SINCALA

SUPPORTING INFORMAL CARERS: A WHOLE-FAMILY & LIFECOURSE APPROACH

GUIDE FOR PROFESSIONALS
TO IDENTIFY AND ADDRESS ISSUES THAT EMERGE FROM "LISTEN TO MY STORY" WORKSHOPS

Guide for professionals to identify and address issues that emerge from "Listen to my story" workshops

This guide has been coordinated by Union of Women Associations of Heraklion Prefecture (UWAH), in close cooperation with the partners of the 'S.IN.CA.L.A. II – Supporting Informal Carers: A Whole-Family & Life course Approach' project.

Developed by Union of Women Associations of Heraklion Prefecture (UWAH)

Project partners:

- Women's Support and Information Centre (WSIC) - Estonia
- University of Tartu (UT) - Estonia
- Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas) - Greece
- Anziani e Non Solo - Italy
- Centro de Atendimento e Servicos 50+, Associacao - Portugal
- Spominčica (Forget-me-not) – Alzheimer Slovenia - Slovenia

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Foreword

SINCALA Project

This guide was designed as part of the SINCALA Project, a 30-month Erasmus+ project launched in January 2021. SINCALA (Supporting Informal Carers: A Whole-Family & Lifecourse Approach II) aims to disseminate information for identifying and addressing issues connected to violence in informal caregiving relationships and provide training and online education programs for informal carers. This guide will support the training of this group and strives to provide professionals working with older people and their informal carers with guidelines to help them identify and address issues such as burnout, elder abuse, or other forms of domestic violence.

Who is this guide for and why?

The guide is for health and social care professionals working with older people and their informal carers, considering that they often are ill-equipped to identify the warning signs of issues related to elder abuse. This guide is a handbook that provides these professionals with guidelines on how to respond to violence in informal caregiving relationships. It will also help workshop facilitators identify and address issues that emerge from "Listen to my Story" workshops and will serve as the basis for the MOOC and online materials. The audience may come from different backgrounds and have different previous knowledge. These differences must be kept in mind throughout the manual, as the goal is for everyone to reach the same level of knowledge and understanding.

Guide structure: How to use the guide

Each chapter consists of the theoretical portion and the practical elements. More precisely, the chapters combine theoretical information on the subject and proposed exercises for the professionals to facilitate them when working with informal carers on the topics addressed.

The theoretical portion includes information about informal carers, prevention of abuse, maintenance of respect, and the workshops piloted in all partner countries (Estonia, Italy, Portugal, Greece, and Slovenia) as well as the European and national context. The following project partners wrote the country-specific information concerning the national context: the Women's Support and Information Centre-WSIC (Estonia), the University of Tartu-UT (Estonia), the Union of Women Associations of Heraklion Prefecture-UWAH, and the Greek Association of Alzheimer's Disease and Related Disorders-Alzheimer Hellas (Greece), Anziani e Non Solo (Italy), Centro de Atendimento e Servicos 50+, Associacao (Portugal) and Spominčica -Forget-me-not – Alzheimer Slovenia (Slovenia).

The practical elements include exercises specially designed for the targeted audience. These exercises vary according to the learning goal. They may consist of case studies, discussion questions, role play, audio-visual material, and more.

Learning goals and objectives of this guide

This guide targets social and health care professionals working with older people and their informal carers to help them identify and address violence-related issues in informal caregiving relationships. It aims to equip professionals to integrate tools and approaches in their work with informal carers related to burnout, neglect, abuse, and more. Thanks to the manual, social and health care professionals and informal carers can gain competencies such as comprehension, knowledge, application, evaluation, and synthesis.

After the completion of **Chapter 1** of this guide, learners will be capable of:

- 💜 Exploring and discussing the role and the importance of the carer.
- 💜 Having a more profound knowledge and identifying the different roles, situations, and difficulties carers could experience depending on the kinship with the recipient.
- 💜 Preparing the carer for the care at home and creating safer environments for both the recipient and the informal carer.
- 💜 Discovering and addressing the carer's needs.
- 💜 Recognizing all the challenges and emotions that the carer could experience.
- 💜 Developing daily strategies to prevent and mitigate any difficulties (carer stress, exhaustion).
- 💜 Knowing of and defining resilient abilities through dedicated pedagogical methods.
- 💜 Understanding the aging and illness aspects of a person in need of care.
- 💜 Improving knowledge of identifying violence that could arise from older people against the carer.
- 💜 Having a more profound knowledge and recognizing carer burden and burnout and the link to violence and abuse.
- 💜 Assessing and improving the carer's communication, creativity, and time management skills.
- 💜 Exploring and assessing the carer's assertiveness.
- 💜 Comprehending and discussing tips regarding the self-care of carers.
- 💜 Dealing with people with Alzheimer's or dementia and addressing their needs.

After the completion of **Chapter 2** of this guide, learners will be capable of:

- 💜 Understanding and recognizing the assumptions and stereotypes about elder abuse.
- 💜 Identifying forms and signs of elder abuse (addressing neglect, intentional and unintentional abuse).

- Identifying gender-based violence in caregiving relationships (exploring domestic violence).
- Having practical knowledge and distinguishing risk factors and warning signs, identifying and supporting survivors of such violence.
- Providing adult safeguarding.

After the completion of **Chapter 3** of this guide, learners will be capable of:

- Describing the challenges that the whole family could face.
- Applying solutions for addressing violence and carer burnout in a caregiving relationship.
- Identifying, illustrating, and having an increased awareness of the importance of adopting a whole-family approach.
- Easily recognizing the breakdown in family care, identifying and addressing issues that emerge among families.
- Providing and composing new and innovative therapeutic approaches and innovative techniques to improve services in the family context.
- Owning and demonstrating techniques to improve the ability to cope with depressive symptoms, emotional distress, and other caregiver burdens, and methods of safeguarding the well-being of the care recipient.

