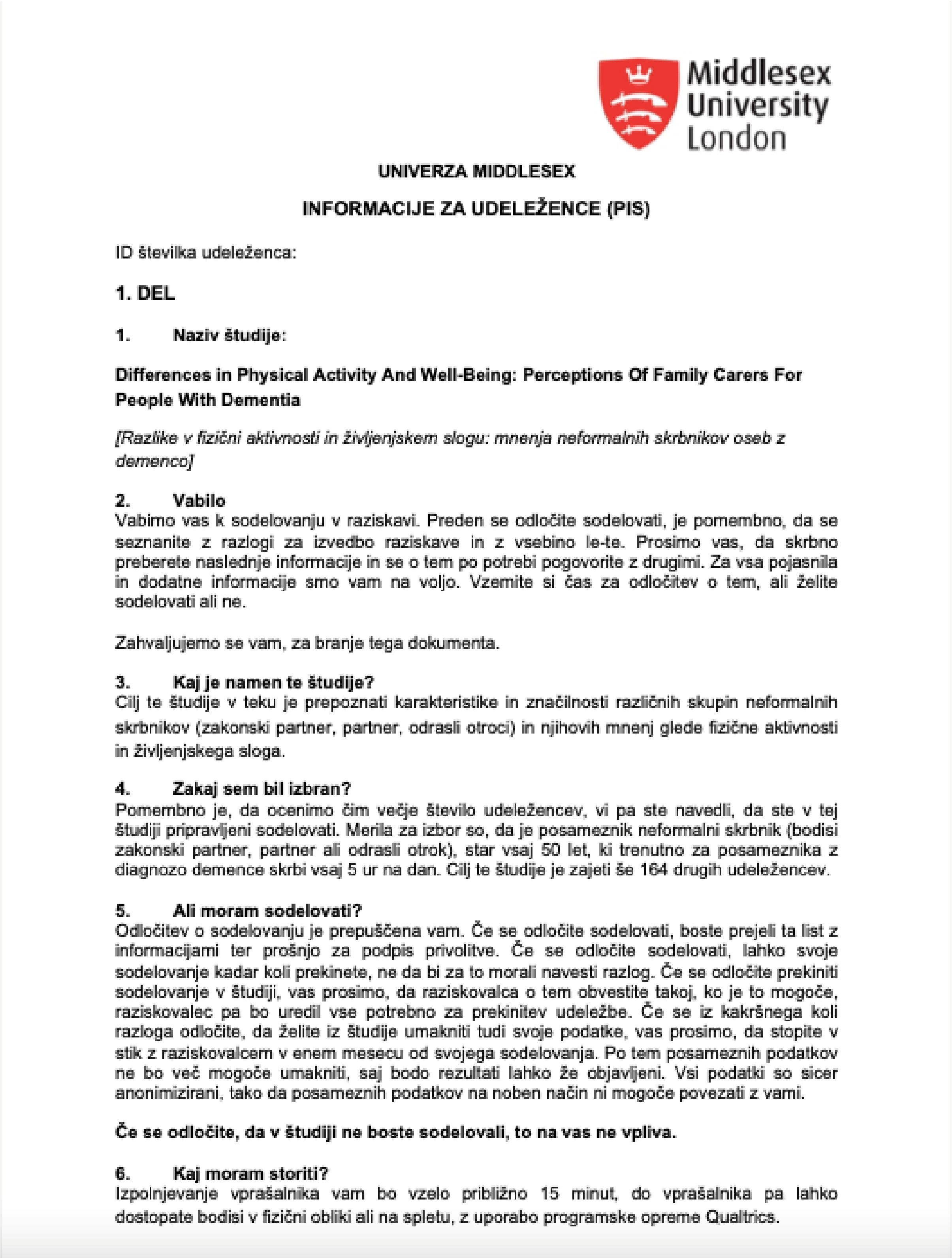
Contact us

The Principal Investigator leading this research is Tija Hubej

t.hubej@mdx.ac.uk

The University's official contact details are:

Data Protection Officer
Middlesex University
The Burroughs
London
NW4 4BT
Tel: +44 (0)20 8411 5555
Email: dpaofficer@mdx.ac.uk



UNIVERZA MIDDLESEX

INFORMACIJE ZA UDELEŽENCE (PIS)

ID številka udeleženca:

1. DEL

1. Naziv študije:

Differences in Physical Activity And Well-Being: Perceptions Of Family Carers For People With Dementia

[Razlike v fizični aktivnosti in življenjskem slogu: mnenja neformalnih skrbnikov oseb z demenco]

2. Vabilo

Vabimo vas k sodelovanju v raziskavi. Preden se odločite sodelovati, je pomembno, da se seznanite z razlogi za izvedbo raziskave in z vsebino le-te. Prosimo vas, da skrbno preberete naslednje informacije in se o tem po potrebi pogovorite z drugimi. Za vsa pojasnila in dodatne informacije smo vam na voljo. Vzemite si čas za odločitev o tem, ali želite sodelovati ali ne.

Zahvaljujemo se vam, za branje tega dokumenta.

3. Kaj je namen te študije?

Cilj te študije v teku je prepoznati karakteristike in značilnosti različnih skupin neformalnih skrbnikov (zakonski partner, partner, odrasli otroci) in njihovih mnenj glede fizične aktivnosti in življenjskega sloga.

4. Zakaj sem bil izbran?

Pomembno je, da ocenimo čim večje število udeležencev, vi pa ste navedli, da ste v tej študiji pripravljeni sodelovati. Merila za izbor so, da je posameznik neformalni skrbnik (bodisi zakonski partner, partner ali odrasli otrok), star vsaj 50 let, ki trenutno za posameznika z diagnozo demence skrbi vsaj 5 ur na dan. Cilj te študije je zajeti še 164 drugih udeležencev.

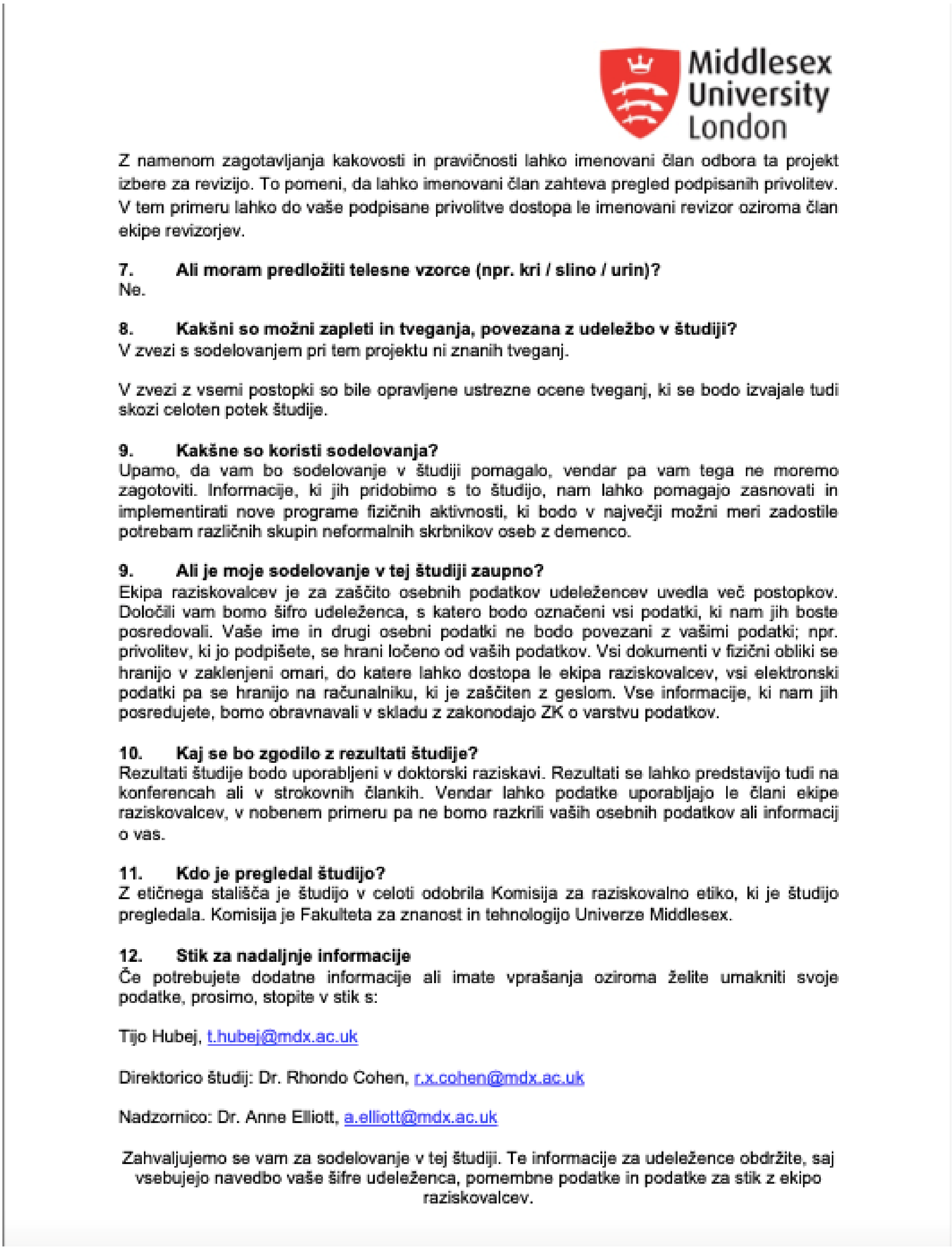
5. Ali moram sodelovati?

Odločitev o sodelovanju je prepuščena vam. Če se odločite sodelovati, boste prejeli ta list z informacijami ter prošnjo za podpis privolitve. Če se odločite sodelovati, lahko svoje sodelovanje kadar koli prekinete, ne da bi za to morali navesti razlog. Če se odločite prekiniti sodelovanje v študiji, vas prosimo, da raziskovalca o tem obvestite takoj, ko je to mogoče, raziskovalec pa bo uredil vse potrebno za prekinitev udeležbe. Če se iz kakršnega koli razloga odločite, da želite iz študije umakniti tudi svoje podatke, vas prosimo, da stopite v stik z raziskovalcem v enem mesecu od svojega sodelovanja. Po tem posameznih podatkov ne bo več mogoče umakniti, saj bodo rezultati lahko že objavljeni. Vsi podatki so sicer anonimizirani, tako da posameznih podatkov na noben način ni mogoče povezati z vami.

Če se odločite, da v študiji ne boste sodelovali, to na vas ne vpliva.

6. Kaj moram storiti?

Izpolnjevanje vprašalnika vam bo vzelo približno 15 minut, do vprašalnika pa lahko dostopate bodisi v fizični obliki ali na spletu, z uporabo programske opreme Qualtrics.



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Z namenom zagotavljanja kakovosti in pravičnosti lahko imenovani član odbora ta projekt izbere za revizijo. To pomeni, da lahko imenovani član zahteva pregled podpisanih privolitev. V tem primeru lahko do vaše podpisane privolitve dostopa le imenovani revizor oziroma član ekipe revizorjev.

7. Ali moram predložiti telesne vzorce (npr. kri / slino / urin)?
Ne.

8. Kakšni so možni zapleti in tveganja, povezana z udeležbo v študiji?
V zvezi s sodelovanjem pri tem projektu ni znanih tveganj.

