

Activity 1

Annexes

care
4YOU
OTHERS

Resilience training
for the new generation
of caregivers

Care4You4Others
Resilience training
for the new generation
of caregivers

2023-1-AT01-KA210-VET-000151863



Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or OeAD-GmbH. Neither the European Union nor the granting authority can be held responsible for them.

Annex 1: Theoretical overview of Informal and formal caregivers resilience	3
Annex 2: Interview template	10
Annex 3: Survey template	15
Annex 4: Survey data – raw	23
Annex 5: Survey data - entry instructions	24
Annex 6: Survey data - visualisations	32

Responsible partner: **Acufade**

Prepared by: **Primoz Skrt, Acufade**

Supporting partners: **bit Bildungswelten, Eclectica+**



Annex 1

Theoretical overview of informal and formal caregivers resilience

INFORMAL AND FORMAL CAREGIVER RESILIENCE

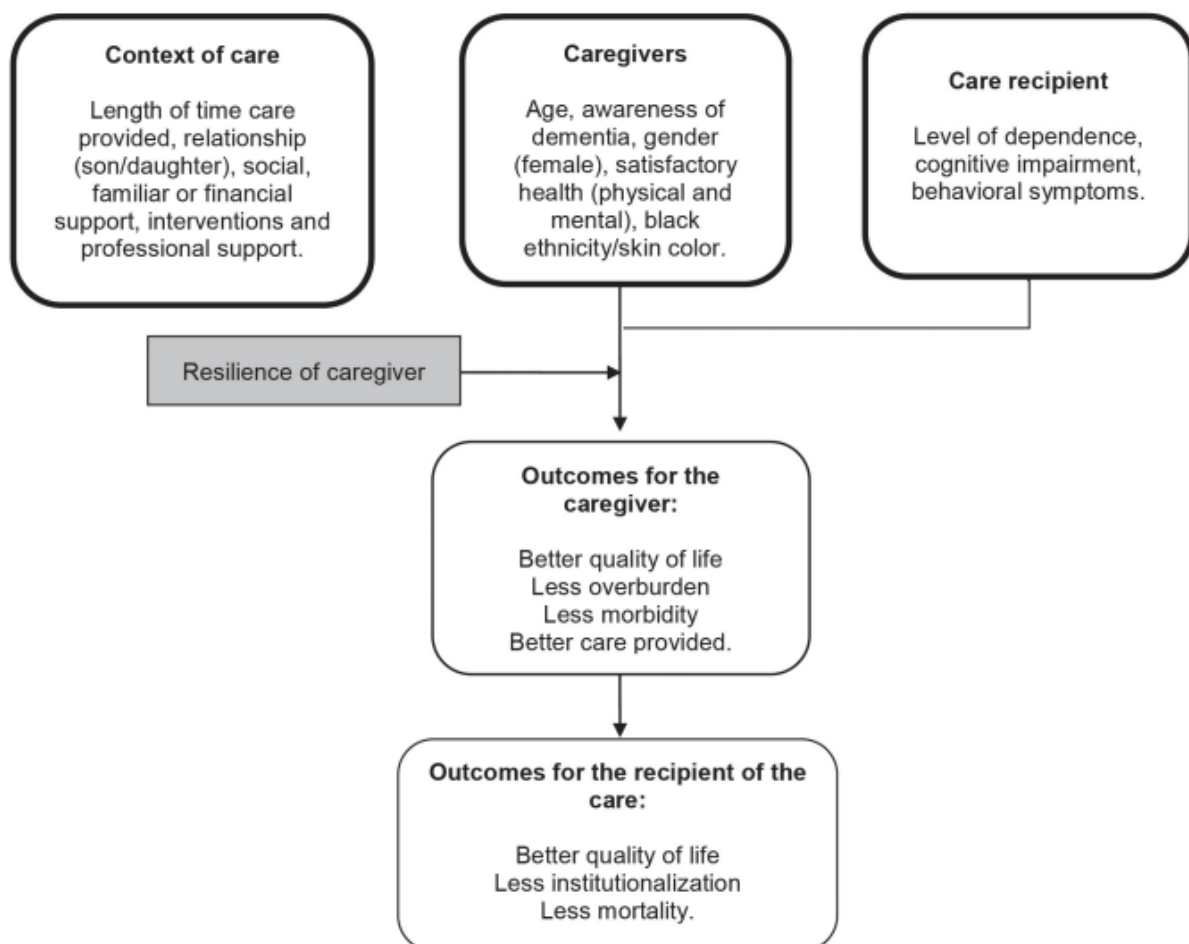
A. INFORMAL CAREGIVER RESILIENCE

Resilience – the lack of a common definition

There isn't a consensus about how to define resilience, as several terms are used as synonyms for it [1,3,4,5,7,8]. This diversity of definitions reflects the variation of ways of looking at resilience across context and situation and under-scores the multidimensionality and complexity of the concept. The lack of a theoretical framework may give rise to several methodological problems, such as the absence of standardized assessment instruments and the impossibility of comparing different studies.

Among the different definitions of resilience, the following one from the American Psychological Association (APA) has considered one of the most complete: *'Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress—such as family and relationship problems, serious health problems or workplace and financial stressors. It means "bouncing back" from difficult experiences.'*¹

Resilience should be understood not only as a personal attribute, but also as the dynamic interaction between biological, psychosocial, and social processes, in association with caregiving tasks [1,4].



[3]

¹ <http://www.apa.org/helpcenter/road-resilience.aspx>

Informal caregiver's average profile

Female, spouse/children, 40-60 years old, caregivers of adult patients with chronic or advanced conditions (dementia/Alzheimer, terminal oncological illness, depression, stroke, transplant, vegetative state).

Caregiver's burden of illness

The overburdening of caregivers occurs as a result of a series of **physical, psychological, emotional, social, and financial problems** such as stress, neuroticism, anxiety, depression, fatigue, insomnia, poor health, drug use, isolation, occupation, and income.

Which interventions to enhance resilience?

Several variables seem to affect the increase in the resilience of caregivers, including the degree of kinship to the patient, quality of life, socioeconomic conditions, assistance with or division of responsibilities. In general, acceptance – hope – awareness/competence/self-efficacy - self-care – family support – social support and interactions - spirituality – communication – empathy – and emotional expression/management increase resilience. In particular, the findings of some studies indicate that **social support** has a positive impact on resilience [8].

Due to the small number of studies identified for each intervention type and the low to moderate quality of all included studies, it remains unclear which intervention and what dosage is the most effective in promoting caregivers' resilience, and no definitive conclusions about the effectiveness of interventions can be drawn [5]. However, the reviews showed that **psychoeducation and training programs appear to have the most consistent positive findings to enhance caregivers' resilience**, reducing levels of stress and strengthening coping strategies [1,2,4,5,6,8]. More, mindfulness (through group sessions and home practice) and Cognitive Behavioral Therapy-based intervention seem to be promising. These three elements may improve caregiver resilience.

References

- [1] Dias R, Santos RL, de Sousa MF, Nogueira MM, Torres B, Belfort T, et al. Resilience of caregivers of people with dementia: a systematic review of biological and psychosocial determinants. *Trends Psychiatry Psychother.* 2014;37(1):12-19. <http://dx.doi.org/10.1590/2237-6089-2014-0032>. Epub Jan 30, 2015.
- [2] Ghaffari F, Rostami M, Fotokian Z, Hajiahmadi M. Effectiveness of Resilience Education in the Mental Health of Family Caregivers of Elderly Patients with Alzheimer's Disease. *Iran J Psychiatry Behav Sci.* 2019;13(3):e69507. <https://doi.org/10.5812/ijpbs.69507>.
- [3] Manzini, Carlene Souza Silva; Brigola, Allan Gustavo; Pavarini, Sofia Cristina Iost; Vale, Francisco Assis Carvalho (2016). Factors associated with the resilience of family caregivers of persons with dementia: a systematic review. *SciELO journals. Dataset.* <https://doi.org/10.6084/m9.figshare.20016637.v1>.
- [4] Palacio G C, Krikorian A, Gómez-Romero MJ, Limonero JT. Resilience in Caregivers: A Systematic Review. *Am J Hosp Palliat Care.* 2020 Aug;37(8):648-658. doi: 10.1177/1049909119893977. Epub 2019 Dec 13. PMID: 31830813.
- [5] Chi NC, Han S, Lin SY, Fu YK, Zhu Z, Nakad L, Demiris G. Resilience-enhancing interventions for family caregivers: A systematic review. *Chronic Illn.* 2023 May 31:17423953231174928. doi: 10.1177/17423953231174928. Epub ahead of print. PMID: 37259541.
- [6] Ghezselfloo M, Saadati N, Yousefi Z, Zamanpour M. Study the Effect of Resilience Training on Reducing Stress and Communication Problems in the Primary Caregivers of the Elderly With Alzheimer Disease.

Salmand: Iranian Journal of Ageing 2019; 14 (3) :284-297
URL: <http://salmandj.uswr.ac.ir/article-1-1503-en.html>.