After the completion of **Chapter 4** of this guide, learners will be capable of:

- Having a general overview and reproducing information on the older adult population and statistics about older people in Europe
- Indicating and improving knowledge of the problems that other countries and organizations face regarding informal caregiver support and what solutions are available
- Understanding best practices, networks, and policies supporting informal caregivers in Europe

After the completion of **Chapter 5** of this guide, learners will be capable of:

- Having increased awareness, reviewing and explaining the topic at a national level (policies, legislations, communication channels, home support services, caregiver networks, training/awareness for informal caregivers, programs, and services)
- Reproducing valuable resources on the topic

Chapter 1: Informal carers

1.1 Informal carers' identity

1.1.1 Who are informal carers?

The demographic pyramid is changing, with an exponential increase in the average life expectancy and, therefore, in the number of older adults, which raises many questions. People live longer but with lower quality of life. The increased number of people suffering from chronic and disabling diseases and the lack of long-term care have created new needs (Sakakibara, Kabayama, & Ito, 2015). Given that health care and formal care do not proliferate at the same pace as the needs of older adults, informal carers are responsible for providing care and support at home at several levels (Silva, Teixeira, Teixeira, & Freitas, 2013; Zwaanswijk, Peeters, Beek, Meerveld, & Francke, 2013).

According to different authors, the definition of an informal caretaker - although with some distinctions - presents some common aspects regarding the type of support provided. In this sense, an informal carer is a member of the family, a friend, or a neighbor who, in an unpaid position, provides support to a physically, emotionally, financially, and informally ill or physically disabled person (Bove, Zakrisson, Midtgaard, Lomborg, & Overgaard, 2016; Horrel, Stephens, & Breheny, 2015; Vaigankar et al., 2013). Eurocarers simplifies this concept by defining it as "a person who provides – usually – unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework." (Eurocarers, 2021)

Culturally, the family is generally the first line of response regarding care (Vaigankar et al., 2013). Across Europe, most care is provided by relatives (Gonçalves-Pereira, & Sampaio, 2011; Jayani & Hurria, 2012; Bruggen et al., 2016; McCabe, You, & Tatangelo, 2016). According to Thompson and Roger (2014), the percentage is between 60 and 80%, and Hawranik and Strain (2007), between 75 and 90%. However, globalization has also brought about changes in the availability and motivation to care for, with geographically dispersed relatives and women working outside the home impacting this matter (Horrel et al., 2015).

Regarding the socio-demographic characteristics of family carers, studies are not unanimous. In terms of age, research shows a predominance of middle-aged people as carers (Jayani & Hurria, 2012; Silva, Teixeira, Teixeira, & Freitas, 2013). However, some authors refer to an increase in younger carers (Blanton, 2013). Regarding the kinship with the person cared for, spouses occupy the first place, immediately followed by children (Buscemi et al., 2010; Zwaanswijk et al., 2013). For other researchers, the ratio is the inverse, with children being the primary carers, followed by spouses (Bruggen et al., 2016; Horrell et al., 2015). In terms of

gender, studies show a predominance of women as main carers (Buscemi et al., 2010; Roberto & Jarrott, 2008; Silva et al., 2013; Zwaanswijk et al., 2013). According to Campbell (2010), daughters are more likely to be their parents' carers than their brothers, who rely on their wives if married when fulfilling the carer role. Although, for a long time, caring was primarily considered to be "women's work" (Anderson, 1987), some authors have mentioned the growing role of men as family carers (Blanton, 2013; Campbell, 2010; Hawranik & Strain, 2007; Roberto & Jarrott, 2008). Carers are a heterogeneous group, and their response to caring correlates to their age, sex, and relationship with the dependent person.

1.1.2 Why are informal carers important?

Informal caretakers are essential since they guarantee and provide the majority of care in Europe – 80%. The types of care include personal care, financial management, transportation, emotional support, and other dimensions of care (Bove et al., 2016). Carers are invaluable to society, as they allow the cared-for person to remain at home for longer, providing humane and dignified care. Most informal carers have a great deal of experiential knowledge about care provision gained through contact with various health and social professionals, which should be recognized and built upon. Informal carers are crucial since they support their loved ones with personal care, domestic tasks, emotional support, and medical care. They advocate for those who receive care and cannot or will not speak for themselves.

Informal carers are highly valued from a social and humanitarian standpoint since most informal carers care for vulnerable groups, such as people with disabilities, dementia, chronic disease, or other conditions. They do this not because of personal interest but because others need this support. Besides its humanitarian dimension, informal care represents a high economic saving on formal care costs. The economic value of this unpaid care – as a percentage of the overall cost of formal Long-Term Care provision in the EU – ranges from 50-90 % (Eurocarers, 2021). Caring and its impact on those who carry out the role and those who receive care engage civil, political, and socio-economic rights (Eurocarers, 2021), which justifies the importance of informal carers in our society.

1.1.3 Different roles and experiences of informal carers

The caring process may translate into very different experiences and perspectives. Caring for a relative can have a positive or a negative impact on the carer. Positive aspects of caring for someone include feelings of affection and closeness within the caring relationship and a sense of personal satisfaction and purpose in life (Penning & Wu, 2016; Litwin, Stoeckel, & Roll, 2014). However, in general, the impact of caring is quite negative on the carer since providing care for a person with a chronic illness is ongoing, demanding, and stressful. Therefore, it is likely to negatively affect carers' mental health and well-being (Penning & Wu, 2016).

Despite the type of impact – whether it is positive or negative – it can be influenced by the type of kinship. According to Penning and Wu (2016), although caring is, in general, stressful, "caring for an older parent seems particularly stressful and, consequently, has a more negative impact on care receivers' mental health and well-being than is caring for an older spouse or another family member." For Jayani and Hurria (2012), daughters were impacted most by the caring role. A study by Bruggen et al. (2016) involving 2701 carers concluded that adult children encounter more problems, which are also more challenging to manage.