V zvezi z vsemi postopki so bile opravljene ustrezne ocene tveganj, ki se bodo izvajale tudi skozi celoten potek študije.

9. Kakšne so koristi sodelovanja?
Upamo, da vam bo sodelovanje v študiji pomagalo, vendar pa vam tega ne moremo zagotoviti. Informacije, ki jih pridobimo s to študijo, nam lahko pomagajo zasnovati in implementirati nove programe fizičnih aktivnosti, ki bodo v največji možni meri zadostile potrebam različnih skupin neformalnih skrbnikov oseb z demenco.

9. Ali je moje sodelovanje v tej študiji zaupno?
Ekipa raziskovalcev je za zaščito osebnih podatkov udeležencev uvedla več postopkov. Določili vam bomo šifro udeleženca, s katero bodo označeni vsi podatki, ki nam jih boste posredovali. Vaše ime in drugi osebni podatki ne bodo povezani z vašimi podatki; npr. privolitev, ki jo podpišete, se hrani ločeno od vaših podatkov. Vsi dokumenti v fizični obliki se hranijo v zaklenjeni omari, do katere lahko dostopa le ekipa raziskovalcev, vsi elektronski podatki pa se hranijo na računalniku, ki je zaščiten z geslom. Vse informacije, ki nam jih posredujete, bomo obravnavali v skladu z zakonodajo ZK o varstvu podatkov.

10. Kaj se bo zgodilo z rezultati študije?
Rezultati študije bodo uporabljeni v doktorski raziskavi. Rezultati se lahko predstavijo tudi na konferencah ali v strokovnih člankih. Vendar lahko podatke uporabljajo le člani ekipe raziskovalcev, v nobenem primeru pa ne bomo razkrili vaših osebnih podatkov ali informacij o vas.

11. Kdo je pregledal študijo?
Z etičnega stališča je študijo v celoti odobrila Komisija za raziskovalno etiko, ki je študijo pregledala. Komisija je Fakulteta za znanost in tehnologijo Univerze Middlesex.

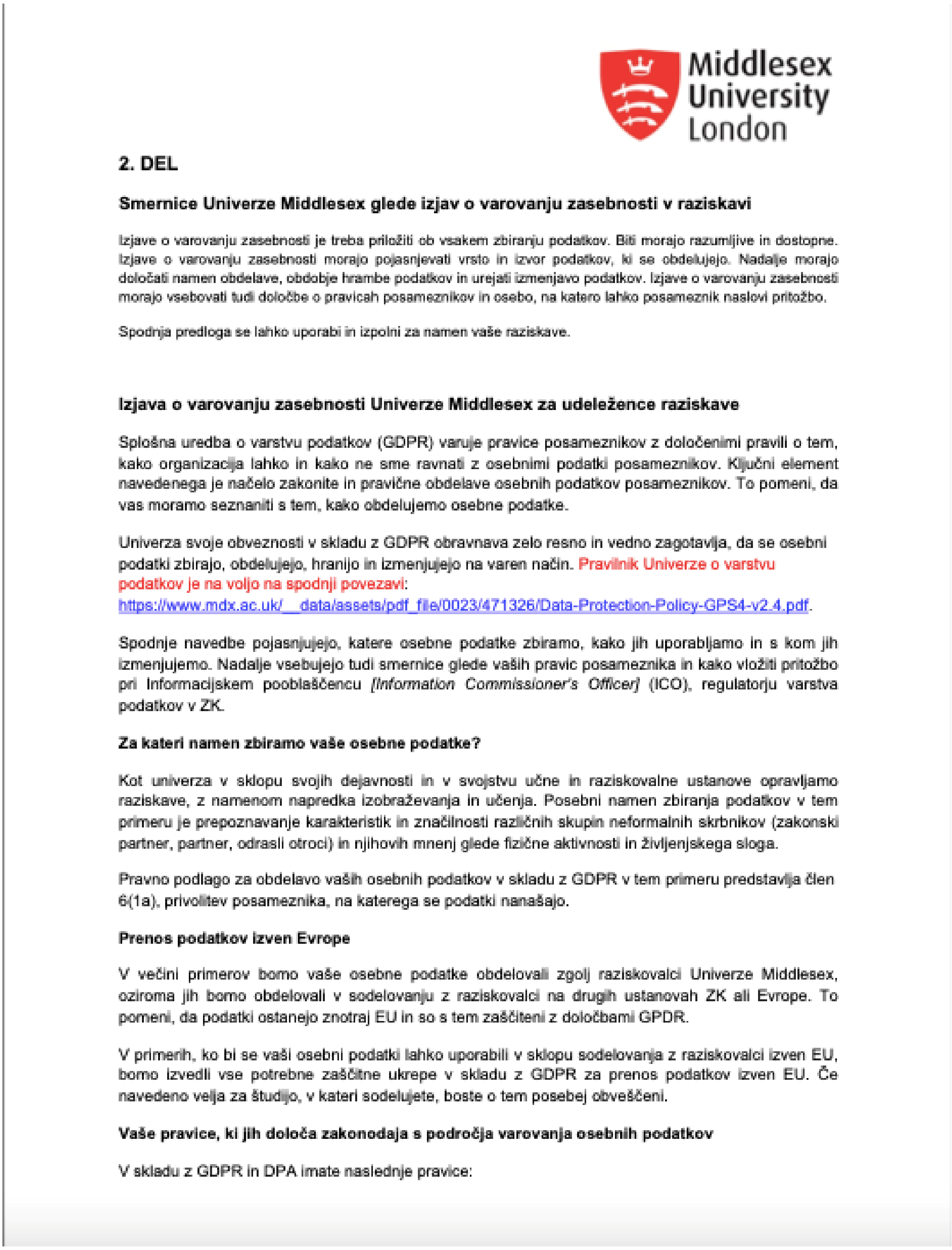
12. Stik za nadaljnje informacije
Če potrebujete dodatne informacije ali imate vprašanja oziroma želite umakniti svoje podatke, prosimo, stopite v stik s:

Tijo Hubej, t.hubej@mdx.ac.uk

Direktorico študij: Dr. Rhondo Cohen, r.x.cohen@mdx.ac.uk

Nadzornico: Dr. Anne Elliott, a.elliott@mdx.ac.uk

Zahvaljujemo se vam za sodelovanje v tej študiji. Te informacije za udeležence obdržite, saj vsebujejo navedbo vaše šifre udeleženca, pomembne podatke in podatke za stik z ekipo raziskovalcev.



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2. DEL

Smernice Univerze Middlesex glede izjav o varovanju zasebnosti v raziskavi

Izjave o varovanju zasebnosti je treba priložiti ob vsakem zbiranju podatkov. Biti morajo razumljive in dostopne. Izjave o varovanju zasebnosti morajo pojasnjevati vrsto in izvor podatkov, ki se obdelujejo. Nadalje morajo določati namen obdelave, obdobje hrambe podatkov in urejati izmenjavo podatkov. Izjave o varovanju zasebnosti morajo vsebovati tudi določbe o pravicah posameznikov in osebo, na katero lahko posameznik naslovi pritožbo.

Spodnja predloga se lahko uporabi in izpolni za namen vaše raziskave.

Izjava o varovanju zasebnosti Univerze Middlesex za udeležence raziskave

Splošna uredba o varstvu podatkov (GDPR) varuje pravice posameznikov z določenimi pravili o tem, kako organizacija lahko in kako ne sme ravnati z osebnimi podatki posameznikov. Ključni element navedenega je načelo zakonite in pravične obdelave osebnih podatkov posameznikov. To pomeni, da vas moramo seznaniti s tem, kako obdelujemo osebne podatke.

Univerza svoje obveznosti v skladu z GDPR obravnava zelo resno in vedno zagotavlja, da se osebni podatki zbirajo, obdelujejo, hranijo in izmenjujejo na varen način. Pravilnik Univerze o varstvu podatkov je na voljo na spodnji povezavi: https://www.mdx.ac.uk/__data/assets/pdf_file/0023/471326/Data-Protection-Policy-GPS4-v2.4.pdf.

Spodnje navedbe pojasnjujejo, katere osebne podatke zbiramo, kako jih uporabljamo in s kom jih izmenjujemo. Nadalje vsebujejo tudi smernice glede vaših pravic posameznika in kako vložiti pritožbo pri Informacijskem pooblaščencu *[Information Commissioner's Officer]* (ICO), regulatorju varstva podatkov v ZK.

Za kateri namen zbiramo vaše osebne podatke?

Kot univerza v sklopu svojih dejavnosti in v svojstvu učne in raziskovalne ustanove opravljamo raziskave, z namenom napredka izobraževanja in učenja. Posebni namen zbiranja podatkov v tem primeru je prepoznavanje karakteristik in značilnosti različnih skupin neformalnih skrbnikov (zakonski partner, partner, odrasli otroci) in njihovih mnenj glede fizične aktivnosti in življenjskega sloga.

Pravno podlago za obdelavo vaših osebnih podatkov v skladu z GDPR v tem primeru predstavlja člen 6(1a), privolitev posameznika, na katerega se podatki nanašajo.