[7] Sophie Opsomer , Jan De Lepeleire , Emelien Lauwerier & Peter Pype (2020) Resilience in family caregivers of patients diagnosed with advanced cancer – unravelling the process of bouncing back from difficult experiences, a hermeneutic review, European Journal of General Practice, 26:1, 79-85, DOI: [10.1080/13814788.2020.1784876](https://doi.org/10.1080/13814788.2020.1784876)

[8] Noelia Durán-Gómez, Jorge Guerrero-Martín, Demetrio Pérez-Civantos, Casimiro Fermín López Jurado, Patricia Palomo-López & Macarena C Cáceres (2020) Understanding Resilience Factors Among Caregivers of People with Alzheimer’s Disease in Spain, Psychology Research and Behavior Management, 13:, 1011-1025, DOI: [10.2147/PRBM.S274758](https://doi.org/10.2147/PRBM.S274758)

B. FORMAL CAREGIVER – HEALTHCARE PROFESSIONALS’ - RESILIENCE

Burnout among healthcare professionals

Maslach and Jackson’s conceptualised burnout as a three-dimensional construct consisting of:

- Emotional Exhaustion (tiredness, somatic symptoms, decreased emotional resources and a feeling that one has nothing left to give to others)
- Depersonalisation (negative, cynical attitudes, and impersonal feelings towards patients which results in treating them as objects)
- Reduced personal accomplishment (feelings of incompetence, inefficiency, and inadequacy) [1].

Healthcare professionals are experiencing unprecedented levels of occupational stress and burnout. More than half of US physicians are experiencing substantial symptoms of burnout, and several studies have also found a high prevalence of burnout and depression among medical students. Studies of nurses report a similarly high prevalence of burnout and depression [2]. In the UK, the proportion of National Health Service (NHS) staff feeling unwell due to work-related stress increased from 28% in 2009 to 40% in 2018, and in a recent study of seven European nations, it was estimated that around a third of doctors and nurses were suffering from burnout [8].

Work process inefficiencies, excessive workloads, work-home conflicts, organizational climate factors (e.g., management culture; lack of physician-nurse collaboration, value congruence, and social support), and deterioration in control, autonomy, and meaning at work have been associated with burnout among physicians and nurses [2]. Furthermore, healthcare professionals are exposed to a plethora of emotions arisen from the doctor-patient relationship, including a sense of failure and frustration when the patient's illness progresses, feelings of powerlessness, grief, fear of becoming ill oneself or dying, facing uncertainty in clinical practice, or a desire to separate from and avoid patients to escape these feelings [3].

Registered nurses who worked in nursing homes may also be at higher risk for burnout than nurses who work in other settings. Some studies have found female physicians to have 30–60 percent increased odds of burnout; younger physicians are also at increased odds of burnout [2].

Healthcare professionals’ burnout represents real suffering among people dedicated to preventing and relieving the suffering of others.

Coronavirus-19 pandemic exacerbated the scenario of healthcare workers who experienced a considerable amount of stress [5,7]. Clinicians rarely access available support from mental health providers after adverse and other emotionally stressful events, even after a collective trauma [7].

Relatively few methodologically robust intervention studies have been conducted on how to improve the work-lives and well-being of health care professionals.

The role of resilience

In general, three levels of change are recommended in order to reduce the risk of burnout:

1. modifying the organisational structure and work processes;
2. improving the fit between the organisation and the individual doctor through professional development programmes;
3. individual-level actions to reduce stress and poor health symptoms through effective coping and promoting healthy behaviours [2].

Building resilience at an individual level is often suggested as a preventative strategy against burnout among healthcare professionals [4,5,6]. Previous studies indicate these may confer a range of benefits on

healthcare professionals, including lower levels of depression and burnout and increased wellbeing [8]. Among the different definitions - to date, there is no accepted universal definition - a study identified resilience as a dynamic, evolving process of positive attitudes and effective strategies such as maintaining interest, continuing professional development, increasing self-awareness and accepting personal limitations, pursuing supportive relations, good communication and teamwork skills, time and technology management [4].

Which interventions to enhance resilience?

Personal resilience

Personal resilience has been described as a series of individual behaviors, skills, and attitude involving emotional, social, physical and personal wellbeing, following a multiple approach.

Educational interventions like coaching training, behavioural therapy, empathy, emotional competencies problem solving, mindfulness, and art-therapy, can lead to strategies for enhancing personal resilience [5,6,7,8,9].

Regarding coaching training, **results from literature support the feasibility of delivering a psychological resilience intervention to multidisciplinary healthcare professionals and provide preliminary evidence that this may be effective for improving their general resilience** [8]. Moreover, in the cases of common trauma like Covid-19, peer support programs and discussion workshops can contribute to reconstitute the lost sense of community, overcoming isolation and creating a sense of “shared organizational responsibility” and renewing a sense of professionalism [7,8].

Considering mindfulness practice and art-based therapy, over the past two decades, a burgeoning of the literature has revealed their beneficial effects on mental health promotion and stress reduction. Mindfulness-based interventions provide both short-term and long-term benefits to individuals’ physical and psychological health, including the reduction of stress, anxiety, depressive symptoms, greater emotional regulation, and improvement in chronic disease management [10]. Art therapy provides individuals with the means to reframe and communicate experiences and feelings that are difficult to comprehend and verbalize, enabling deep reflections, and self-expressions [9].

Finally, **web-based interventions designed to enhance resilience may be effective in clinical practice settings** and have the potential to provide support to frontline staff experiencing prolonged workplace stress across a range of health care professional groups. The development of effective, evidence-based digital interventions was identified as playing a potentially important role during the COVID-19 pandemic. The studied interventions included a variety of formats such as web-based videoconferencing platforms, resilience training, peer groups, and wellness newsletters. Findings showed improvements in resilience or proxy measures of resilience (anxiety, depression, well-being, stress, work engagement, or positive emotions). Still, many of the interventions included interactions with peers or intervention facilitators, suggesting that person-to-person interaction, whether face-to-face or on the web, may increase the likelihood of successful outcomes [11].

However, only a limited literature has previously tested resilience interventions in healthcare professionals, and more studies are needed to produce a robust evidence base on which to develop recommendations related to building resilience. Moreover, the interest on treatments aimed to promote providers’ wellness and resilience has increased, but it is important to recognise focusing on resilience training of the individual doctor will be effective unless attention is paid to enhancing a positive work environment. Mixed together, the whole path is greater than the sum of its parts.

References

- [1] Maslach, C.; Jackson, S. Maslach Burnout Inventory manual, 2nd ed.; Consulting Psychologist Press: Palo Alto, CA, USA, 1986.
- [2] Dyrbye, Lotte N., et al. "Burnout among health care professionals: a call to explore and address this underrecognized threat to safe, high-quality care." *NAM perspectives* (2017).
- [3] Kumar S. Burnout and Doctors: Prevalence, Prevention and Intervention. *Healthcare* (Basel). 2016 Jun 30;4(3):37. doi: 10.3390/healthcare4030037. PMID: 27417625; PMCID: PMC5041038.
- [4] Jensen, P.M.; Trollope-Kumar, K.; Waters, H.; Everson, J. Building physician resilience. *Can. Fam. Physician* 2008, 54, 722–729.
- [5] Sheikhrabari A, Peyrovi H, Khankeh H. The Main Features of Resilience in Healthcare Providers: A Scoping Review. *Med J Islam Repub Iran*. 2022 Feb 3;36:3. doi: 10.47176/mjiri.36.3. PMID: 35999934; PMCID: PMC9386779.
- [6] Zanatta F, Maffoni M, Giardini A. Resilience in palliative healthcare professionals: a systematic review. *Support Care Cancer*. 2020 Mar;28(3):971-978. doi: 10.1007/s00520-019-05194-1. Epub 2019 Dec 6. PMID: 31811483; PMCID: PMC7223999.
- [7] Resnick KS, Fins JJ. Professionalism and Resilience After COVID-19. *Acad Psychiatry*. 2021 Oct;45(5):552-556. doi: 10.1007/s40596-021-01416-z. Epub 2021 Mar 2. PMID: 33649940; PMCID: PMC7920636.
- [8] Johnson, J., Simms-Ellis, R., Janes, G. *et al.* Can we prepare healthcare professionals and students for involvement in stressful healthcare events? A mixed-methods evaluation of a resilience training intervention. *BMC Health Serv Res* **20**, 1094 (2020). <https://doi.org/10.1186/s12913-020-05948-2>.
- [9] Ho AHY, Tan-Ho G, Ngo TA, Ong G, Chong PH, Dignadice D, Potash J. A Novel Mindful-Compassion Art-Based Therapy for Reducing Burnout and Promoting Resilience Among Healthcare Workers: Findings From a Waitlist Randomized Control Trial. *Front Psychol*. 2021 Oct 21;12:744443. doi: 10.3389/fpsyg.2021.744443. PMID: 34744918; PMCID: PMC8566679.
- [10] Jiménez-Picón, N.; Romero-Martín, M.; Ponce-Blandón, J.A.; Ramirez-Baena, L.; Palomo-Lara, J.C.; Gómez-Salgado, J. The Relationship between Mindfulness and Emotional Intelligence as a Protective Factor for Healthcare Professionals: Systematic Review. *Int. J. Environ. Res. Public Health* 2021, 18, 5491. <https://doi.org/10.3390/ijerph18105491>.
- [11] Henshall C, Ostinelli E, Harvey J, Davey Z, Aghanenu B, Cipriani A, Attenburrow MJ. Examining the Effectiveness of Web-Based Interventions to Enhance Resilience in Health Care Professionals: Systematic Review. *JMIR Med Educ*. 2022 Sep 6;8(3):e34230. doi: 10.2196/34230. PMID: 36066962; PMCID: PMC9490530.