Several aspects can help predict the extent caring will have on carers. They include the characteristics of the person to be cared for and their level of dependency (Roberto & Jarrott, 2008); the type of disease – in cases of cognitive illness such as dementia, the negative impact is more significant than the positive effects (Bruggen et al., 2016; Thompson & Roger, 2014; Roberto & Jarrott, 2008); the duration of care and the unpredictability of its course (Thompson & Roger, 2014; Zwaanswijk et al., 2013) and the previous relationship with the carer - the caring process seemed to exacerbate the pre-existing connections and difficulties in family relationships (Blanton, 2013; Campbell, 2010)

From previous work developed under the scope of the S.IN.CA.L.A project, it is possible to state that, in general, adult children perceive their role as carers of their parents as a way to reciprocate what they had done for them during their lives. Kinship is at the center of the experience of being a carer for their parents. However, in cases where the relationship between parents and children was already complicated, the perception and feelings about the caring role were mainly reported negatively, influenced by the pre-existing relationship with parents. As mentioned before, the type of disease also impacts the burden felt by carers (Bruggen et al., 2016) and the relationship between family members. In this sense, in the face of a dementia diagnosis, the decision-making about care becomes a family matter. This can cause difficulties between siblings with different understandings of the parent's illness and needs.

In another study by Roberto and Jarrott (2008), wives appear to show higher levels of depression and poor quality of social interactions. Although becoming a carer of their spouse seems the natural step for spouses, motivated either by love/emotional bond or by a sense of duty/marital responsibility, they also point to difficulties and challenges regarding caring. Taking care of a spouse is financially and emotionally demanding. The constant feeling of fear and impotence for the spouse's safety and well-being seems familiar to most carers. Burden, constant tiredness, the feeling of losing their partner and becoming a carer and no longer a spouse, and the sense of being a prisoner, are some of the negative and challenging aspects that spouses mentioned.

1.1.4 Preparing for care at home

As mentioned before, the care provided by informal carers allows the cared-for person to remain at home for longer. Helping a loved one aging in place may imply anything from stopping by a parent's house to checking in daily to assist a spouse in bathing. What do informal carers need to know when preparing for care at home? The steps that need to be taken to get the

home fully prepared will vary depending on the nature of the care required; however, it is important to analyze the environment and look for things that may become an obstacle or a danger. If the person cared for has difficulty getting around or has compromised vision or hearing, it is vital to consider ways to make the home less dangerous. For instance: informal carers may consider making simple fixes for fall prevention (e.g., removing rugs on which your family member can stumble; making sure the house is well lit; etc.).

Structural changes may be needed when physical limitations are more severe, such as installing wheelchair ramps or creating widening doorways. Taking care of someone with dementia may imply other particular challenges. To reduce some risks, informal carers may consider installing remote door locks and disabling the stove when it is not in use, among other things.

In addition to these, there are a few things that every informal carer can take into account when preparing to take care of their loved one at home:

They must learn about the family member's illness or disability and how to care for it. The more information an informal carer has, the more they will be able to adapt the housing context to the needs of the person being cared for; be able to anticipate certain behaviors or attitudes, and, consequently, be able to reduce anxiety and stress levels.

They should promote the family member's independence and autonomy for as long as possible by engaging them in simple daily activities.

It is vital to create and maintain an updated medication list with the name, dosage, prescribing doctor, and other relevant information — an accessible document to bring to medical appointments - and make sure all legal documents are in order.

1.1.5   Addressing the needs of carers

Carers are an essential and central part of care and are involved in everything from medical decisions (e.g., medication choices) to emotional support. Despite their significant role, carers' needs are often overlooked in conversation. Carers' needs are influenced by several aspects, for instance, kinship. From work developed in S.IN.CA.L.A, children with a carer role need information and training, support from other relatives, and financial support. Spouses also highlight the need for information about the disease of the person they care for and financial support. Grandchildren mention the need for psychological support.

The sociocultural context where carers live may also impact their needs. Different contexts may influence the care type (and who provides it). For instance, there are countries where patients and carers rely on a network of well-established formal services, such as daycare, home care, and long-term care facilities. In other countries where there is a scarcity or lack of these services, relatives assume the primary responsibility for providing care. All of this will, consequently, impact carers' needs. The literature reveals that carers' needs can range from receiving information on the disease process, supportive health care resources and access to

health services (developed countries) to needs more related to the performance of instrumental support activities, fear of not providing proper care, family dynamics, lack of information on the health condition, total dedication to care, financial expenses, and more (developing countries) (Bierhals, Santos, Fengler, Raubustt, Forbes, & Paskulin, 2017).

The condition/situation of the person who is receiving care has a significant impact on carers' needs. For example, caring for a loved one with dementia can be burdensome, and many carers suffer from reduced quality of life, limiting social engagement and support, depression, and anxiety (Queluz, Kervin, Wozney, Fancey, McGrath, & Keefe, 2019; Laks, Goren, Dueñas, Novick, & Kahle-Wrobleski, 2016; Tomomitsu, Perracini, & Neri, 2014; Sörensen & Conwell, 2011). When comparing carers of people with dementia to other carers, the former had significantly worse subjective well-being and physical health (Queluz et al., 2019; Pinto & Barham, 2014). In this sense, the most frequently mentioned need of carers of someone with dementia is related to the carers' health, particularly their emotional health (Queluz et al., 2019).

Although several different aspects impact carers' needs, they generally are related to carers' emotional health, formal or informal help received from others, and information about the disease/situation of the care recipient. The wide-ranging needs and complex caregiving contexts highlight the importance of understanding and assessing the unique needs of carers. In this sense, more information is crucial. It can convey different areas: self-care, relationship management with others involved in caring, social interactions (communication, empathy, etc.), and general information (disease evolution and consequences, social support available, etc.).

1.2 Informal carer's challenges

1.2.1 Emotions that carers experience

As mentioned in the previous section, informal carers are individuals, usually family members, providing unpaid care and support to loved ones living in chronic medical conditions or facing end-of-life issues (Milligan, 2017). The requirements of caring differ from one family to another, as they depend upon the medical conditions of the person needing help. The intensity of care depends on the severity of the disease and how far along the disease continuum a loved one's condition has progressed (Simmons University, 2016). Moreover, informal caring entails two dimensions (Thomas et al., 2002). The first is the material dimension related to the physical labour of caring. The second is the emotional dimension, associated with the affective aspects of caring. Research shows evidence of a significant amount of emotional investment in the caring relationship between informal carers and the cared person and that informal carers are more prone to psychopathology than the general population due to their caring role (Milligan, 2005).