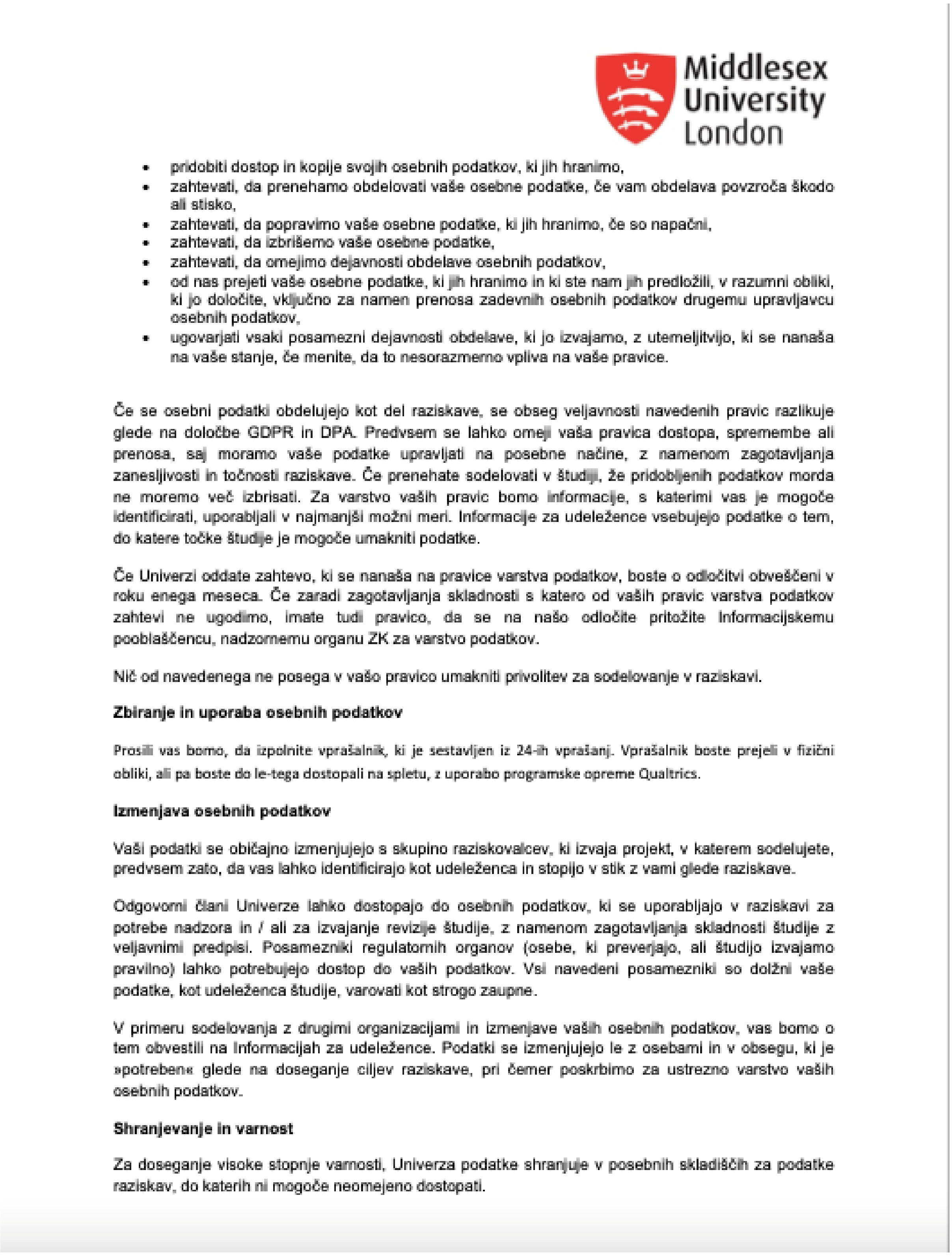
Prenos podatkov izven Evrope

V večini primerov bomo vaše osebne podatke obdelovali zgolj raziskovalci Univerze Middlesex, oziroma jih bomo obdelovali v sodelovanju z raziskovalci na drugih ustanovah ZK ali Evrope. To pomeni, da podatki ostanejo znotraj EU in so s tem zaščiteni z določbami GPDR.

V primerih, ko bi se vaši osebni podatki lahko uporabili v sklopu sodelovanja z raziskovalci izven EU, bomo izvedli vse potrebne zaščitne ukrepe v skladu z GDPR za prenos podatkov izven EU. Če navedeno velja za študijo, v kateri sodelujete, boste o tem posebej obveščeni.

Vaše pravice, ki jih določa zakonodaja s področja varovanja osebnih podatkov

V skladu z GDPR in DPA imate naslednje pravice:



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- pridobiti dostop in kopije svojih osebnih podatkov, ki jih hranimo,
- zahtevati, da prenehamo obdelovati vaše osebne podatke, če vam obdelava povzroča škodo ali stisko,
- zahtevati, da popravimo vaše osebne podatke, ki jih hranimo, če so napačni,
- zahtevati, da izbrišemo vaše osebne podatke,
- zahtevati, da omejimo dejavnosti obdelave osebnih podatkov,
- od nas prejeti vaše osebne podatke, ki jih hranimo in ki ste nam jih predložili, v razumni obliki, ki jo določite, vključno za namen prenosa zadevnih osebnih podatkov drugemu upravljavcu osebnih podatkov,
- ugovarjati vsaki posamezni dejavnosti obdelave, ki jo izvajamo, z utemeljitvijo, ki se nanaša na vaše stanje, če menite, da to nesorazmerno vpliva na vaše pravice.

Če se osebni podatki obdelujejo kot del raziskave, se obseg veljavnosti navedenih pravic razlikuje glede na določbe GDPR in DPA. Predvsem se lahko omeji vaša pravica dostopa, spremembe ali prenosa, saj moramo vaše podatke upravljati na posebne načine, z namenom zagotavljanja zanesljivosti in točnosti raziskave. Če prenehate sodelovati v študiji, že pridobljenih podatkov morda ne moremo več izbrisati. Za varstvo vaših pravic bomo informacije, s katerimi vas je mogoče identificirati, uporabljali v najmanjši možni meri. Informacije za udeležence vsebujejo podatke o tem, do katere točke študije je mogoče umakniti podatke.

Če Univerzi oddate zahtevo, ki se nanaša na pravice varstva podatkov, boste o odločitvi obveščeni v roku enega meseca. Če zaradi zagotavljanja skladnosti s katero od vaših pravic varstva podatkov zahtevi ne ugodimo, imate tudi pravico, da se na našo odločite pritožite Informacijskemu pooblaščencu, nadzornemu organu ZK za varstvo podatkov.

Nič od navedenega ne posega v vašo pravico umakniti privolitev za sodelovanje v raziskavi.

Zbiranje in uporaba osebnih podatkov

Prosili vas bomo, da izpolnite vprašalnik, ki je sestavljen iz 24-ih vprašanj. Vprašalnik boste prejeli v fizični obliki, ali pa boste do le-tega dostopali na spletu, z uporabo programske opreme Qualtrics.

Izmenjava osebnih podatkov

Vaši podatki se običajno izmenjujejo s skupino raziskovalcev, ki izvaja projekt, v katerem sodelujete, predvsem zato, da vas lahko identificirajo kot udeleženca in stopijo v stik z vami glede raziskave.

Odgovorni člani Univerze lahko dostopajo do osebnih podatkov, ki se uporabljajo v raziskavi za potrebe nadzora in / ali za izvajanje revizije študije, z namenom zagotavljanja skladnosti študije z veljavnimi predpisi. Posamezniki regulatornih organov (osebe, ki preverjajo, ali študijo izvajamo pravilno) lahko potrebujejo dostop do vaših podatkov. Vsi navedeni posamezniki so dolžni vaše podatke, kot udeleženca študije, varovati kot strogo zaupne.

V primeru sodelovanja z drugimi organizacijami in izmenjave vaših osebnih podatkov, vas bomo o tem obvestili na Informacijah za udeležence. Podatki se izmenjujejo le z osebami in v obsegu, ki je »potreben« glede na doseganje ciljev raziskave, pri čemer poskrbimo za ustrezno varstvo vaših osebnih podatkov.

Shranjevanje in varnost

Za doseganje visoke stopnje varnosti, Univerza podatke shranjuje v posebnih skladiščih za podatke raziskav, do katerih ni mogoče neomejeno dostopati.

Poleg zadevnih tehničnih ukrepov so v veljavi tudi podrobni in učinkoviti pravilniki ter postopki, s katerimi zagotavljamo, da so uporabniki in upravitelji podatkov Univerze seznanjeni s svojimi dolžnostmi in odgovornostmi za podatke, do katerih dostopajo. Posamezniki načeloma lahko dostopajo le do tistih podatkov, ki jih potrebujejo za opravljanje svojih nalog. Novo osebje, ki se pridruži Univerzi, mora opraviti usposabljanje, obstoječe osebje pa ima po potrebi na voljo dodatna usposabljanja in dostop do strokovnega mnenja.

Obdobje hrambe

V skladu z GDPR in DPA se osebni podatki za namene raziskave lahko hranijo neomejeno obdobje, če to ne vpliva na vas na način, ki presega obseg študije, za katero ste podali privolitev v sodelovanje.

Ob upoštevanju navedenega je obdobje hrambe vaših osebnih podatkov odvisno od več dejavnikov, vključno s pomembnostjo podatkov, potrebami po financiranju, naravo študije in zahtevami založnika. Podrobnosti posameznega projekta bodo navedene na informacijah za udeležence.

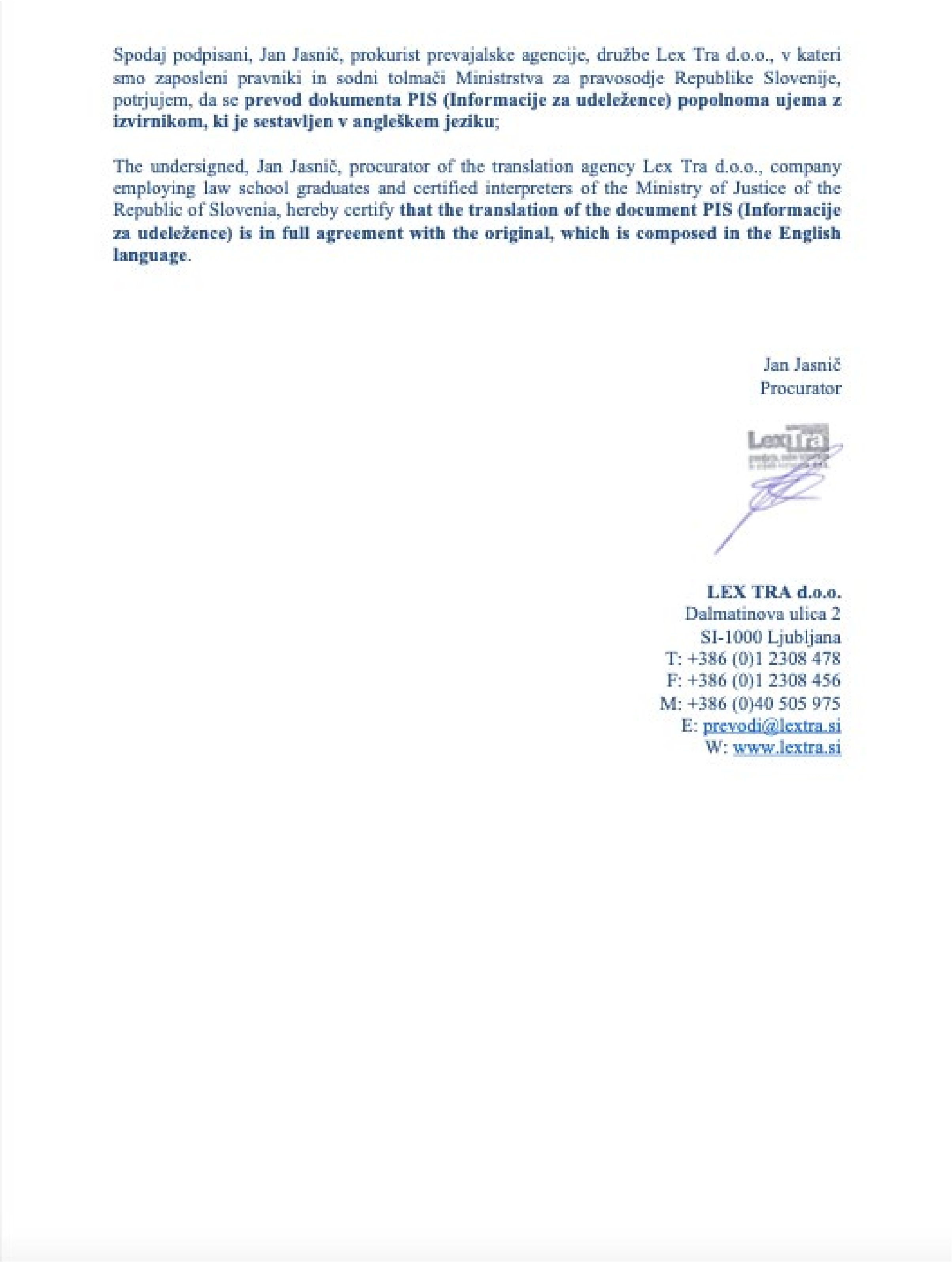
Stopite v stik z nami

Glavni raziskovalec, ki vodi to študijo, je Tija Hubej

t.hubej@mdx.ac.uk

Podatki za stik z organi Univerze:

Pooblaščena oseba za varstvo podatkov
Middlesex University
The Burroughs
London
NW4 4BT
Tel: +44 (0)20 8411 5555
Elektronska pošta: dpaofficer@mdx.ac.uk



Spodaj podpisani, Jan Jasnič, prokurist prevajalske agencije, družbe Lex Tra d.o.o., v kateri smo zaposleni pravniki in sodni tolmači Ministrstva za pravosodje Republike Slovenije, potrjujem, da se **prevod dokumenta PIS (Informacije za udeležence) popolnoma ujema z izvirnikom, ki je sestavljen v angleškem jeziku**;

The undersigned, Jan Jasnič, procurator of the translation agency Lex Tra d.o.o., company employing law school graduates and certified interpreters of the Ministry of Justice of the Republic of Slovenia, hereby certify **that the translation of the document PIS (Informacije za udeležence) is in full agreement with the original, which is composed in the English language**.