Annex 2

Interview template

Internal Guidance for the Survey with Experts

A. INTRODUCTION

This task is part of the activity 1 which aims to clearly define **what content and what topics should be elaborated in an online training course** about resilience, tailored to the needs of caregivers and future caregivers.

This will be achieved through:

- desk research of existing practices, projects, activities, literature.
- field research by interviewing experts in the field of care and/or resilience.
- survey carried out among professional and informal carers.

This guidance will provide necessary elements to perform interviews with previously identified experts from Austria, Italy and Spain.

B. METHODOLOGICAL CONCEPT

Timeline: October 2023

Target value: minimum 6 interviews (2 per country)

Gender perspective: consider gender balance of interviewers that is especially important when we are talking about caring challenges.

Interview methodology: personal or video-call following slots and guiding questions designed bellow.

Time needed: 30-45 minutes

Language: interview can be carried out in national languages; summary should be done in English.

Objective:

- I. receive information and opinion from the expert.
- II. Further engage expert in the project process (in the survey testing; feedback on the course)

Analysis: descriptive summary for each interview + common transnational summary of all interviews

C. GUIDING QUESTIONS FOR THE INTERVIEW

SLOT 0: Our presentation

(present ourselves, the project, and objectives of the interview)

SLOT 1: Introduction and Background of the Interviewer

(the objective is to receive information from the interviewer – mainly what is relationship, experiences with caregiving challenges and/or resilience topic)

Q1.1 Can you please introduce yourself and provide your professional background and your expertise in the field of caregiving and resilience? (what, where, how long)

SLOT 2: Understanding Resilience in Care

(the objective is to receive the perception on how the expert understands challenges related to caregiving, impacts of caregiving on wellbeing and efficacy, differences among professional and informal caregivers)

Q.2.1 Could you share some examples of challenges that caregivers commonly face in relation to their professional and everyday lives?

Q.2.2 What does resilience in the context of caregiving mean to you?

Q.2.3 Are there any major differences where it comes to the resilience if we talk about professional or informal carers? What is different? What is common?

SLOT 3: Tools and Strategies for Resilience Building

(the objective is to investigate which topics should be addressed, how can caregivers be supported and learn about potential tools, strategies, and existing projects activities in the field)

Q3.1 From your experience, what are the key components of resilience that caregivers need to develop or strengthen?

Q3.2 How can caregivers be supported to improve their resilience: on individual level, on organizational level?

Q3.3 Can you share any success stories, projects, tolls, best practices from your work that exemplify resilience in care?

Explain briefly the activity 2 of the project here before going to the next slot – e.g. state that we will design online course and we are in the phase of investigating needs in order to prepare tailored and useful course.

SLOT 4: Online Course for Caregivers

(the objective is to get inputs about learning objectives, materials, approaches to design the online course)

Q4.1 Learning objectives- which topics should be addressed through an online course?

(support with examples if needed: e.g.: raising awareness – importance of selfcare; practical knowledge through practical exercises and case studies; increasing theoretical knowledge)

Q4.2 How to tackle different cultural, social, economic challenges in universal online course?

Q4.3 Learning materials – any specific recommendations for an online course? How can the course be integrated/used with other interventions/resources?

Q4.4 Any other specific comments?

SLOT 5: Conclusion

(the objective is to invite the expert to be further involved in the project activities)

Q5.1 Would you be interested to be further involved in the project activities by testing the survey/online course or be informed about outcomes?

Q5.2 If yes, how can we contact you?

These questions will help us gather valuable information and will be used for the design of a comprehensive survey for both informal and professional caregivers as well as to create a tailored online course as part of the Care4You4Others project. Thank you for your valuable input. We will contact you and inform you about the progress of the project.

Annex 3

Survey template

Internal Guidance for the Survey with Caregivers

A. INTRODUCTION

This task is part of activity 1 which aims to clearly define **what content and what topics should be elaborated in an online training course** about resilience, tailored to the needs of caregivers and future caregivers.

This will be achieved through:

- desk research of existing practices, projects, activities, literature.
- field research by interviewing experts in the field of care and/or resilience.
- **survey carried out among professional and informal carers.**

This guidance will provide necessary elements to perform the survey among professional and family carers Austria, Italy and Spain.

B. METHODOLOGICAL CONCEPT

Timeline: November/January 2023

Target value: minimum 120 survey replies (40 from each country)

Caring perspective: each partner will consider equal share among professional and family caregivers.

Survey methodology: via Microsoft forms based on template questions described below.

Time needed: not more than 15 minutes for each survey.

Language: survey template questions will be designed in English; each partner should translate the final version to its local language

Objective:

- I. receive information and opinion from the caregivers about the care challenges they are facing.
- II. Understand their expectations and needs.
- II. Further engage carers in the project activities – online course and 1-minute wonder cards

Analysis: quantitative and qualitative summary will be carried out and available in the activity report.

C. GUIDING QUESTIONS FOR THE SURVEY

SLOT 0: Introduction

Dear Caregiver,

First, we would like to thank you for dedicating your valuable time to participate in the survey below.

The survey is an integral part of the EU project Care4You4Others, which aims to address the unique challenges caregivers encounter and develop a range of targeted tools to empower caregivers and their resilience.

The survey will help us define what content and what topics should be elaborated in **an online training course on the subject of resilience tailored to the needs of caregivers and future caregivers.**

The survey is expected to take approximately 15 minutes to complete. It is entirely anonymous, and the data collected will not be shared with any third parties. Your input will be exclusively utilized for the purposes of the Care4You4Others project.

The data collected and used in this survey complies with EU General Data Protection Regulation (GDPR) [General Data Protection Regulation \(GDPR\) Compliance Guidelines](#)

Thank you for your commitment to making a difference in the caregiving community.

Care4You4Others Team

SLOT 1: Background of the Caregiver

(the objective is to receive personal information from the caregiver that should be considered when performing analysis)

Q1.1 Country of residence:

- Austria
- Italy
- Spain
- Other: _____

Q1.2 Your nationality: (not obligatory)

- _____

Q1.3 Age:

- Less than 25
- 26-35
- 36-50
- 51-65
- More than 65

Q1.4 Highest level of education:

- Obligatory School
- Secondary School
- University degree or higher

Q1.5 Special qualification in the care sector (diploma, course) (not obligatory)

- _____

Q1.6 Gender:

- Female
- Male
- Non-binary
- Don't want to answer.

Q1.7 Employment Status:

- Employed - full time.
- Employed - part time.
- Unemployed
- Retired
- Studying
- Other: _____

SLOT 2: Caregiving background

(the objective is to understand caregivers` background that should be considered when performing analysis)

Q2.1 You are:

- Formal caregiver (employed/studying in the care sector)
- Informal caregiver (not formally employed in the care sector)
- Both

Q2.2 You have been caregiving for:

- Less than a year
- 1-5 years
- 6-10 years
- More than 10 years

Q2.3 Number of dependents/assisted persons you care for:

- 1
- 2-5
- 6-10

More than 10

Q2.4 Assisted person's condition (multiple answers possible)

- Physical impairment (low)
- Physical impairment (medium)
- Physical impairment (severe)
- Mental impairment (low)
- Mental impairment (medium)
- Mental impairment (severe)

Q2.5 (If you are an informal caregiver) Which is the relationship with the assisted person(s)? (Multiple answer is possible)

- 1st or 2nd degree: parents & children; grandparents & grandchildren; siblings
- 3rd or 4th degree: all other relatives
- Friendship
- Other _____
-

Q2.6 Assisted target(s) (multiple answers possible)

- Young people
- Adults
- Elderly people

Q2.7 Weekly time dedicated to caregiving:

- Less than 4 hours per week
- 4-20 hours per week
- More than 20 but less than 40 hours per week
- 40 hours per week
- More than 40 hours per week

Q2.8 Primary caregiving responsibilities: (multiple answer is possible)

- Medical care support (accompanying medical visits, giving medications, monitoring vital signs)
- Personal care (bathing, dressing, feeding)
- Meal preparation (preparing meals, consider dietary restriction)
- Household support (housekeeping, groceries)
- Emotional support (meditation, talks, emotional therapies)
- Companionship (spending time together)
- Communication (with health care provider, family members)
- End-life support
- Other support in long term care (cognitive stimulation, personal autonomy)
- Other (please specify)

SLOT 3: Perception of care

(the objective is to receive the perception on how caregiver feels about their task/job and understands most common challenges related to caregiving)

Q.3.1 Caregiving is: (4 fully agree; 3 partly agree, 2- partly disagree, 1 fully disagree):

- My job
- My responsibility
- My passion
- My privilege
- My sacrifice
- My obligation
- My choice
- My burden

Q3.2 Select, based on your experiences, the three most relevant **positive** aspects of caregiving:

- Personal fulfilment through helping others.
- Professional development – caregiving has helped me develop valuable skills.