Regarding the physical labor of caring, informal carers usually deal with the consequences of the caring tasks they are responsible for (Day & Anderson, 2011). They must cope with the significant strains caring includes, and as a result, they feel worn down. This level of fatigue can cause significant physical exhaustion, associated with a variable pattern of systemic symptoms, including insomnia, fatigue, or weight changes.

The primary emotional challenges that older adults and their informal carers experience at the beginning which need to be addressed are uncertainty about the future, sudden onset of problems, role changes in relationships and at home, and adjustment to life changes due to the caring situation (Bom, Bakx, Schut, & van Doorslaer, 2019). In this phase of caring, it is common for carers to experience denial and to have difficulties accepting the situation, which can be perceived as threatening and dangerous. Moreover, health issues in later life may result in death, profound disability, potential injuries and hospitalizations, and altered life prospects for older people can cause fear, anxiety, and extreme emotional distress for both recipients and carers. Research on stroke patients found that significant emotional distress in the form of depression, anxiety, shock, and post-traumatic symptoms is widespread and remains chronic in both patients and informal carers (McCurley et al., 2019).

Carers usually report that professional services are directed to the needs of older people, not those of the carers and that they feel abandoned by the healthcare system (Milligan, 2005). This situation leads to feelings of anger, disappointment, resentment, and sadness. Furthermore, the fact that informal carers seek assistance from professional health services can cause guilt, betrayal, grief, and failure due to their inability to continue providing adequate care for older people at home. Feelings of guilt and remorse can also occur when informal carers experience emotions of helplessness, hopelessness, apathy, or an inability to be empathic. These conditions can lead to low life satisfaction and quality of life, impacting many aspects of life. More specifically, increased errors at work and reduced job satisfaction due to the demands of caring can lead to anger and disappointment (Milligan, 2005).

Informal carers often go through feelings of anger and frustration. They are often reluctant to share these feelings with others for fear of being perceived as 'morally disreputable' if, for example, they complain about their workload and say they cannot stand the person in need anymore (Milligan, 2005). Besides the inability to express their emotions freely, informal carers often face social isolation. Firstly, they spend most of their time caring for the person in need and therefore are left with little time to cultivate social relations. Secondly, friends and family of informal carers might not understand the situation, as they have never been in their position. They might isolate the informal carer as a consequence of this misunderstanding. This leaves the informal carers alone in a time when they need family and friendship networks the most, as they could provide them with the emotional support they need to reinforce their determination and ability to continue taking care (Milligan, 2005). Relationships with recipients can also be impacted. Some carers note that they are often on the receiving end of recipients' frustration and anger, which leads to conflict between them and the person being cared for (Price, Surr, Gough, & Ashley, 2020).

It is worth mentioning that Harding and Higginson (2001) found high levels of ambivalence among carers. *Ambivalence* is defined as simultaneous attraction to and repulsion from an action, inhibiting individuals who experience it from making decisions and taking action. Younger carers reported great ambivalence about the choice between caring and other social and professional activities. Therefore, any intervention for carers must consider the ambivalence of their unmet needs (Harding & Higginson, 2001) and how this may transfer into the act of caring and support provided to the person they care for.

The well-being of the informal carer is crucial if patients are to be cared for at home (Lee, Brennan, & Daly, 2001). Some carers acknowledge positive emotions and growth from their caring roles, such as pride, enhanced learning, and greater empathy. In particular, some carers express pride and gratitude in being able to give back to their loved ones. Furthermore, informal carers feel safe and secure as long as they are responsible for caring for their loved ones. This is because the atmosphere within the care home engenders a sense of safety, love, and caring, as well as feelings of warmth and inclusion stemming from the interrelationships between informal carers and recipients. It is also noted that having a positive attitude towards caring helped them through difficult periods; this role made them feel valued and was a source of personal accomplishment and joy. The ability for carers to find positive meaning in their carer experiences, such as meaning-based coping, was associated with higher carer quality of life. Informal carers can also develop empathy and domains of psychosocial resilience, such as mindfulness, coping, intimate bond, and self-efficacy through this process (Shaffer, Riklin, Jacobs, Rosand, & Vrancecau, 2016).

1.2.2 Stress, exhaustion, burden, and burnout: Signs and vulnerability

Taking care of someone at home can be very challenging and demanding. Often the care provided exceeds the physical and mental capacity of the carers, leading to a chronic stress situation, referred to in the literature as carer burden (Zarit, 2002). Stress and exhaustion are everyday situations among informal carers, and it has been found that emotional exhaustion is closely related to depersonalization, anxiety, and depressive symptoms. Therefore, it is crucial to learn how to recognize signs of carer stress to avoid reaching high levels of exhaustion. So how does a carer reach the point of exhaustion? It can result from the informal carer's tendency not to ask for help or try to do more than they are capable of, as they feel overwhelmed by their caregiving experience and lack physical, mental, emotional, or financial support (Pathak, 2020). So, due to the amount of attention given to the person in need, a persistent lack of self-care may occur. Besides this, other elements can lead to carer exhaustion. For instance, carers may have difficulties separating their role as a carer from the role of a spouse, child, or friend.

Furthermore, carers could get their hopes up and believe their care will positively affect the health and happiness of the person they are caring for. However, this may be unrealistic, for example, for patients who have a progressive disease such as Parkinson's or Alzheimer's. A carer might get frustrated due to the lack of money, resources, and skills to manage their loved

one's care well, or they might take on too much, partly because they see providing care as their only job (Pathak, 2020).