Jan Jasnič
Procurator

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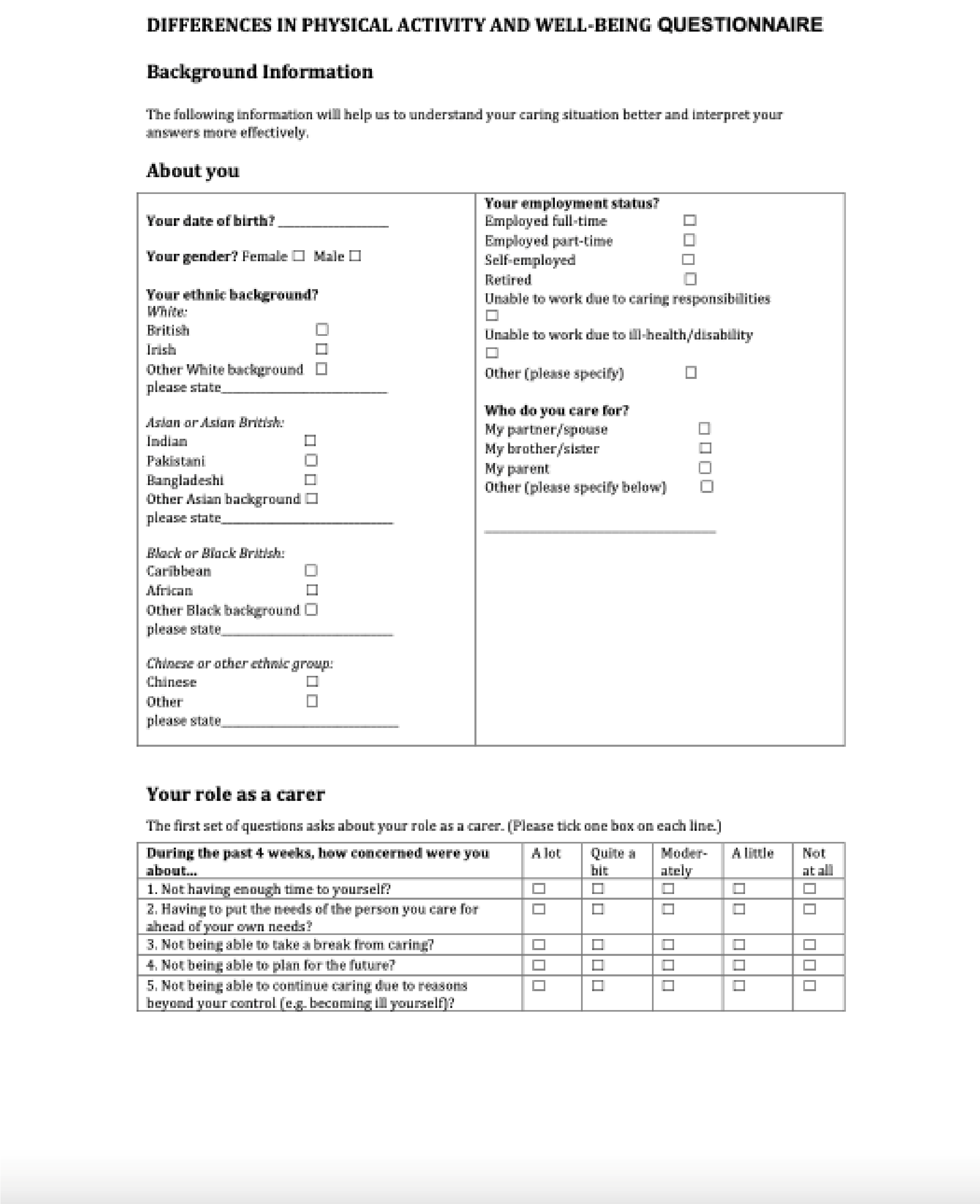
Appendix D: Questionnaire with Translation



DIFFERENCES IN PHYSICAL ACTIVITY AND WELL-BEING QUESTIONNAIRE

Background Information

The following information will help us to understand your caring situation better and interpret your answers more effectively.

About you

Your date of birth? ________________

Your gender? Female ☐ Male ☐

Your ethnic background?
White:
British ☐
Irish ☐
Other White background ☐
please state________________________

Asian or Asian British:
Indian ☐
Pakistani ☐
Bangladeshi ☐
Other Asian background ☐
please state________________________

Black or Black British:
Caribbean ☐
African ☐
Other Black background ☐
please state________________________

Chinese or other ethnic group:
Chinese ☐
Other ☐
please state________________________

Your employment status?
Employed full-time ☐
Employed part-time ☐
Self-employed ☐
Retired ☐
Unable to work due to caring responsibilities ☐
Unable to work due to ill-health/disability ☐
Other (please specify) ☐

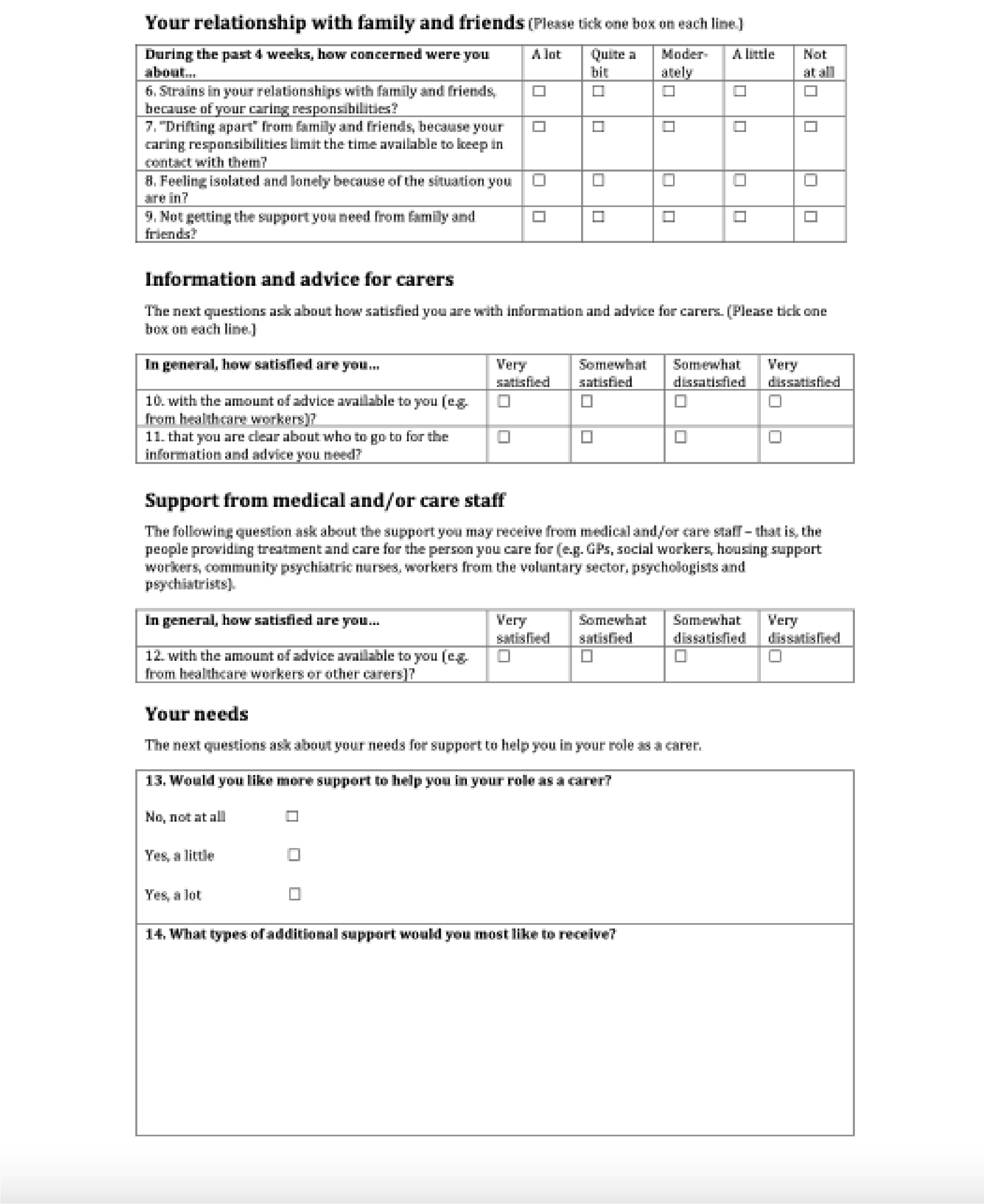
Who do you care for?
My partner/spouse ☐
My brother/sister ☐
My parent ☐
Other (please specify below) ☐

____

Your role as a carer

The first set of questions asks about your role as a carer. (Please tick one box on each line.)

During the past 4 weeks, how concerned were you about...	A lot	Quite a bit	Moder-ately	A little	Not at all
1. Not having enough time to yourself?	☐	☐	☐	☐	☐
2. Having to put the needs of the person you care for ahead of your own needs?	☐	☐	☐	☐	☐
3. Not being able to take a break from caring?	☐	☐	☐	☐	☐
4. Not being able to plan for the future?	☐	☐	☐	☐	☐
5. Not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself)?	☐	☐	☐	☐	☐



Your relationship with family and friends (Please tick one box on each line.)

During the past 4 weeks, how concerned were you about...	A lot	Quite a bit	Moder-ately	A little	Not at all
6. Strains in your relationships with family and friends, because of your caring responsibilities?	☐	☐	☐	☐	☐
7. "Drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	☐	☐	☐	☐	☐
8. Feeling isolated and lonely because of the situation you are in?	☐	☐	☐	☐	☐
9. Not getting the support you need from family and friends?	☐	☐	☐	☐	☐

Information and advice for carers

The next questions ask about how satisfied you are with information and advice for carers. (Please tick one box on each line.)

In general, how satisfied are you...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
10. with the amount of advice available to you (e.g. from healthcare workers)?	☐	☐	☐	☐
11. that you are clear about who to go to for the information and advice you need?	☐	☐	☐	☐

Support from medical and/or care staff

The following question ask about the support you may receive from medical and/or care staff – that is, the people providing treatment and care for the person you care for (e.g. GPs, social workers, housing support workers, community psychiatric nurses, workers from the voluntary sector, psychologists and psychiatrists).

In general, how satisfied are you...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
12. with the amount of advice available to you (e.g. from healthcare workers or other carers)?	☐	☐	☐	☐

Your needs

The next questions ask about your needs for support to help you in your role as a carer.