- Receiving positive feedback when caring for dependent individuals/assisted persons.
- Economic compensation.
- Engaging in something I generally love doing.
- Ethical-value motivation

Add any other positive aspect: _____

Q3.3 Select, based on your experiences, the three most relevant **negative** aspects of caregiving:

- Detrimental effect on my mental and emotional well-being.
- Impact on my physical health, leading to fatigue and frequent illness.
- Not having enough time for myself and/or my other loved ones
- Relational conflicts with patients/their relatives
- Lack of recognition as a caregiver
- Economic compensation

Add any other negative aspect: _____

Q3.4 How frequently do you encounter the following challenges in your caregiving role? ((1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often 5 = Always / not applicable):

- Balancing caregiving with personal, work, and social life.
- Insufficient knowledge about caregiving tasks
- Lack of support or commitment from colleagues at work
- Lack of support from my family members.
- Inadequate access to targeted services and resources for caregivers.
- Limited time and opportunities for professional growth.
- Insufficient information and skills to face bureaucracy
- Insufficient access to sanitary and care services
- Personal burnout (emotional exhaustion, depersonalization..)

SLOT 4: Support for caregivers (external support and self-care)

(the objective is to investigate caregivers' awareness and evaluation of the support they receive as well as needs where support is needed)

Q4.1 On a scale of 1 to 4, how would you rate the level of support/understanding you receive from various sources? (1 = Very low, 2 = rather low, 3 = quite high, 4 = Very high; not applicable):

- Public care system
- Co-workers /colleagues
- Friends
- Your family members
- Other healthcare professionals
- Online support communities or resources
- In-person support groups or communities

Q4.2 As a caregiver, please prioritize from most to least relevant the type of support you would most appreciate, from most to least relevant:

- FOR EMOTIONAL HEALTH: Enhancing my emotional well-being (managing stress, addressing sadness, reducing depression, combating loneliness).
- FOR NEW SKILLS: Acquiring new skills to better cope with caregiving responsibilities.
- FOR PHYSICAL HEALTH: Enhancing my physical health (alleviating headaches, combating tiredness, and addressing general discomfort).

- FOR TIME RELIEF: Finding time/tools for temporary relief from caregiving.

Q4.3 In order to improve my situation as a caregiver I mostly need:

- Theoretical knowledge.
- Practical exercises.
- Short hints, suggestions
- Peer-to-peer support
- Access to support groups
- Improved communication skills,
- Improved emotional management,
- Empathy
- Other: _____

Q4.4 Can you name one or more example(s) of useful support you have received so far from previous caregivers support activities?

Q4.5 Please select the statement that best describes your situation with regards the self-care - to better cope with the various challenges related to caregiving activities:

- Self-care is an integral part of my caregiving routine.
- I struggle to find the time to dedicate to self-care.
- I require further guidance on how to systematically implement self-care
- I face resource constraints, particularly in terms of time.
- I don't know what self-care is

Q4.6 How much time do you dedicate to the following activities in your daily life

(4 fully sufficient, 3 quite sufficient, 2 rather insufficient, 1 insufficient)

- Healthy eating habits
- Sleeping hours
- Social life
- Educational activities
- Physical exercises
- Leisure activities
- Meditation/prayer and relaxation practices

Q4.7 How do you envision your caregiving role in the future? Are there any changes or improvements you hope to make in your caregiving situation?

Q.4.8 Would you like to add something else

SLOT 5: Conclusion

(the objective is to invite caregivers to be further involved in the project activities)

Q5.1 Would you be interested to be further involved in the online training course or be informed about outcomes of the questionnaire/project?

- Yes
- No
- I don't know

Q5.2 If yes, how can we contact you? Please provide your email or phone contact details

Your answers will help us gather valuable information and will be used for the design of a comprehensive course and other tools for both informal and professional caregivers as well as to create a tailored online course as part of the Care4You4Others project. Thank you for your valuable input. We will contact you and inform you about the progress of the project.

Also, if you have any general questions about the project or the survey, please feel free to contact <national contact to be given here>.

Annex 4

Survey data – raw

Please see extra download file

Annex 5

Survey data - entry instructions

Instructions for the survey data entry

In the excel form:

- Each row corresponds to a questionnaire
- You have to fill in each cell the number corresponding to the right item based on the following tables

Note that multiple answers questions have been split in different columns, so that, for each item (possible answer), you have to indicate if it has been selected or not (respectively with 1 or 0). In the excel form, we highlighted with different colours these multiple questions (columns), in order to better recognized them.

SLOT 1: Background of the Caregiver

Q1.1 Country of residence:

	Code assigned
Austria	1
Italy	2
Spain	3
Other	4

Q1.2 Your nationality: (not obligatory)

	Code assigned
Austrian	1
Italian	2
Spanish	3
Other	4

Q1.3 Age:

	Code assigned
Less than 25	1
26-35	2
36-50	3
51-65	4
More than 65	5

Q1.4 Highest level of education:

	Code assigned
Obligatory school	1
Secondary school	2
University degree or higher	3

Q1.5 Special qualification in the care sector (diploma, course) (not obligatory) **OPEN ANSWER**

Q1.6 Gender:

	Code assigned
Female	1
Male	2
Don't want to answer/not binary	3

Q1.7 Employment Status:

	Code assigned
Employed - full time.	1
Employed – part time	2
Unemployed	3
Retired	4
Studying	5
Other	6

SLOT 2: Caregiving background

Q2.1 You are:

	Code assigned
Formal caregiver (employed/studying in the care sector)	1
Informal caregiver (not formally employed in the care sector)	2
Both	3

Q2.2 You have been caregiving for:

	Code assigned
Less than a year	1
1-5 years	2
6-10 years	3
More than 10 years	4

Q2.3 (If you are an informal caregiver) Which is the relationship with the assisted person(s)? (Multiple answer is possible):

	Code assigned	
	Selected	Not selected (empty cell)
1st or 2nd degree: parents & children; grandparents & grandchildren; siblings	1	0
3rd or 4th degree: all other relatives	1	0
Friendship	1	0
Other	1	0

Q2.4 Assisted person's condition (multiple answers possible)

	Code assigned	
	Selected	Not Selected (empty cell)
Physical impairment (low)	1	0
Physical impairment (medium)	1	0
Physical impairment (severe)	1	0
Mental impairment (low)	1	0
Mental impairment (medium)	1	0
Mental impairment (severe)	1	0

Q2.5 Assisted target(s) (multiple answers possible):

	Code assigned	
	Selected	Not selected (empty cell)
Young people	1	0
Adults	1	0
Elderly people	1	0

Q2.6 Number of dependents/assisted persons you care for:

	Code assigned
1	1
2-5	2
6-10	3
More than 10	4

Q2.7 Weekly time dedicated to caregiving:

	Code assigned
Less than 4 hours per week	1
4-20 hours per week	2
More than 20 but less than 40 hours per week	3
40 hours per week	4
More than 40 hours per week	5

Q2.8 Primary caregiving responsibilities: (multiple answer is possible)

	Code assigned	
	Selected	Not selected (empty cell)
Medical care support (accompanying medical visits, giving medications, monitoring vital signs)	1	0
Personal care (bathing, dressing, feeding)	1	0
Meal preparation (preparing meals, consider dietary restriction)	1	0
Household support (housekeeping, groceries)	1	0
Emotional support (meditation, talks, emotional therapies)	1	0

Companionship (spending time together)	1	0
Communication (with health care provider, family members)	1	0
End-life support	1	0
Other support in long term care (cognitive stimulation, personal autonomy)	1	0
Other (please specify)	1	0

SLOT 3: Perception of care

Q.3.1 Caregiving is:

CODE ASSIGNED: 4=fully agree; 3=partly agree, 2=partly disagree, 1=fully disagree

- My job
- My responsibility
- My passion
- My privilege
- My sacrifice
- My obligation
- My choice
- My burden

Q3.2 Select, based on your experiences, the three most relevant **positive** aspects of caregiving:

	Code assigned	
	Selected	Not selected (empty cell)
Personal fulfilment through helping others.	1	0
Professional development – caregiving has helped me develop valuable skills.	1	0
Receiving positive feedback when caring for dependent individuals/assisted persons.	1	0
Economic compensation.	1	0
Engaging in something I generally love doing.	1	0
Ethical-value motivation	1	0
Add any other positive aspect	1	0

Q3.3 Select, based on your experiences, the three most relevant **negative** aspects of caregiving:

	Code assigned	
	Selected	Not selected (empty cell)

Detrimental effect on my mental and emotional well-being.	1	0
Impact on my physical health, leading to fatigue and frequent illness.	1	0
Not having enough time for myself and/or my other loved ones	1	0
Relational conflicts with patients/their relatives	1	0
Lack of recognition as a caregiver	1	0
Economic compensation	1	0
Add any other negative aspect	1	0

Q3.4 How frequently do you encounter the following challenges in your caregiving role?