Informal carers are often also full-time employees (or students, if they are young carers). Raising children, and providing financial support for their families makes caring a challenge on multiple levels. Balancing these responsibilities can severely affect informal carers' health conditions (Souza Alves et al., 2019). Caring can raise stress levels to the point that it reaches the so-called "carer burnout," namely a state of emotional, mental, and physical exhaustion in which the informal carer and the person they are caring for both suffer (Smith, 2020). Burnout can sometimes be perceived as feeling overly tired or occasionally exhausted. However, being tired can often be resolved by taking a break, getting a little more sleep, or actively trying to relax, while burnout is not so easy to relieve (Caring, N.A.). In the USA, carers are among the three most-stressed groups in the country, with 70% of family carers showing signs of depression, which is a very high rate compared to individuals who are not informal carers (Caring, N.A.). To this extent, individuals who experience carer burnout tend to face all-encompassing fatigue that impacts multiple areas of their lives. Burnout can occur because informal carers often focus so intently on the needs of the individual receiving care that they may neglect their own health and wellness.

Burnout can result in a change in attitude, from positive and caring to negative and unconcerned. Carers begin experiencing fatigue, stress, anxiety, depression, and even guilt if they perceive that they spend time on themselves rather than on their ill or older loved ones (Pathak, 2020). When these signs are not considered, and the informal carers do not seek help, they eventually reach burnout, which also has its signs and symptoms (Souza Alves et al., 2019). For example, carers have much less energy than they once had, are constantly exhausted, even after sleeping or taking a break, and neglect their own needs because they are too busy or do not care anymore. Although their lives revolve around caring, it gives them little satisfaction, and they have trouble relaxing, even when help is available. They can become increasingly impatient and irritable with the person they are caring for and, finally, feel helpless and hopeless (Smith, 2020). Moreover, carers' emotional and physical exhaustion provokes feelings of wanting to hurt themselves or the person for whom they are caring (Pathak, 2020).

Informal carers may start withdrawing from friends and family, experiencing a loss of interest in activities they used to enjoy, changes in appetite, weight, or both, and changes in sleep patterns. A visible sign of burnout is a significant weight change. They can significantly lose weight, often due to a lack of time to eat adequately or nutritiously, but also affected by anxiety that tends to lower their appetite. On the other hand, it is also possible for them to gain weight, as they start eating quickly and unhealthy food and snacking all the time, as a form of dealing with the accumulated stress. They also tend to get sick more often, getting chronic back or neck aches or developing high blood pressure. Mental and emotional stress lower immunity and can lead to physical disorders that manifest more frequently, persistently, or potently than usual.

If carers find themselves crying or feeling despair unexpectedly or more often, that could be another warning sign, especially considering that developing depression is a risk for them (Caring, N.A.). Another symptom of burnout is when carers start having sleep problems. Caring can be physically exhausting, and thus, we could expect carers to start sleeping as soon as their head touches the pillow, but the emotional load that comes with their work can instead lead to sleepless nights, which can become a vicious cycle.

Concerning the social life of carers who are reaching burnout, they start socially isolating themselves, seeing only their care recipients during the day (Caring, N.A.). They can do it if their care recipient's behavioral changes make them feel embarrassed or feel like they cannot find the time to go out, as they invest all their time and energy in providing care. At the same time, carers might start getting complaints from other family members, who can also begin expressing concerns about their well-being. Careers often take on all the burden of care without asking for help. Of course, this only worsens things, as it increases the overall stress due to the situation.

It is worth mentioning that the caregiving situation is related to stress, burnout, care burden, restricted activities, fear, insecurity, loneliness, facing death, and lack of support (Leite et al., 2017). This situation places the carer in conditions of biological and psychological vulnerability while the older person is already in a vulnerable position. *Vulnerability* refers to their susceptibility to physical and emotional stresses resulting from their care activities in particular places. The two factors that informal carers describe as creating their vulnerability are being in an unfamiliar environment and having an older adult experience health problem due to old age.

1.2.3 Protective Factors and Carer's Coping Strategies

Therefore, social workers, policymakers, funders, and advocacy groups should prioritize designing and implementing protective practices and an environment with high effectiveness. In particular, there should be efforts to build individual and family resilience, which can be achieved through various processes. *Resilience* is relative resistance to adversity or risk and is considered essential to well-being in later life. It is shaped by socioeconomic, psychosocial, and social support as well as cultural circumstances. These circumstances, or, in other words, protective factors, are often referred to as internal attributes, for example, self-esteem and self-efficacy, and external resources, such as social support and financial resources. Through caring for and supporting older adults, informal carers can play a significant role in their resilience. More specifically, resilience could be acquired when an informal carer receives material and emotional support from the extended family and society, and the older person maintains self-efficacy and whole family involvement with life-stage congruent life roles. Informal carers must deal with adversities and vulnerabilities and overcome the odds to achieve more positive family outcomes (Leite et al., 2017).

A study on informal caring in Ghana (Agyemang-Duah, Abdullah, Mensah, Arthur-Holmes, & Addai, 2020) has found that a strong sense of resilience can be created through personal and environmental resources. More precisely, personality and societal characteristics are a source of support during times of distress, vulnerability, and burden. The extended family, the church community, and neighbors help develop spirituality and resilience, which can offer strength, support, and comfort to the older person and the carer. The study findings suggest that carers believed that caring for older people is a call from God that will be rewarded and that assisting older people leads to developing the mental toughness to resist negative thoughts of quitting their caregiving responsibilities. It also appears that the lack of alternative carers encouraged carers to accept their caregiving role (Agyemang-Duah et al., 2020).

As mentioned before, caring is known to take a toll on informal carers' well-being and has been associated with increased levels of depression and anxiety, poorer self-reported physical health, compromised immune function, and increased mortality (Dharmawardene, Givens, Wachholtz, Makowski, & Tjia, 2016). In order to tackle the challenging journey of caring, carers need information about support mechanisms, service provision, and treatment options (Dharmawardene et al., 2016). Even though professional carers' support is insufficient in informal caring, it is worth noting that healthcare providers should train informal carers to give them basic knowledge on how to provide certain services that are important to the well-being of older people. Moreover, professional carers can increase the knowledge of informal carers on the process of aging, caring, and elder abuse, foster the expression of feelings about caring and enhance coping skills and strategies in caring.