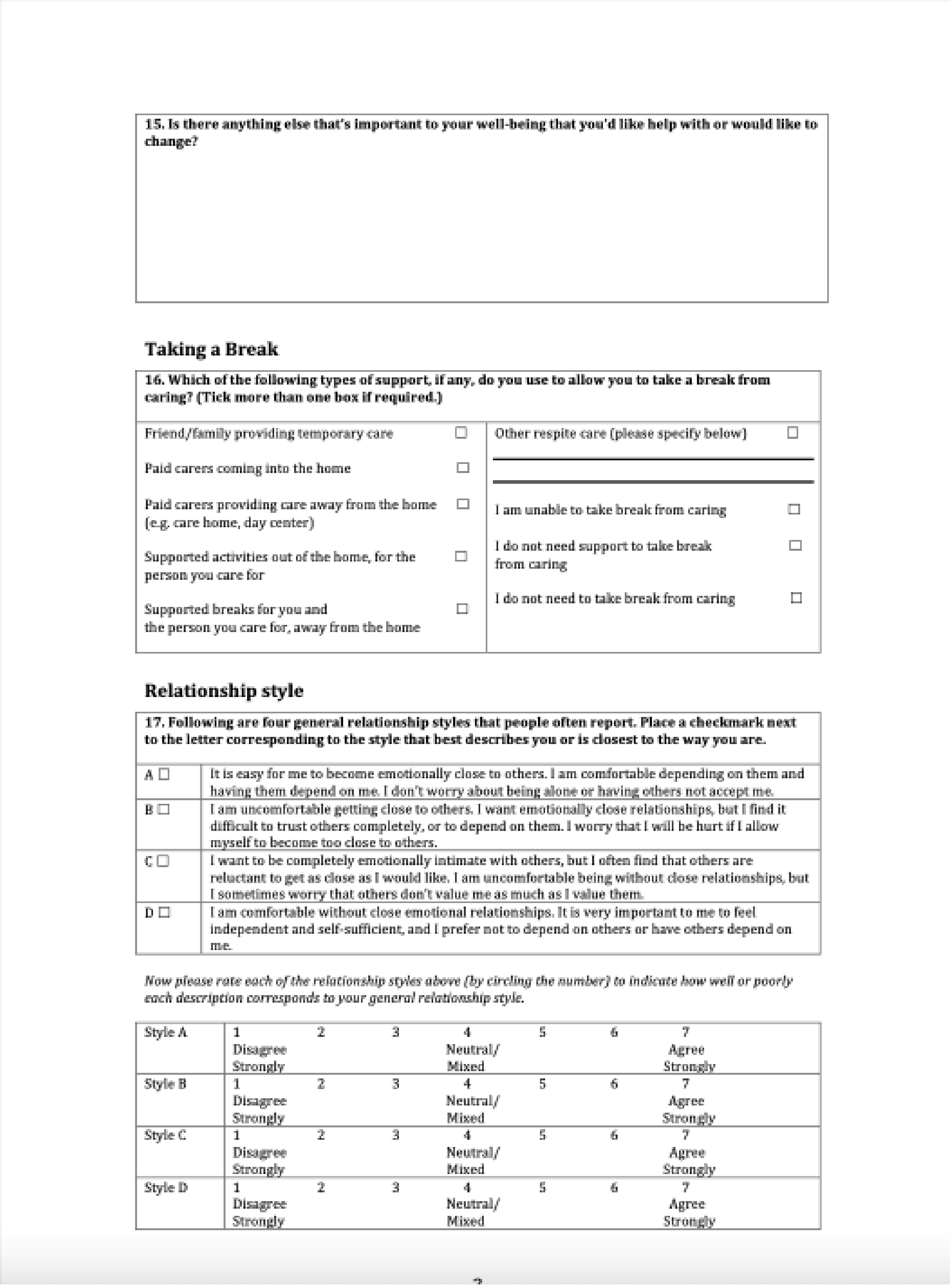
13. Would you like more support to help you in your role as a carer?

No, not at all ☐

Yes, a little ☐

Yes, a lot ☐

14. What types of additional support would you most like to receive?



15. Is there anything else that's important to your well-being that you'd like help with or would like to change?

Taking a Break

16. Which of the following types of support, if any, do you use to allow you to take a break from caring? (Tick more than one box if required.)

Friend/family providing temporary care ☐

Paid carers coming into the home ☐

Paid carers providing care away from the home (e.g. care home, day center) ☐

Supported activities out of the home, for the person you care for ☐

Supported breaks for you and the person you care for, away from the home ☐

Other respite care (please specify below) ☐

I am unable to take break from caring ☐

I do not need support to take break from caring ☐

I do not need to take break from caring ☐

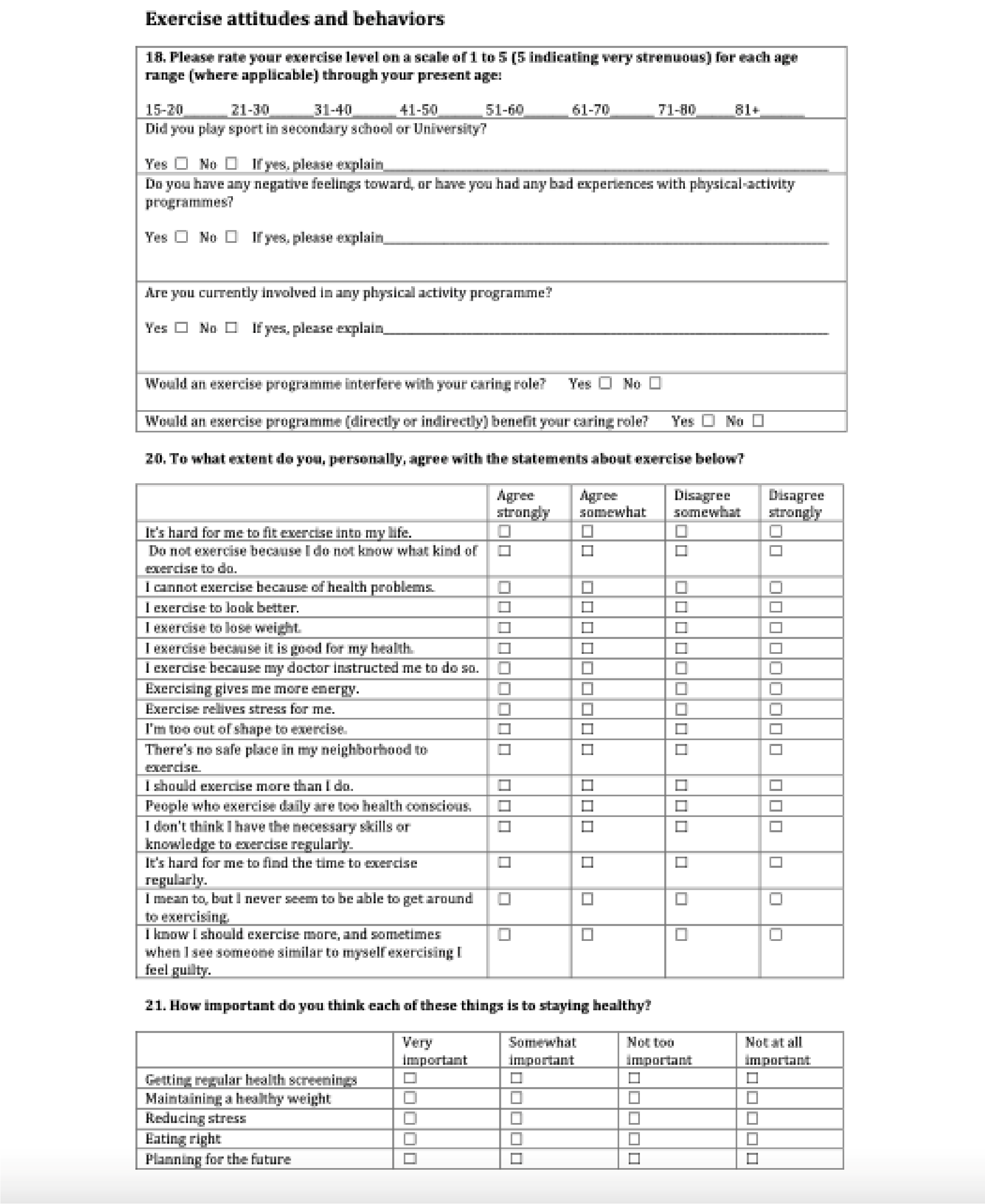
Relationship style

17. Following are four general relationship styles that people often report. Place a checkmark next to the letter corresponding to the style that best describes you or is closest to the way you are.

A ☐	It is easy for me to become emotionally close to others. I am comfortable depending on them and having them depend on me. I don't worry about being alone or having others not accept me.
B ☐	I am uncomfortable getting close to others. I want emotionally close relationships, but I find it difficult to trust others completely, or to depend on them. I worry that I will be hurt if I allow myself to become too close to others.
C ☐	I want to be completely emotionally intimate with others, but I often find that others are reluctant to get as close as I would like. I am uncomfortable being without close relationships, but I sometimes worry that others don't value me as much as I value them.
D ☐	I am comfortable without close emotional relationships. It is very important to me to feel independent and self-sufficient, and I prefer not to depend on others or have others depend on me.

Now please rate each of the relationship styles above (by circling the number) to indicate how well or poorly each description corresponds to your general relationship style.

Style A	1 Disagree Strongly	2	3	4 Neutral/ Mixed	5	6	7 Agree Strongly
Style B	1 Disagree Strongly	2	3	4 Neutral/ Mixed	5	6	7 Agree Strongly
Style C	1 Disagree Strongly	2	3	4 Neutral/ Mixed	5	6	7 Agree Strongly
Style D	1 Disagree Strongly	2	3	4 Neutral/ Mixed	5	6	7 Agree Strongly



Exercise attitudes and behaviors

18. Please rate your exercise level on a scale of 1 to 5 (5 indicating very strenuous) for each age range (where applicable) through your present age:

15-20______ 21-30______ 31-40______ 41-50______ 51-60______ 61-70______ 71-80______ 81+______

Did you play sport in secondary school or University?

Yes ☐ No ☐ If yes, please explain____

Do you have any negative feelings toward, or have you had any bad experiences with physical-activity programmes?

Yes ☐ No ☐ If yes, please explain____

Are you currently involved in any physical activity programme?