CODE ASSIGNED: 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Always, 0 = not applicable

- Balancing caregiving with personal, work, and social life.
- Insufficient knowledge about caregiving tasks
- Lack of support or commitment from colleagues at work
- Lack of support from my family members.
- Inadequate access to targeted services and resources for caregivers.
- Limited time and opportunities for professional growth.
- Personal burnout (emotional exhaustion, depersonalization...)
- Insufficient information and skills to face bureaucracy
- Insufficient access to sanitary and care services

SLOT 4: Support for caregivers (external support and self-care)

Q4.1 On a scale of 1 to 4, how would you rate the level of support/understanding you receive from various sources?

CODE ASSIGNED: 1 = Very low, 2 = rather low, 3 = quite high, 4 = Very high; 0=not applicable

- Public care system
- Co-workers /colleagues
- Friends
- Family (specify, could be also the patient’s relatives?)
- Other healthcare professionals
- Online support communities or resources
- In-person support groups or communities

Q4.2 As a caregiver, please prioritize from most to least relevant the type of support you would most appreciate, from most to least relevant:

	Code assigned
--	----------------------

FOR EMOTIONAL HEALTH: Enhancing my emotional well-being (managing stress, addressing sadness, reducing depression, combating loneliness).	1
FOR NEW SKILLS: Acquiring new skills to better cope with caregiving responsibilities.	2
FOR PHYSICAL HEALTH: Enhancing my physical health (alleviating headaches, combating tiredness, and addressing general discomfort).	3
FOR TIME RELIEF: Finding time/tools for temporary relief from caregiving.	4

Q4.3 In order to improve my situation as a caregiver I mostly need:

	Code assigned	
	Selected	Not selected (empty cell)
Theoretical knowledge	1	0
Practical exercises	1	0
Short hints, suggestions	1	0
Peer-to-peer support	1	0
Access to support groups	1	0
Improved communication skills	1	0
Improved emotional engagement	1	0
Empathy	1	0
Other	1	0

Q4.4 Can you name one or more example(s) of useful support you have received so far from previous caregivers support activities? **OPEN ANSWER**

Q4.5 Please select the statement that best describes your situation with regards the self-care - to better cope with the various challenges related to caregiving activities:

	Code assigned
Self-care is an integral part of my caregiving routine	1
I struggle to find the time to dedicate to self-care	2
I require further guidance on how to systematically implement self-care	3
I face resource constraints, particularly in terms of time	4
I don't know what self-care is	5

Q4.6 How much time do you dedicate to the following activities in your daily life

CODE ASSIGNED: 4=fully sufficient, 3=quite sufficient, 2=rather insufficient, 1=insufficient

- Healthy eating habits
- Sleeping hours

- Social life
- Educational activities
- Physical exercises
- Leisure activities
- Meditation/prayer and relaxation practices

Q4.7 How do you envision your caregiving role in the future? Are there any changes or improvements you hope to make in your caregiving situation? **OPEN ANSWER**

Q.4.8 Would you like to add something else **OPEN ANSWER**

SLOT 5: Conclusion

Q5.1 Would you be interested to be further involved in the online training course or be informed about outcomes of the questionnaire/project?

	Code assigned
Yes	1
No	2
I don't know	3

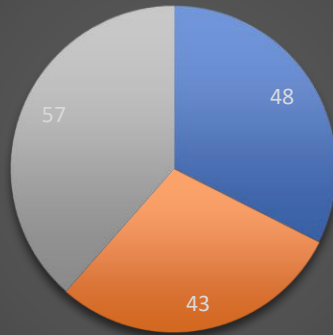
Q5.2 If yes, how can we contact you? Please provide your email or phone contact details **OPEN ANSWER**

Annex 6

Survey data - visualisations

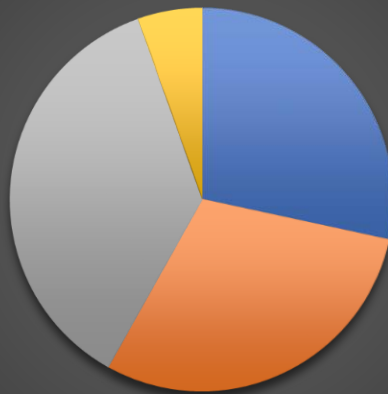
Caregiver profile

Coutry of residence



■ Austria ■ Italy ■ Spain

Nationality



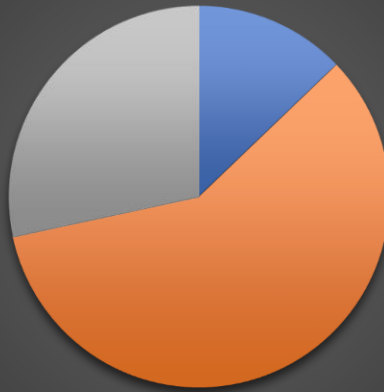
■ Austrian ■ Italian ■ Spanish ■ Other

Age



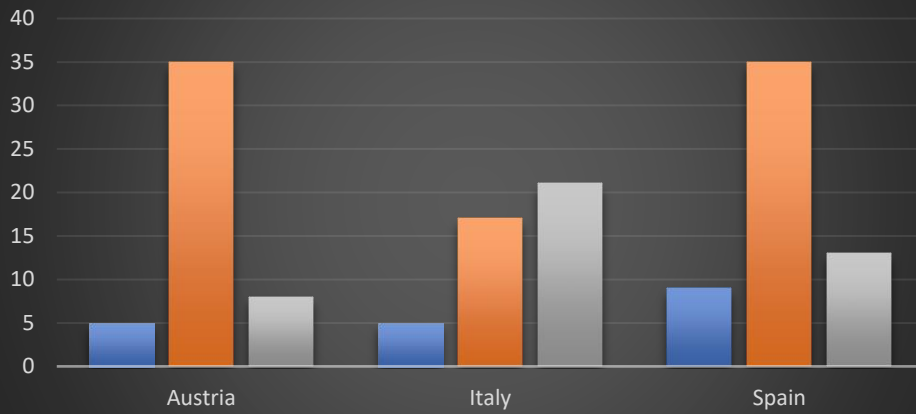
■ less than 25 ■ 26-35 ■ 36-50 ■ 51-65 ■ more than 65