According to a review (Kamalpour et al., 2020), there are two main potential benefits of online health communities for informal carers that can support resilience among older adults. The first benefit of online health communities is based on the idea of carers sharing and receiving social support, including knowledge and experience sharing, meaningful and altruistic activities, emotional support, and tangible and intangible financial support. It stems from the notion that online health communities can support carers by providing them with informational, emotional, and financial support and allowing them to participate in charitable activities. The second benefit is based on the self and moral empowerment of carers, including self-empowerment and improving carers' well-being. It is grounded on the notion that by participation in online health communities, carers become stronger and more confident in the journey of caring. They might have fewer experiences of distress and emotional turmoil as knowledge exchange in these communities can positively impact the well-being of carers by attenuating the adverse effects of caring (Kamalpour et al., 2020).

Regarding the association between the potential benefits of online health communities for informal carers and the resilience of older adults, we take into account nine resilience factors among older adults, which were suggested by a systematic review carried out by Bolton, Praetorius, and Smith-Osborne (as cited in Kamalpour et al., 2020). Resilience factors are environmental and personality characteristics associated with positive outcomes against adversity. The benefits of online health communities play an essential role in resilience factors such as external connection, which can provide social support and capital access and

empower older adults through contribution to self-esteem. Other resilience factors that can be encouraged by online health communities are physical and mental self-care. Beneficial activities and resources include staying healthy and active, availability of health and social services, access to care, curiosity, and altruism through advocacy, volunteer work, and generativity. All these things help older adults be more resilient and independent, which is related to control of choice and behavior. No association was found with other resilience factors, like meaningfulness, grit, positive perspective on life, previous experience with hardship, and self-acceptance, as these factors are primarily internal rather than environmental (Kamalpour et al., 2020).

The needs of informal carers are certainly not negligible and require a great deal of attention. Informal carers can develop several strategies for coping and relief from the caregiving demands and satisfying their own needs.

Self-care is of fundamental importance for informal carers. Stress-reduction techniques like getting adequate rest and eating a balanced diet are recommended by experts, as well as taking guilt-free time off and paying attention to health care needs. By strengthening free time and their own desires and needs, the carers also take care of their identity, and by that, they answer the question of the meaning or purpose of life (Simmons University, 2016).

Keeping interests unrelated to caring and dedicating time to visit places and friends satisfies their need to connect and socialize with other people and occupy their minds with other activities to relax and rejuvenate themselves for the task ahead. Continuation of the carer's activities, such as social contacts and hobbies, efforts to keep control over their involvement in the patient's care, satisfaction with the assistance they offer to the recipient, and positive feelings about caring may decrease vulnerability.

Work should also remain unrelated to caring as it is an activity that constitutes a human need. People use it to form a personal identity and organize their daily lives. By working, adults feel helpful, connect with others, and expand their social capital. Employment also brings financial independence to the carer. Work encourages individuals to be active in society.

Regular physical activity can also improve their social network and mental health (von Känel et al., 2011; Paluska & Schwenk, 2000). In case they are not used to physical activity, they can decide to start by taking a walk around the city. Walking stimulates blood flow and delivers oxygen to the cells. An adult's recommended daily physical activity is at least 30 minutes per day.

Support groups with informal carers of older adults can satisfy the need for inclusion and commitment that stems from the need for integration. Informal carers often experience stigma, isolation, and exclusion as they care for a person with a chronic illness. These groups provide platforms for carers to exchange skills and share coping and self-care strategies, reduce isolation by engaging carers in social activities, and offer psychosocial support and problem-solving skills. Support groups aimed at relatives caring for older people also help by expressing feelings of guilt, shame, and anger (Proot et al., 2003).

Another good way for informal carers to lighten the load and find more balance in their lives is to change their mindset around it. For instance, instead of asking themselves why they ended up in that situation, it would be good to try practicing acceptance of the circumstances instead (Smith, 2020). If they care for the person in need, there must be a reason other than mere need or necessity. It is better for carers to focus on their caregiving choice rather than feeling sorry for themselves or searching for someone to blame. In the same way, carers could try to focus on the positive aspects of caring, such as the stronger bond built with their loved one or the things they have learned throughout this journey, and maintain their sense of humor (Smith, 2020).

It can be positive for carers to only focus on the things they have direct control over while also celebrating the small victories coming from their caregiving experience, such as simply making them feel loved and safe. Without love, all other needs cannot exist. At the same time, love brings together informal carers and people with chronic illnesses. Love also brings together people who help each other in difficult situations.

Seeking help and consolation from experts can be crucial as every human being needs a safe and warm environment where they are accepted. Informal carers need comfort when their distress is overloaded as they often are misunderstood due to a lack of knowledge of the situation in their own family.

Development of emotional intelligence can also be beneficial as increased knowledge and awareness of strategies to deal with emotions can help informal carers. The goal is to gain greater control over what triggers emotions and how to respond. The first step towards emotional awareness is learning to identify and describe the feelings and their source.

Meditative interventions are increasingly accepted to reduce stress and improve well-being among people with increased vulnerability. Such interventions can encompass a range of techniques, including open awareness, meditation, mindfulness, and mantra-based integrative body movement traditions such as yoga or tai chi. Such programs have been tested on carers and teach them how to cope with stress, pain, and illness by paying moment-to-moment attention to aspects of daily life in an intentional, non-judgmental and non-reactive way. For informal carers, there were significant improvements in their mood regarding depression and anxiety, stress, exhaustion, and carer burden (Dharmawardene et al., 2016).