Yes ☐ No ☐ If yes, please explain____

Would an exercise programme interfere with your caring role? Yes ☐ No ☐

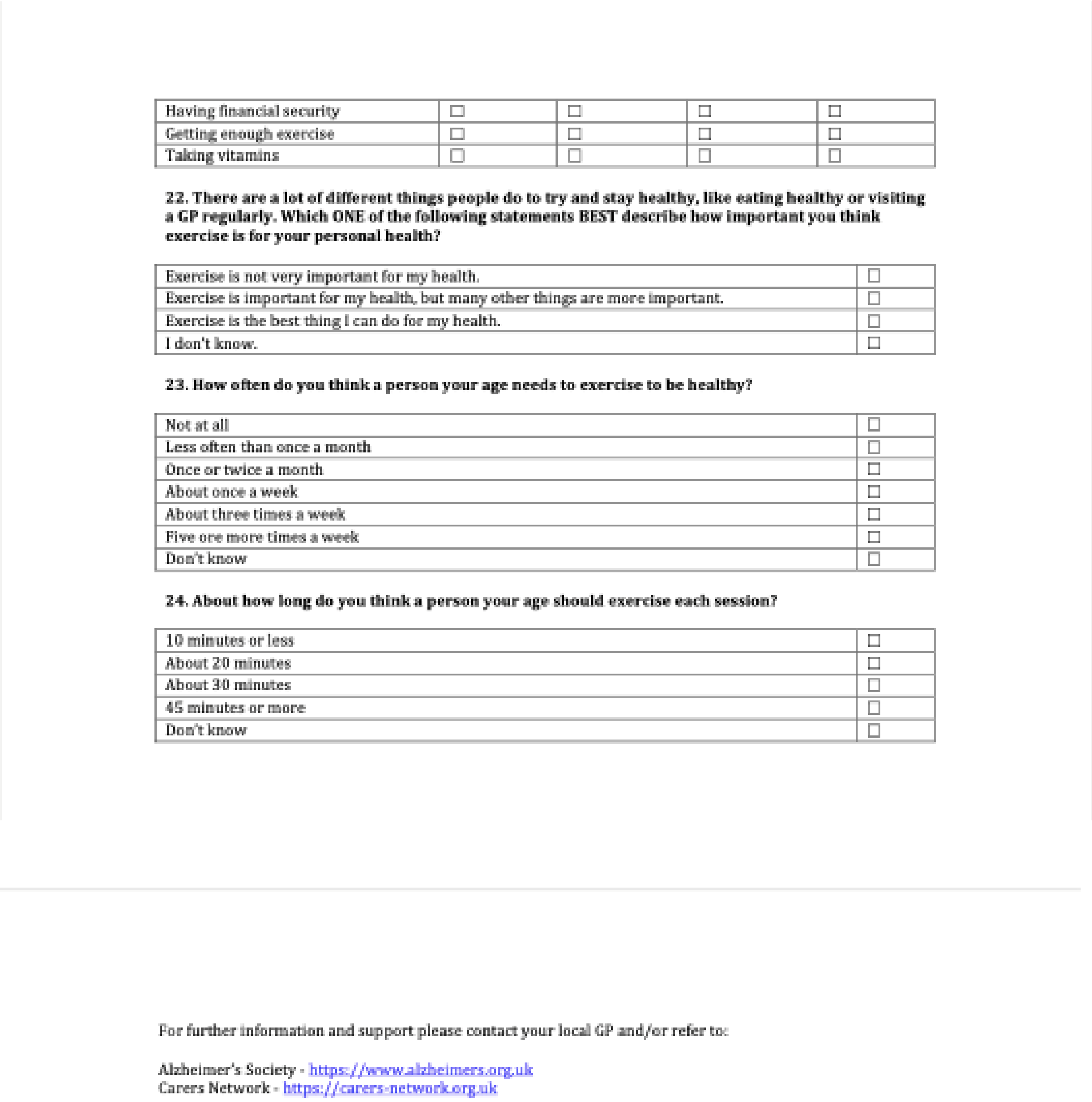
Would an exercise programme (directly or indirectly) benefit your caring role? Yes ☐ No ☐

20. To what extent do you, personally, agree with the statements about exercise below?

	Agree strongly	Agree somewhat	Disagree somewhat	Disagree strongly
It's hard for me to fit exercise into my life.	☐	☐	☐	☐
Do not exercise because I do not know what kind of exercise to do.	☐	☐	☐	☐
I cannot exercise because of health problems.	☐	☐	☐	☐
I exercise to look better.	☐	☐	☐	☐
I exercise to lose weight.	☐	☐	☐	☐
I exercise because it is good for my health.	☐	☐	☐	☐
I exercise because my doctor instructed me to do so.	☐	☐	☐	☐
Exercising gives me more energy.	☐	☐	☐	☐
Exercise relives stress for me.	☐	☐	☐	☐
I'm too out of shape to exercise.	☐	☐	☐	☐
There's no safe place in my neighborhood to exercise.	☐	☐	☐	☐
I should exercise more than I do.	☐	☐	☐	☐
People who exercise daily are too health conscious.	☐	☐	☐	☐
I don't think I have the necessary skills or knowledge to exercise regularly.	☐	☐	☐	☐
It's hard for me to find the time to exercise regularly.	☐	☐	☐	☐
I mean to, but I never seem to be able to get around to exercising.	☐	☐	☐	☐
I know I should exercise more, and sometimes when I see someone similar to myself exercising I feel guilty.	☐	☐	☐	☐

21. How important do you think each of these things is to staying healthy?

	Very important	Somewhat important	Not too important	Not at all important
Getting regular health screenings	☐	☐	☐	☐
Maintaining a healthy weight	☐	☐	☐	☐
Reducing stress	☐	☐	☐	☐
Eating right	☐	☐	☐	☐
Planning for the future	☐	☐	☐	☐



Having financial security	☐	☐	☐	☐
Getting enough exercise	☐	☐	☐	☐
Taking vitamins	☐	☐	☐	☐

22. There are a lot of different things people do to try and stay healthy, like eating healthy or visiting a GP regularly. Which ONE of the following statements BEST describe how important you think exercise is for your personal health?

Exercise is not very important for my health.	☐
Exercise is important for my health, but many other things are more important.	☐
Exercise is the best thing I can do for my health.	☐
I don't know.	☐

23. How often do you think a person your age needs to exercise to be healthy?

Not at all	☐
Less often than once a month	☐
Once or twice a month	☐
About once a week	☐
About three times a week	☐
Five ore more times a week	☐
Don't know	☐

24. About how long do you think a person your age should exercise each session?

10 minutes or less	☐
About 20 minutes	☐
About 30 minutes	☐
45 minutes or more	☐
Don't know	☐

For further information and support please contact your local GP and/or refer to:

Alzheimer's Society - https://www.alzheimers.org.uk
Carers Network - https://carers-network.org.uk

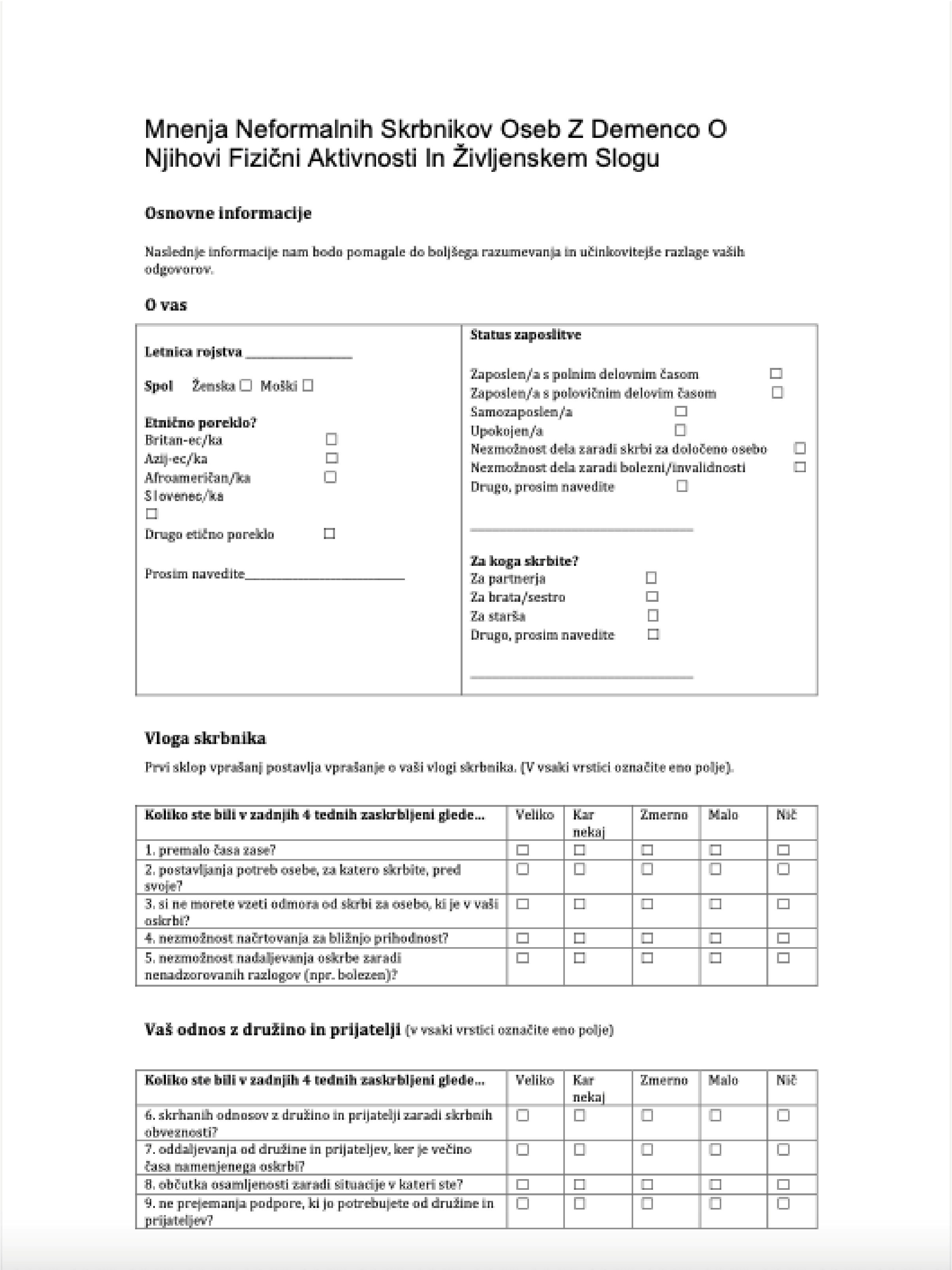
Iskreno se vam zahvaljujemo, ker ste se odločili sodelovati v naši spletni raziskavi. Namen raziskave je proučiti mnenja neformalnih skrbnikov oseb z demenco o njihovi fizični aktivnosti in življenskem slogu. Ugotoviti želimo dejavnike, ki motivirajo skrbnike k večji skrbi za lastno zdravje in boljši življenjski slog.
Raziskavo vodi Tija Hubej, doktorska študentka na Middlesex University v Londonu.

Anketa je anonimna, za izpolnjevanje pa boste potrebovali do 15 minut svojega časa. Zbrani podatki bodo obravnavani zaupno in analizirani na splošno (nikakor ne na ravni posameznika). Iz raziskave lahko kadarkoli izstopite.

V primeru, da bi vas katero od vprašanj vznemirilo, se obrnite na osebnega zdravnika ali svetovalca.

Prosimo, da potrdite spodnje polje, če se strinjate s sodelovanjem v študiji.

Strinjam se　　Ne strinjam se



Mnenja Neformalnih Skrbnikov Oseb Z Demenco O Njihovi Fizični Aktivnosti In Življenskem Slogu

Osnovne informacije

Naslednje informacije nam bodo pomagale do boljšega razumevanja in učinkovitejše razlage vaših odgovorov.