Highest level of education



■ Obligatory school ■ Secondary school ■ University degree or higher

Education by country

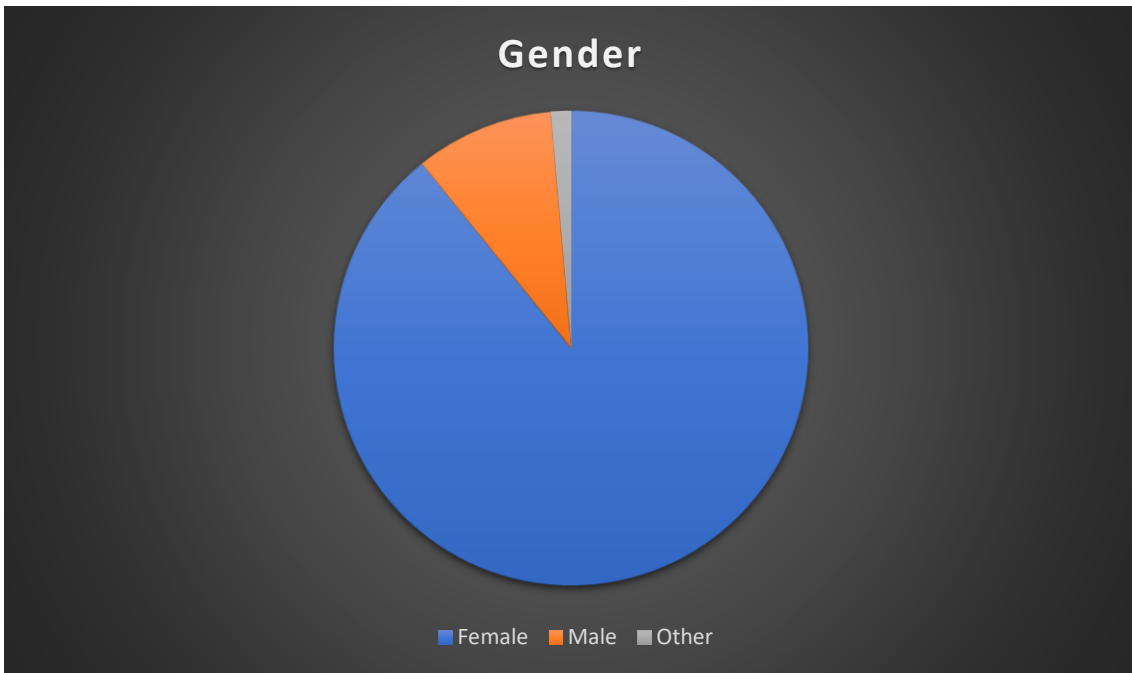


■ Obligatory school ■ Secondary school ■ University degree or higher

Employment status



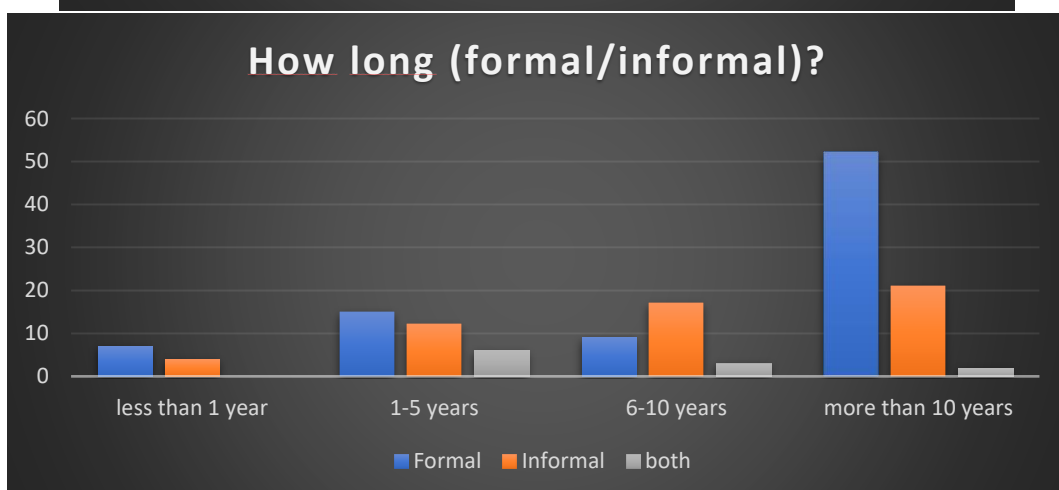
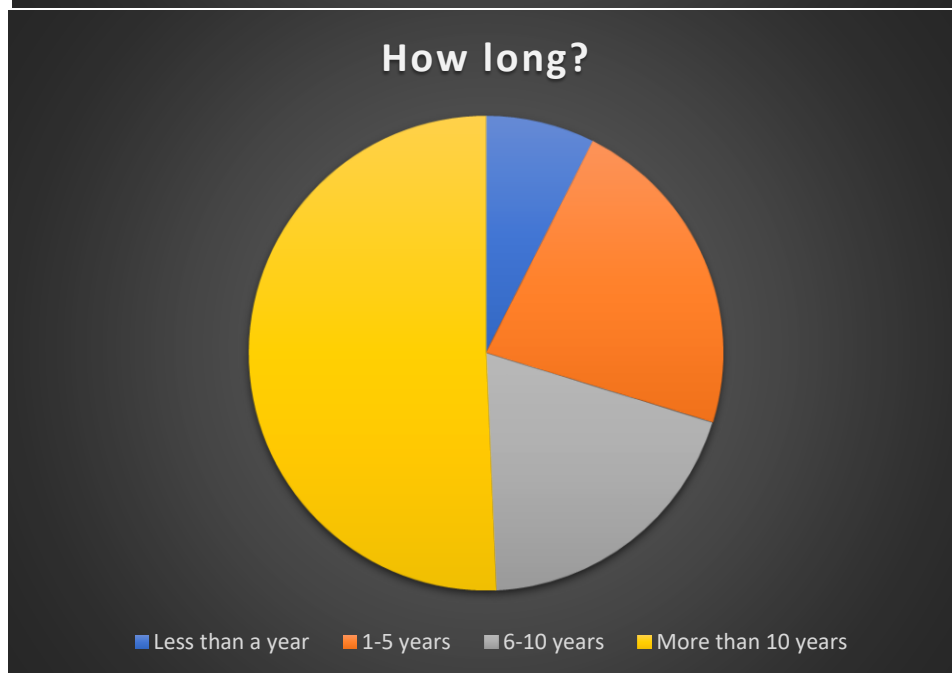
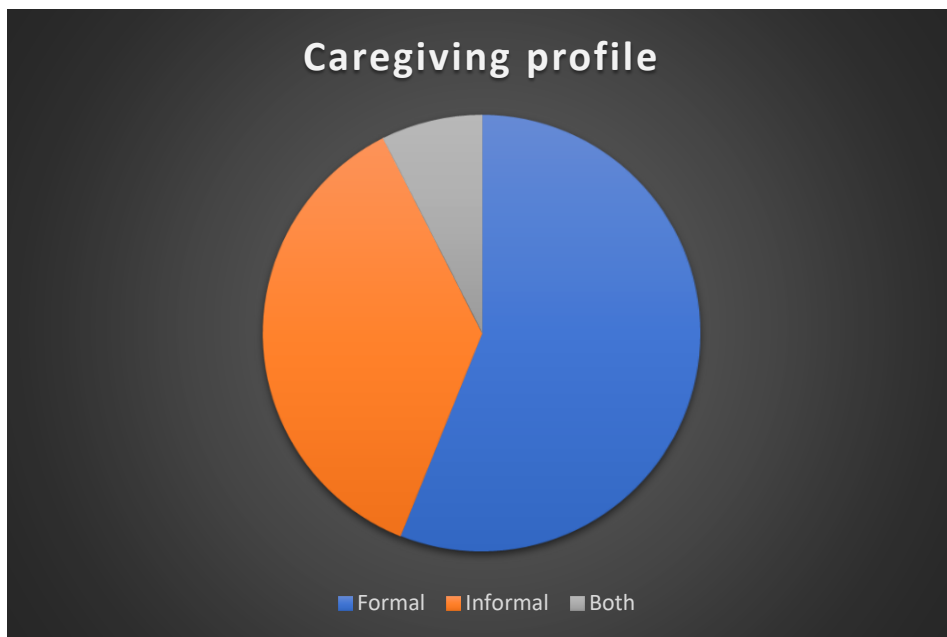
■ Employed - full time. ■ Employed – part time ■ Unemployed
■ Retired ■ Studying ■ Other



Average caregiver is:

- 51-65 years old
- Female!!
- With secondary school
- Significant% of unemployed and part-time employed

Caregiving background

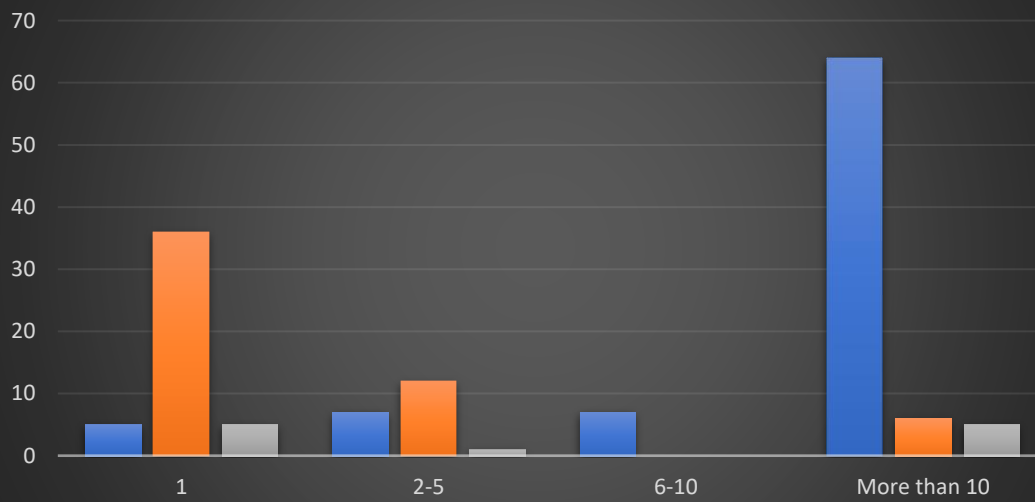


Number of dependents/assisted persons you care for



■ 1 ■ 2-5 ■ 2-10 ■ More than 10

Number of assisted persons



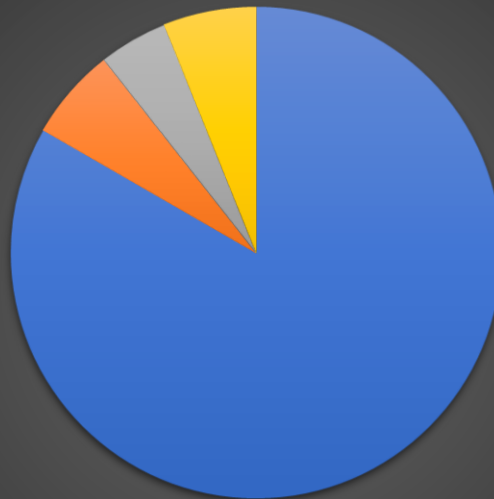
■ Formal ■ Informal ■ both

Weekly time dedicated to caregiving



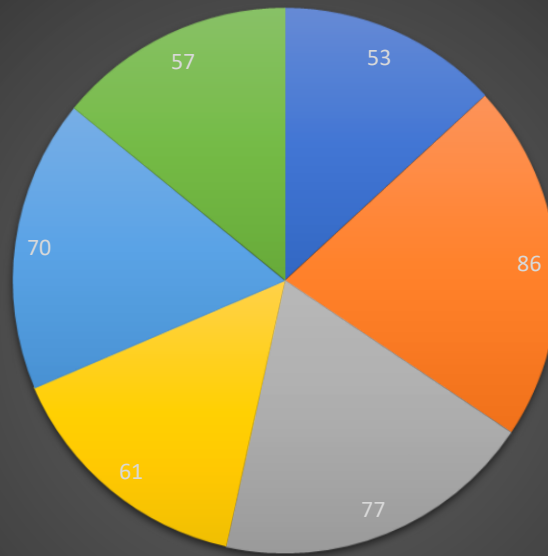
- Less than 4 hours per week
- 4-20 hours per week
- More than 20 but less than 40 hours per week
- 40 hours per week
- More than 40 hours per week

relationship with the assisted person(s)?