1.2.4 Violence against carers by older people

The aging process can also bring new behavioral changes in an older adult. Some informal carers report sudden behavioral changes in care recipients or relatives. An older person can become mentally or physically violent toward an informal carer because of diseases impacting cognitive capacities, such as dementia. Often, informal carers report missing "the person" who was there before the diagnosis. Carers find it challenging to deal with a person who is violent towards them due to dementia or other chronic illness. Some relatives report that people with dementia repeatedly insult them. It also happens that an older person physically hits a carer at

night when he is in a delirious mode. Individuals can physically attack their informal carers daily. It can be difficult for an informal carer to cope with this.

In many cases, informal carers report that they may overhear the insults but cannot tolerate physical violence. In case the older adult has not been diagnosed with dementia, it is recommended that he or she who is committing violence against the carer is taken to a personal doctor who will do a test for dementia or another disease. The carer can also manage violence by identifying the factors that trigger violent behavior in the care recipient and trying to anticipate them.

Personality changes can be very pronounced in people with dementia. They can suddenly become upset or even violent in contact with strangers, in tasks that they cannot cope with, or in the face of rapid environmental changes. Relatives need to be alert to possible outbreaks of violence in a person with dementia. We can prevent unpleasant and difficult situations with the communication technique of diverting the patient with dementia elsewhere. By diverting attention, for example, to another task or conversational topic, we can prevent a sudden outburst of emotions. A distinction needs to be made between agitation and violence. *Agitation* represents psychomotor restlessness, psychological and physical agitation, and psychomotor agitation. It is a state of pronounced mental agitation with associated psychomotor activity. It usually manifests as psychomotor and verbal hyperactivity with insults, threats, screaming, and physical violence. It can range from mild restlessness to extreme agitation with senseless psychomotor actions. There is a high risk that in a state of aggression, a person with dementia will be physically aggressive and injure themselves or the carer or the medical staff. Although the boundaries are often unclear, an agitated patient should not be mistaken for a violent patient. The violence that is not the result of a medical condition is handled legally, and the agitated patient needs to be treated by the medical staff.

1.3 Carers' skills

1.3.1 Assessing and looking for resources

It is recommended that the informal carer, along with a professional, participates in a search and assessment of needs and services in the assistance process. With the help of the rapid assessment method of needs and services, we can obtain enough information about the problem or distress that the informal carer is experiencing and identify his/her sources of strength. Sources of strength are resources that empower the carer and uplift him in difficult times. With the help of an important concept, which in collaborative conversations is called empowerment, we look for exceptions and unique resources in the community.

1.3.2 Development of carers' communication skills, creativity & time management

A conversation consists of the beginning, core, and termination. For people with dementia, all three phases of conversation are difficult. The informal carer can determine which

communication method is most effective with the care receiver. The carer needs to be very creative and resourceful in talking to a person with a chronic illness or dementia. It is beneficial in interpersonal communication with older people that the carer knows the person well and can expect or anticipate his behavior. When a carer talks to a person with dementia, he should not correct or criticize him, as this can encourage restlessness, anger, or a feeling of helplessness in the person.

A carer can also improve communication skills if he or she actively participates in a self-support group organized by professionals in order to share the experiences of others with similar life experiences (Machiels et al., 2017). When communicating, a carer needs to be patient and allow people time to get in touch with themselves. It can help to choose a suitably safe place to talk. He/she must speak as clearly, loudly, and slowly as possible. With his / her presence and choice of communication, the informal carer mainly takes care of how he/she will influence the care recipient. It is recommended that the informal carer act empathetically and reassuringly. Carers can use short and simple sentences and specific nouns and verbs to avoid abstract concepts and only one (positive) topic of conversation. They can also use music and various creative techniques in the conversation (Deshmukh et al., 2018).

Much of the communication, however, is occupied by nonverbal communication. The carer makes eye contact with the care receiver face to face. A handshake, a hug, and physical proximity, in general, are essential for people receiving care, as they often feel confused, helpless, and unable to articulate their feelings.

1.3.3 Assertiveness

Assertiveness is an essential quality to live in harmony with others. It allows us to express our opinions, feelings and needs respectfully. For carers, it is even more important to be assertive. Assertiveness and emotional expression training promote communication skills and can significantly contribute to an individual's personal growth. Assertive communication is an essential key to a happy life. People change their behavior and communication according to their past life experience of the situation, the interlocutor's status, and their own feelings in a given situation. However, it is important to know that people strive to be understood and accepted in society.

Experts report four ways of communication, and these are aggressive, passive, manipulative, and assertive communication. Assertiveness is a way of behaving, thinking, and communicating in which we express our needs, emotions, desires, and opinions clearly and decisively, verbally and physically, emphasizing respectful expression. Assertive communication means safe and respectful communication. For carers, assertive communication is a necessary competence, as it stems from the position of secure attachment, "I am fine, you are fine." Assertive behavior is based on respect for the interlocutor and one's own needs. An assertive relationship between an informal carer and an older person is a respectful relationship where both can safely express their feelings and opinions.

In assertive communication, we make compromises, accept compliments, look for new possible solutions, use appropriate body language, and take responsibility for our behavior and thoughts. Being assertive means believing in one's decision-making abilities, clearly expressing one's thoughts and feelings in conversation with other people, and taking responsibility for one's behavior.

Informal carers can use assertive communication techniques in conversation with an older person. If the informal carer does not agree with the older person's request, he can firmly and respectfully say "no." We recommend speaking in the first-person singular and expressing our inner feelings "I think ...". In assertive communication, we are tolerant of each other. Our opinions are equal, and no one is less important than another in a relationship. We can use assertive terms like "No, thank you," "I will think about it," and "I could use your help." In assertive behavior, we accept both our positive and negative qualities and try to improve our behavior. We accept the praise of other people and also thank them for it.

1.3.4 How to help a person with Alzheimer's or/and dementia

Coping with a chronic illness is not easy. Living with dementia changes not only the lives of those diagnosed with dementia but also the lives of his/her family members. That is why it is crucial to open a working conversation and talk to family members about how to reorganize life so that it will consider the needs and wishes of all those involved in helping. We can help a person with dementia by making a personal plan with them. It can be a document that covers the goals and desires of the diagnosed person. In a personal plan, we not only capture the issue of the health aspect of a person with dementia but also record and evaluate the goals and desires a person has for their life. For example, "What does he want to experience?". When writing a personal plan, an individual is the main protagonist of his story. Moreover, he is involved in all phases of the working conversation. A personal plan can also be a tool for planning personal care services. It is a good starting point for a conversation between family members about dementia about their expectations, dilemmas, and distresses.