O vas

Letnica rojstva ________________

Spol Ženska ☐ Moški ☐

Etnično poreklo?
Britan-ec/ka ☐
Azij-ec/ka ☐
Afroameričan/ka ☐
Slovenec/ka ☐
Drugo etično poreklo ☐

Prosim navedite________________________

Status zaposlitve

Zaposlen/a s polnim delovnim časom ☐
Zaposlen/a s polovičnim delovim časom ☐
Samozaposlen/a ☐
Upokojen/a ☐
Nezmožnost dela zaradi skrbi za določeno osebo ☐
Nezmožnost dela zaradi bolezni/invalidnosti ☐
Drugo, prosim navedite ☐

____

Za koga skrbite?
Za partnerja ☐
Za brata/sestro ☐
Za starša ☐
Drugo, prosim navedite ☐

____

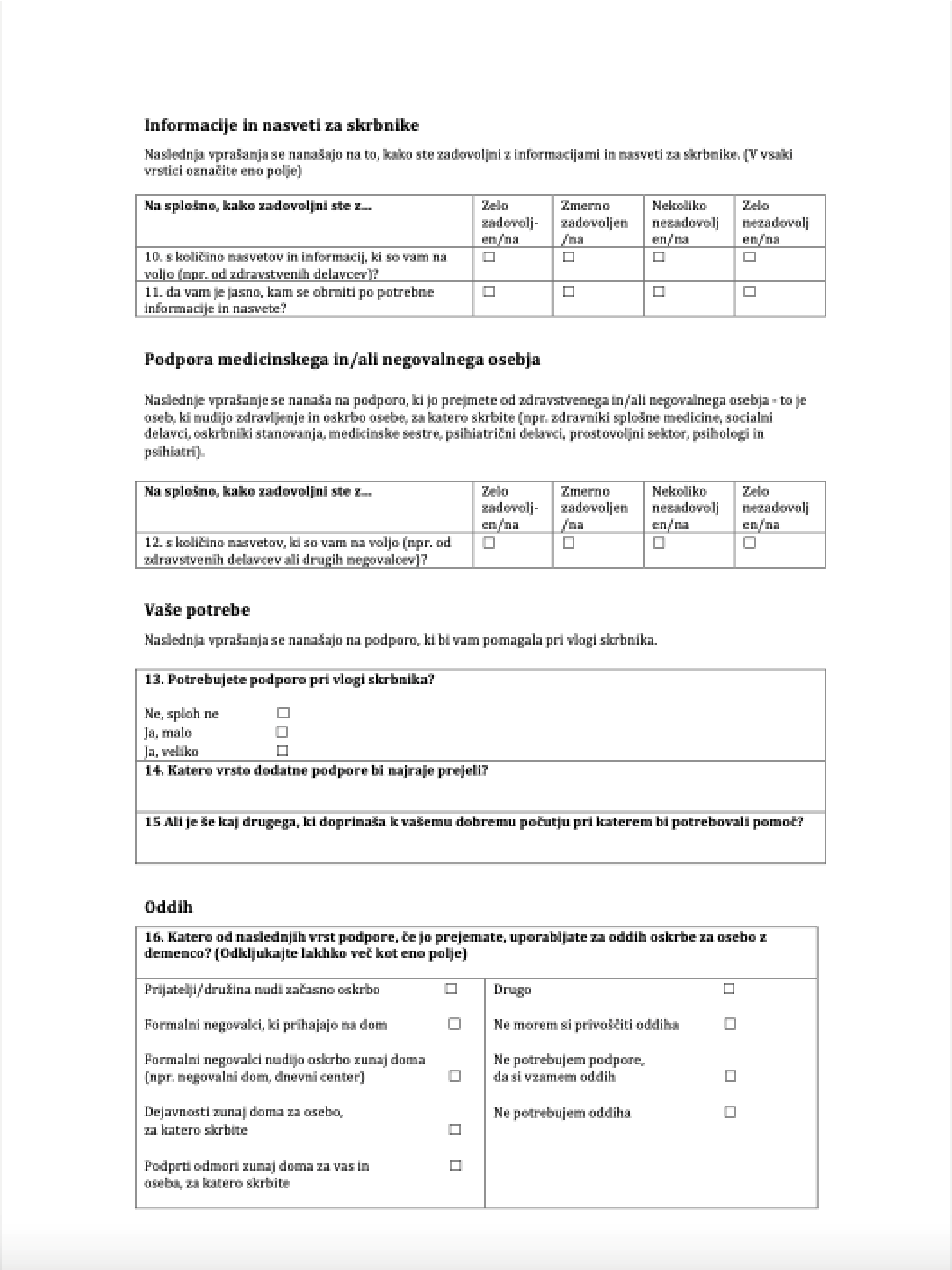
Vloga skrbnika

Prvi sklop vprašanj postavlja vprašanje o vaši vlogi skrbnika. (V vsaki vrstici označite eno polje).

Koliko ste bili v zadnjih 4 tednih zaskrbljeni glede…	Veliko	Kar nekaj	Zmerno	Malo	Nič
1. premalo časa zase?	☐	☐	☐	☐	☐
2. postavljanja potreb osebe, za katero skrbite, pred svoje?	☐	☐	☐	☐	☐
3. si ne morete vzeti odmora od skrbi za osebo, ki je v vaši oskrbi?	☐	☐	☐	☐	☐
4. nezmožnost načrtovanja za bližnjo prihodnost?	☐	☐	☐	☐	☐
5. nezmožnost nadaljevanja oskrbe zaradi nenadzorovanih razlogov (npr. bolezen)?	☐	☐	☐	☐	☐

Vaš odnos z družino in prijatelji (v vsaki vrstici označite eno polje)

Koliko ste bili v zadnjih 4 tednih zaskrbljeni glede…	Veliko	Kar nekaj	Zmerno	Malo	Nič
6. skrhanih odnosov z družino in prijatelji zaradi skrbnih obveznosti?	☐	☐	☐	☐	☐
7. oddaljevanja od družine in prijateljev, ker je večino časa namenjenega oskrbi?	☐	☐	☐	☐	☐
8. občutka osamljenosti zaradi situacije v kateri ste?	☐	☐	☐	☐	☐
9. ne prejemanja podpore, ki jo potrebujete od družine in prijateljev?	☐	☐	☐	☐	☐



Informacije in nasveti za skrbnike

Naslednja vprašanja se nanašajo na to, kako ste zadovoljni z informacijami in nasveti za skrbnike. (V vsaki vrstici označite eno polje)

Na splošno, kako zadovoljni ste z…	Zelo zadovolj-en/na	Zmerno zadovoljen/na	Nekoliko nezadovoljen/na	Zelo nezadovoljen/na
10. s količino nasvetov in informacij, ki so vam na voljo (npr. od zdravstvenih delavcev)?	☐	☐	☐	☐
11. da vam je jasno, kam se obrniti po potrebne informacije in nasvete?	☐	☐	☐	☐

Podpora medicinskega in/ali negovalnega osebja

Naslednje vprašanje se nanaša na podporo, ki jo prejmete od zdravstvenega in/ali negovalnega osebja - to je oseb, ki nudijo zdravljenje in oskrbo osebe, za katero skrbite (npr. zdravniki splošne medicine, socialni delavci, oskrbniki stanovanja, medicinske sestre, psihiatrični delavci, prostovoljni sektor, psihologi in psihiatri).

Na splošno, kako zadovoljni ste z…	Zelo zadovolj-en/na	Zmerno zadovoljen/na	Nekoliko nezadovoljen/na	Zelo nezadovoljen/na
12. s količino nasvetov, ki so vam na voljo (npr. od zdravstvenih delavcev ali drugih negovalcev)?	☐	☐	☐	☐

Vaše potrebe

Naslednja vprašanja se nanašajo na podporo, ki bi vam pomagala pri vlogi skrbnika.

13. Potrebujete podporo pri vlogi skrbnika?

Ne, sploh ne ☐
Ja, malo ☐
Ja, veliko ☐

14. Katero vrsto dodatne podpore bi najraje prejeli?

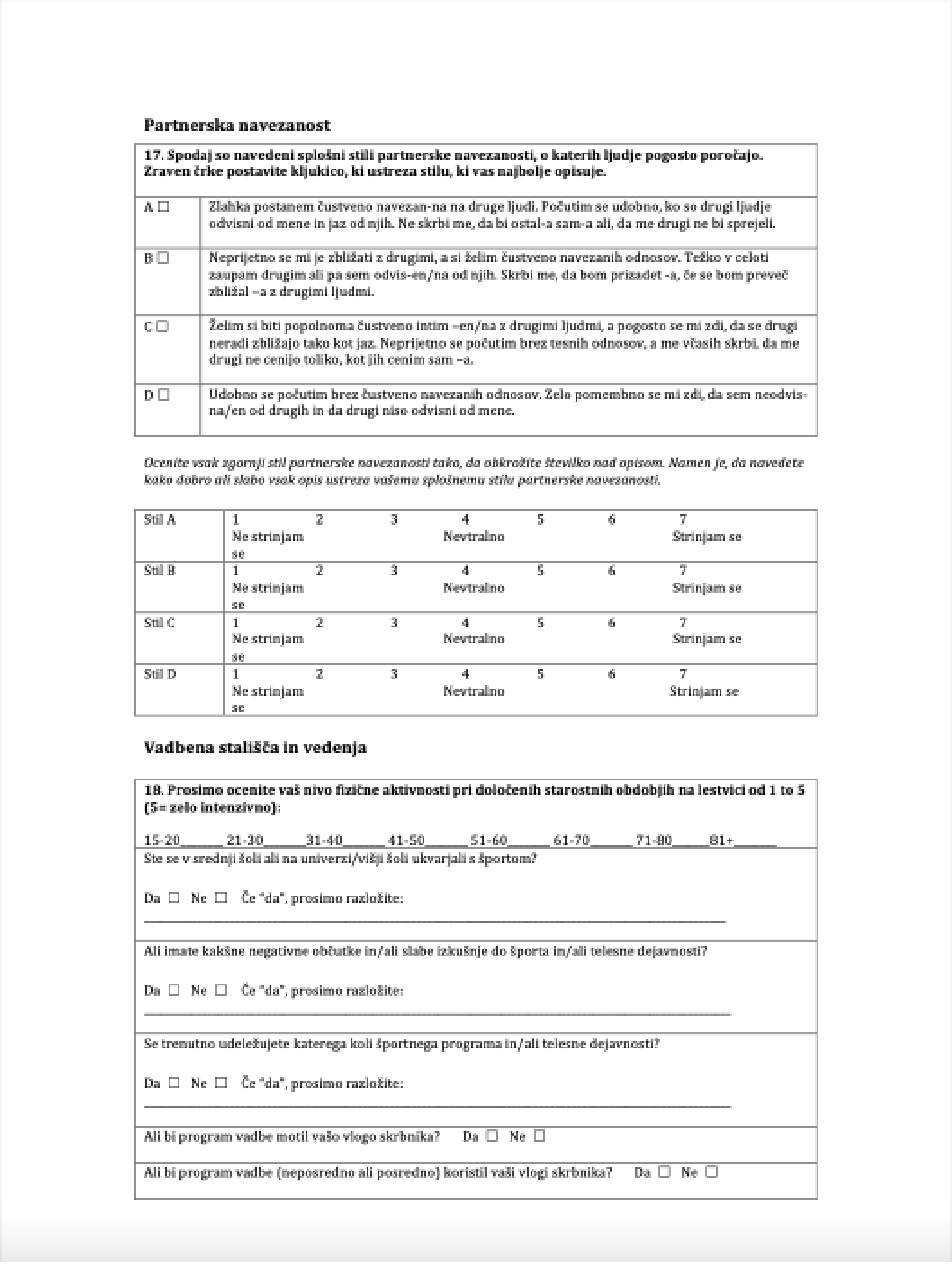
15 Ali je še kaj drugega, ki doprinaša k vašemu dobremu počutju pri katerem bi potrebovali pomoč?