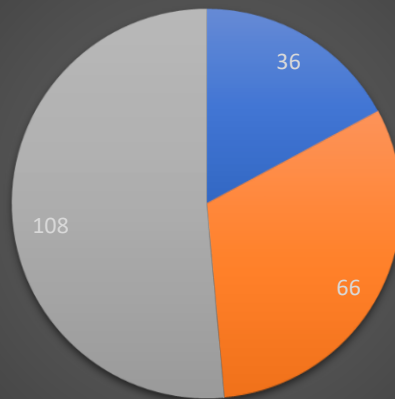
- 1st or 2nd degree: parents & children; grandparents & grandchildren; siblings
- 3rd or 4th degree: all other relatives
- Friendship
- Other

Assisted person's condition

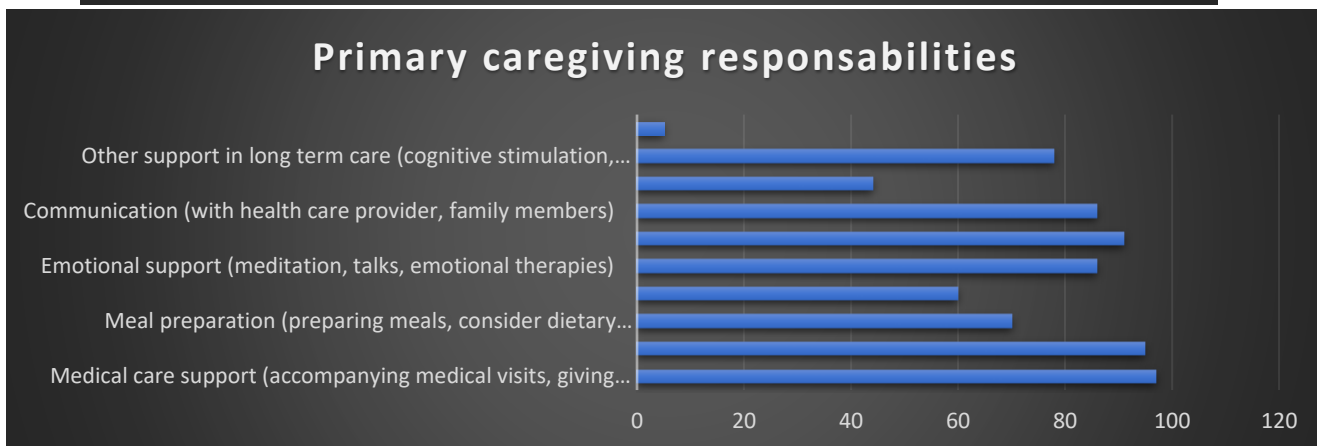
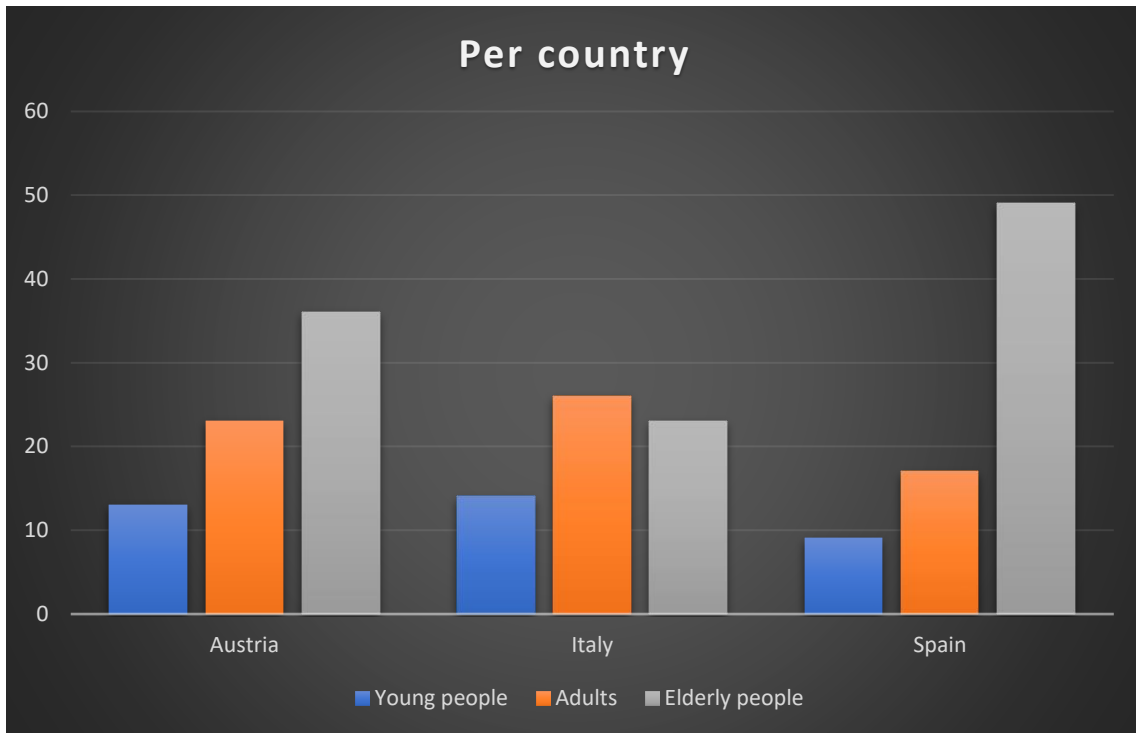


- Physical impairment (low)
- Physical impairment (medium)
- Physical impairment (severe)
- Mental impairment (low)
- Mental impairment (medium)
- Mental impairment (severe)

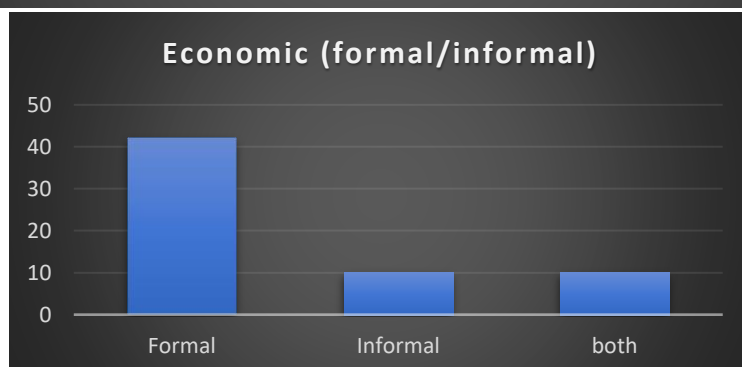
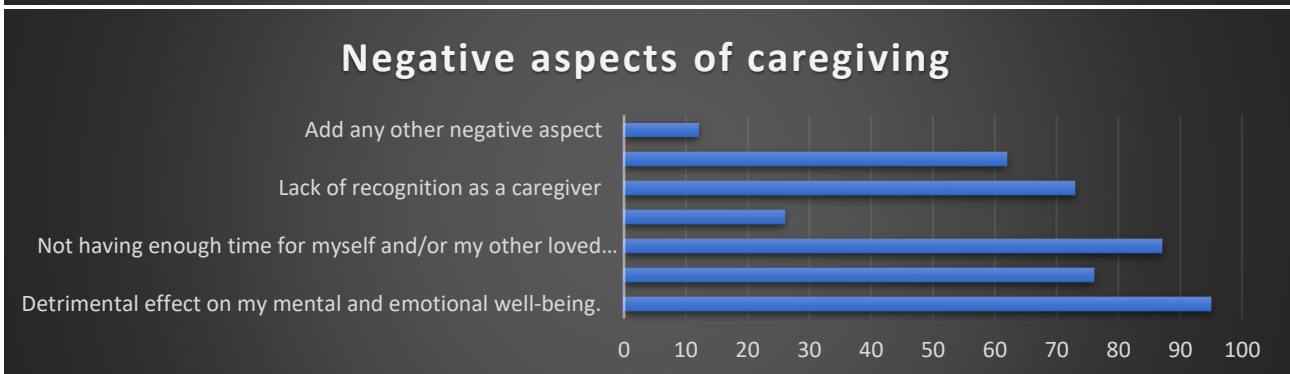
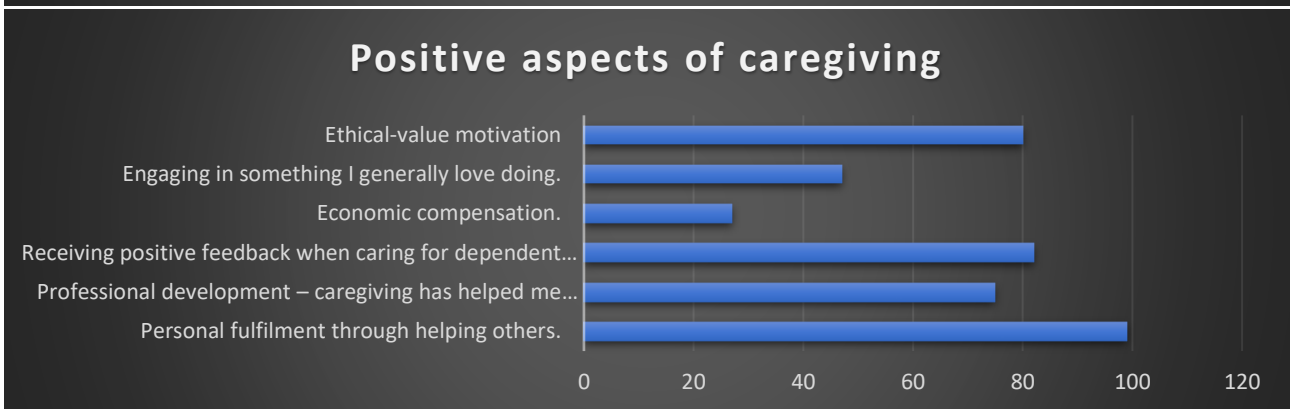
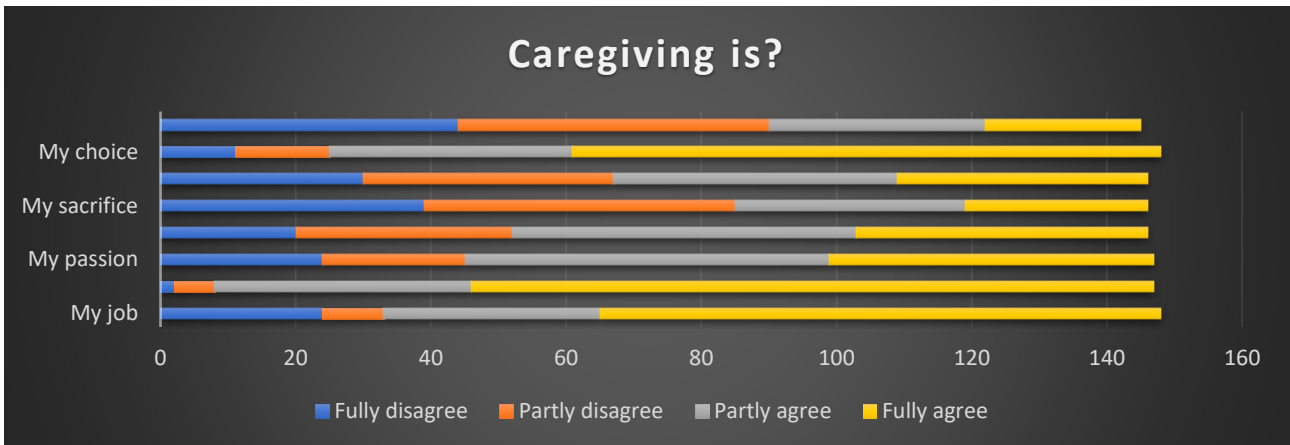
Assisted target(s)



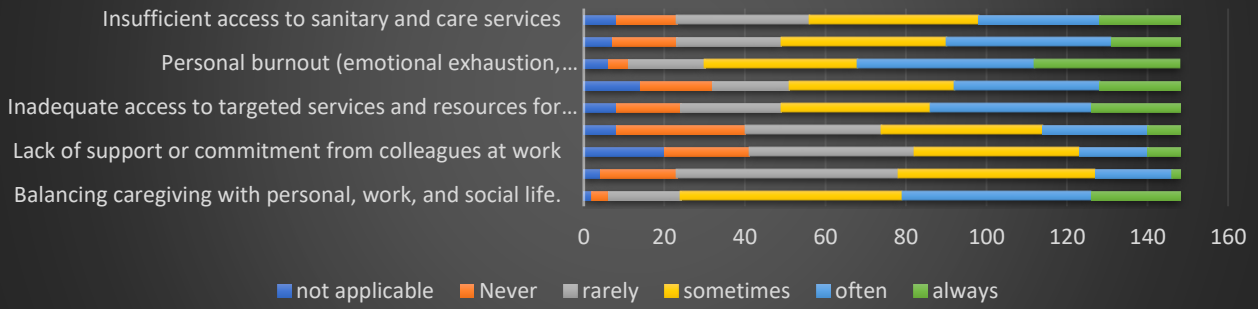
- Young people
- Adults
- Elderly people



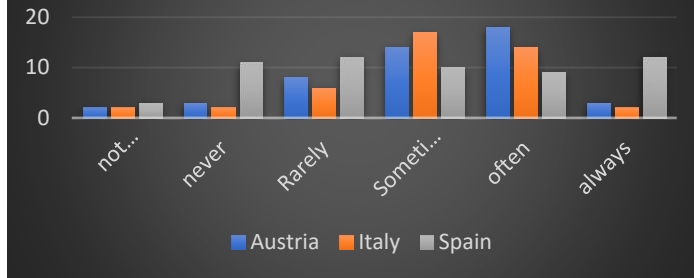
Perception of caregiving



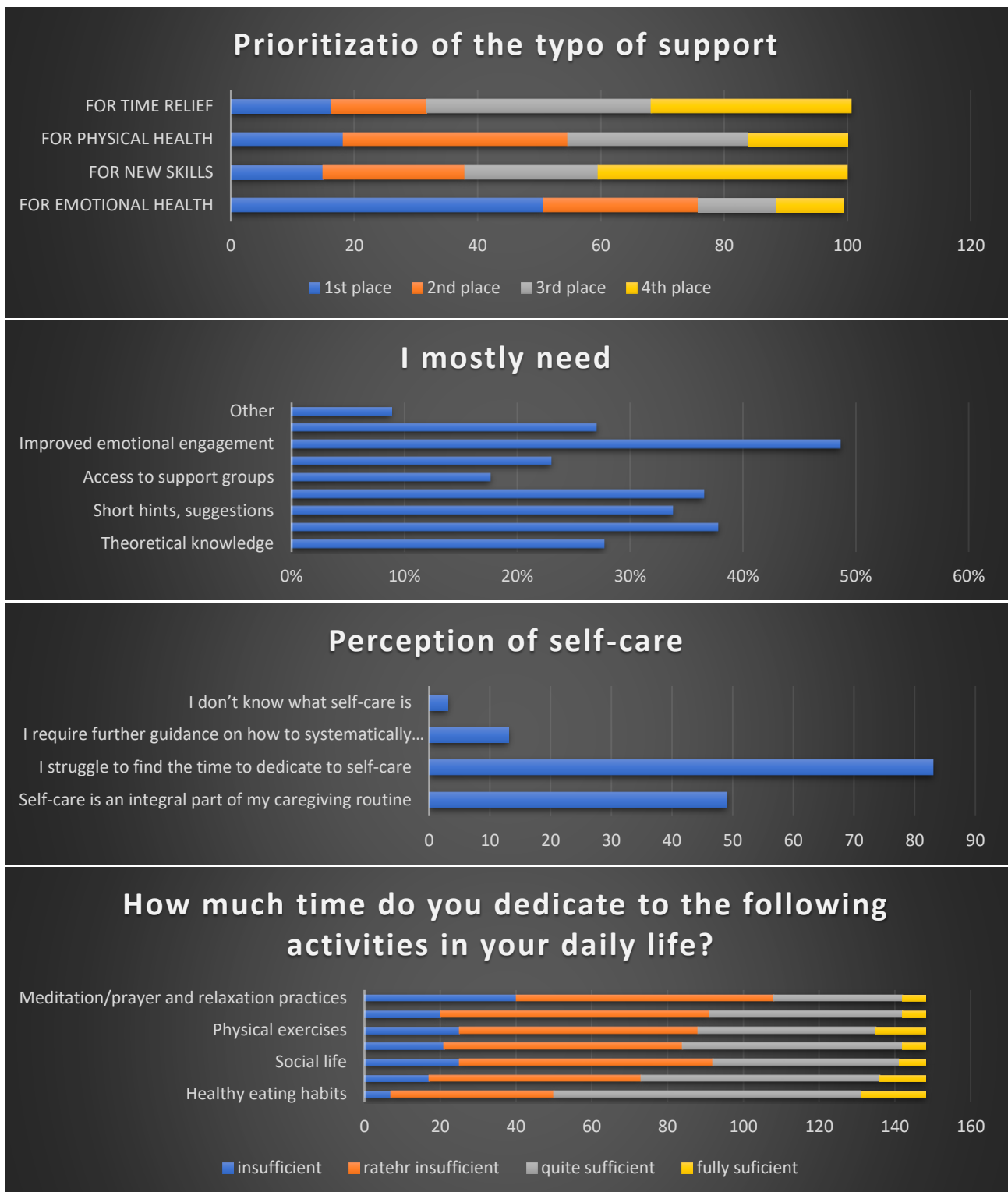
How frequently do you encounter the following challenges in your caregiving role?



facing bureaucracy



Support in care





care

4YOU
OTHERS

Resilience training for the new generation of caregivers

Care4You4Others
Resilience training
for the new generation
of caregivers

2023-1-AT01-KA210-VET-000151863



Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or OeAD-GmbH. Neither the European Union nor the granting authority can be held responsible for them.