Oddih

16. Katero od naslednjih vrst podpore, če jo prejemate, uporabljate za oddih oskrbe za osebo z demenco? (Odkljukajte lahkko več kot eno polje)

Prijatelji/družina nudi začasno oskrbo ☐
Formalni negovalci, ki prihajajo na dom ☐
Formalni negovalci nudijo oskrbo zunaj doma (npr. negovalni dom, dnevni center) ☐
Dejavnosti zunaj doma za osebo, za katero skrbite ☐
Podprti odmori zunaj doma za vas in oseba, za katero skrbite ☐

Drugo ☐
Ne morem si privoščiti oddiha ☐
Ne potrebujem podpore, da si vzamem oddih ☐
Ne potrebujem oddiha ☐



Partnerska navezanost

17. Spodaj so navedeni splošni stili partnerske navezanosti, o katerih ljudje pogosto poročajo. Zraven črke postavite kljukico, ki ustreza stilu, ki vas najbolje opisuje.	
A ☐	Zlahka postanem čustveno navezan-na na druge ljudi. Počutim se udobno, ko so drugi ljudje odvisni od mene in jaz od njih. Ne skrbi me, da bi ostal-a sam-a ali, da me drugi ne bi sprejeli.
B ☐	Neprijetno se mi je zbližati z drugimi, a si želim čustveno navezanih odnosov. Težko v celoti zaupam drugim ali pa sem odvis-en/na od njih. Skrbi me, da bom prizadet -a, če se bom preveč zbližal –a z drugimi ljudmi.
C ☐	Želim si biti popolnoma čustveno intim –en/na z drugimi ljudmi, a pogosto se mi zdi, da se drugi neradi zbližajo tako kot jaz. Neprijetno se počutim brez tesnih odnosov, a me včasih skrbi, da me drugi ne cenijo toliko, kot jih cenim sam –a.
D ☐	Udobno se počutim brez čustveno navezanih odnosov. Zelo pomembno se mi zdi, da sem neodvisna/en od drugih in da drugi niso odvisni od mene.

Ocenite vsak zgornji stil partnerske navezanosti tako, da obkrožite številko nad opisom. Namen je, da navedete kako dobro ali slabo vsak opis ustreza vašemu splošnemu stilu partnerske navezanosti.

Stil A	1 Ne strinjam se	2	3	4 Nevtralno	5	6	7 Strinjam se
Stil B	1 Ne strinjam se	2	3	4 Nevtralno	5	6	7 Strinjam se
Stil C	1 Ne strinjam se	2	3	4 Nevtralno	5	6	7 Strinjam se
Stil D	1 Ne strinjam se	2	3	4 Nevtralno	5	6	7 Strinjam se

Vadbena stališča in vedenja

18. Prosimo ocenite vaš nivo fizične aktivnosti pri določenih starostnih obdobjih na lestvici od 1 to 5 (5= zelo intenzivno):

15-20______ 21-30______ 31-40______ 41-50______ 51-60______ 61-70______ 71-80______ 81+______

Ste se v srednji šoli ali na univerzi/višji šoli ukvarjali s športom?

Da ☐ Ne ☐ Če "da", prosimo razložite:

____

Ali imate kakšne negativne občutke in/ali slabe izkušnje do športa in/ali telesne dejavnosti?

Da ☐ Ne ☐ Če "da", prosimo razložite:

____

Se trenutno udeležujete katerega koli športnega programa in/ali telesne dejavnosti?

Da ☐ Ne ☐ Če "da", prosimo razložite:

____

Ali bi program vadbe motil vašo vlogo skrbnika? Da ☐ Ne ☐

Ali bi program vadbe (neposredno ali posredno) koristil vaši vlogi skrbnika? Da ☐ Ne ☐

20. V kolikšni meri se strinjate s spodnjimi izjavami?

	Močno se strinjam	Nekoliko se strinjam	Nekoliko se ne strinjam	Ne strinjam se
Težko mi je vključiti vadbo in telesno aktivnost v vsakdanje življenje.	☐	☐	☐	☐
Nisem telesno aktiv-na/en, ker ne vem kako in kakšne vaje naj izvajam.	☐	☐	☐	☐
Nisem telesno aktiv-na/en zaradi zdravstvenih problemov.	☐	☐	☐	☐
Telovadim zato, da bolje izgledam.	☐	☐	☐	☐
Telovadim zato, da izgubim težo..	☐	☐	☐	☐
Telovadim zato, ker je dobro za moje zdravje.	☐	☐	☐	☐
Telovadim zato, ker mi je to naročil zdravnik..	☐	☐	☐	☐
Telovadba mi daje več energije.	☐	☐	☐	☐
Telovadba mi zmanjša vsakodnevni stres.	☐	☐	☐	☐
Ne telovadim, ker nisem telesno dobro pripravljen.	☐	☐	☐	☐
V moji soseski ni primernega prostora za telovadbo.	☐	☐	☐	☐
Moral-a bi telovaditi več, kot trenutno.	☐	☐	☐	☐
Ljudje, ki telovadijo vsak dan, so preveč zdravstveno ozaveščeni.	☐	☐	☐	☐
Mislim, da nimam potrebnih veščin ali znanja za redno vadbo.	☐	☐	☐	☐
Težko najdem čas za redno vadbo.	☐	☐	☐	☐
Želim si telovaditi redno, a nikoli nisem uspel-a tega uresničiti.	☐	☐	☐	☐
Vem, da bi moral-a telovaditi več. Včasih, ko vidim telovaditi nekoga podobne starosti, se počutim kriv-o/-ega.	☐	☐	☐	☐

21. Kako pomembne za zdravje so, po vašem mnenju naslednje trditve?

	Zelo pomembno	Nekoliko pomembno	Ne preveč pomembno	Nepomembno
Redni zdravstveni pregledi	☐	☐	☐	☐
Vzdrževanje zdrave telesne teže	☐	☐	☐	☐
Zmanjšanje stresa	☐	☐	☐	☐
Zdrava prehrana	☐	☐	☐	☐
Načrtovanje prihodnosti	☐	☐	☐	☐
Finančna varnost	☐	☐	☐	☐
Biti dovolj telesno aktiv-na/en	☐	☐	☐	☐
Jemanje prehranskih dodatkov/vitaminov	☐	☐	☐	☐

22. Obstaja veliko različnih stvari, ki jih ljudje naredijo, da bi ostali zdravi. Na primer: zdravo jedo ali redno obiskujejo zdravnika. Katera od naslednjih trditev NAJBOLJ opisuje, kako pomembna je telesna aktivnost za vaše osebno zdravje?

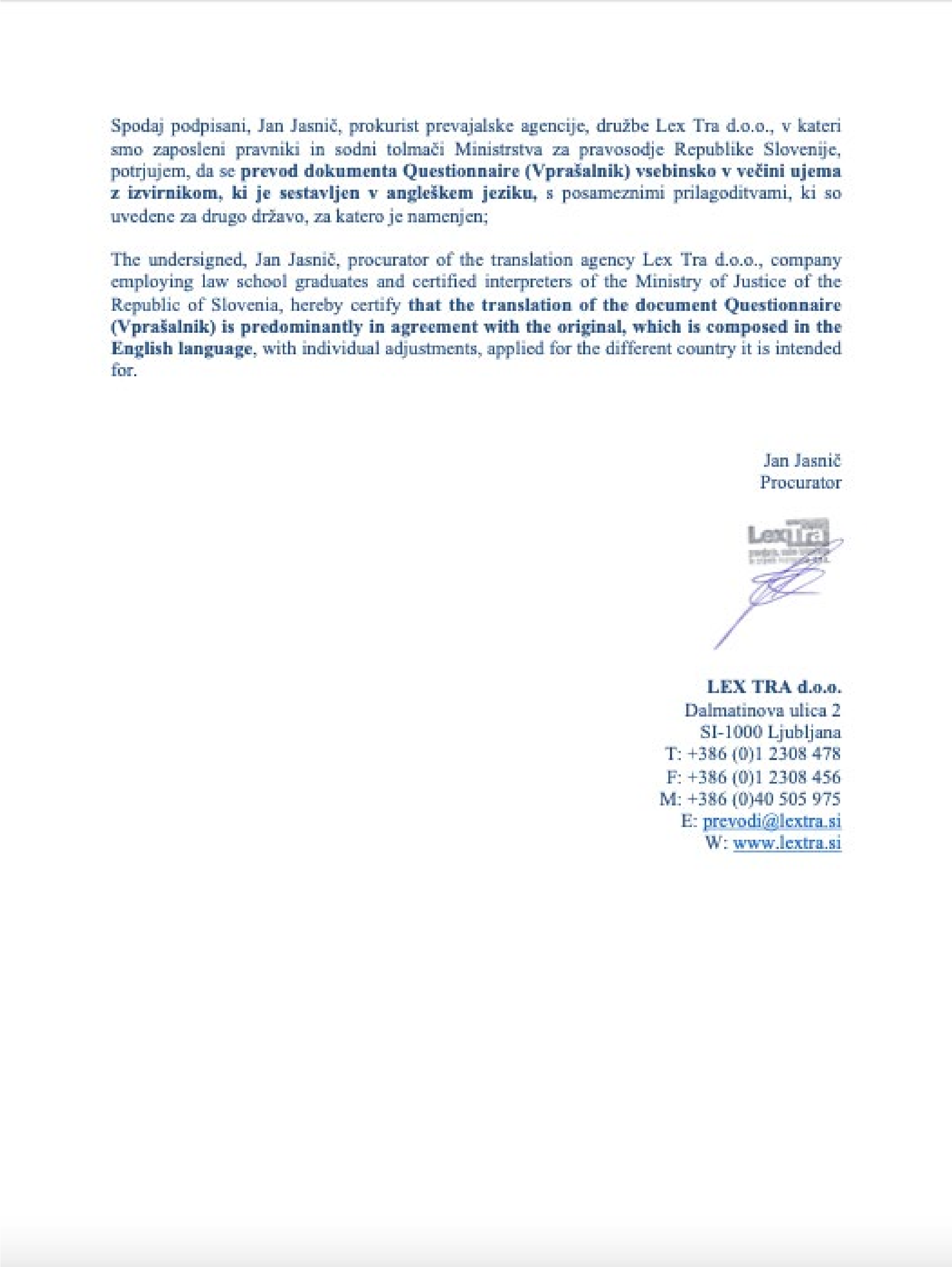
Telesna aktivnost ni pomembna za moje zdravje.	☐
Telesna aktivnost je pomembna za moje zdravje, a je veliko drugih stvari bolj pomembnih.	☐
Telesna aktivnost je najboljše, kar lahko naredim za svoje zdravje.	☐
Ne vem.	☐

23. Kako pogosto menite, da mora biti oseba vaše starosti telesno aktivna?

Ne potrebuje	☐
Manj kot enkrat na mesec	☐
Enkrat ali dvakrat na mesec	☐
Enkrat na teden	☐
Trikrat na teden	☐
Pet ali večkrat na teden	☐
Ne vem	☐

24. Kako dolgo menite, da mora oseba vaše starosti izvajati program telesne vadbe?

10 minut ali manj	☐
Približno 20 minut	☐
Približno 30 minut	☐
45 minut ali več	☐
Ne vem	☐



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The undersigned, Jan Jasnič, procurator of the translation agency Lex Tra d.o.o., company employing law school graduates and certified interpreters of the Ministry of Justice of the Republic of Slovenia, hereby certify **that the translation of the document Questionnaire (Vprašalnik) is predominantly in agreement with the original, which is composed in the English language**, with individual adjustments, applied for the different country it is intended for.

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Procurator

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