We can also help a person with dementia:

- To focus on the individual and not on the disease state.
- To try to maintain good relations with each other.
- That we are as patient and creative as possible in our relationship with a person with dementia
- To believe in the abilities that a person with dementia still has. We let a person with dementia do what they still have the strength, ability, and energy to do.
- Talk to relatives, friends, and neighbors about the disease. This reduces the stigma of dementia and informs loved ones about the course of the disease. Neighbors can thus help us monitor a person with dementia.

- Understand conversation better by using short sentences, repeating the information, and paying attention to our non-verbal communication.
- Feel understood by taking the time to know them well.

1.3.5 Other needs identified by a person with Alzheimer's and/or dementia.

People with dementia state that they need (Orrel, 2008; WHO, 2012, Khanassov, 2016; Curnow, 2021):

- Basic diagnosis and starting point for insight into how they can continue with their life.
- Professional multidisciplinary and psychological support.
- Hope.
- The right to be included in society.
- Understanding the course of the disease itself.
- Destigmatizing the knowledge other people have about dementia.
- Considering other people that a person with dementia had a non-dementia-related life before the disease.
- Compassion.
- Music.
- Photos of memories.
- Self-care needs.

In this chapter, you can find examples of facilitating learning for informal carers on how to support the person they care for and themselves in caregiving relationships. The chapter is meant for facilitators to use exercises and examples to facilitate learning about caregiving relationships.

1. Self-support as an informal carer – our self "disputes" & "supports."

Description: The facilitator asks the participants to think about moments when they provided care to their loved ones, which caused them emotional pressure and made them uncomfortable. The facilitator encourages them to develop their thoughts and state why these thoughts started. For example: *I had to "lock" my mother, who has dementia, at home to do some shopping, and I feel remorse for this action.* Then the facilitator asks: *How do you feel about that? How do you describe this action of yours? Could it be considered a form of abuse?* Then the facilitator invites participants to answer the following questions, reframing their negative and incriminating thoughts with a positive imprint, such as: *How could this action be prevented? What possible difficulties or dangers were prevented by this action/decision?*

2. Johari window

Description: The facilitator asks the participants to draw a square on a piece of paper which will be divided into four parts
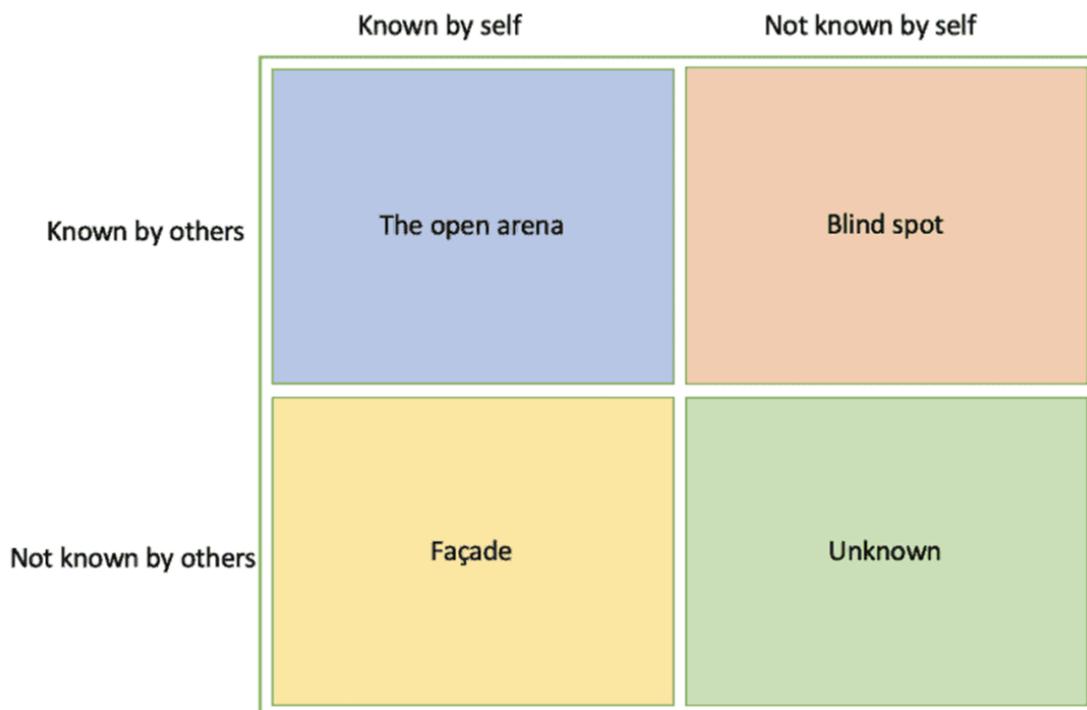
The facilitator asks participants to fill in the squares they can according to what they know about themselves. Then the facilitator leaves the fourth square vacant (top right). This box will be completed by the other participants (https://en.wikipedia.org/wiki/Johari_window).

The facilitator asks participants to write at least two positive thoughts about themselves on a different piece of paper. The facilitator then asks them to write one positive thought for each other group member and place this piece of paper in the fourth square of the person to whom they are referring this thought. Words, expressions, metaphors, images, a song, or anything can be used. ATTENTION: The facilitator needs to consider that it has a positive tone. Then, the facilitator gives participants enough time to study the window as it was configured. Next, the facilitator asks participants to re-edit their window as they see fit after receiving the information. The facilitator encourages participants to express their thoughts and talk about their feelings. The facilitator asks them to share how they feel after the exercise with the group, which characteristics they recognize, would like to develop more, and how they will achieve this. The facilitator asks them how they present themselves in this way. The facilitator also examines what different perspectives of themselves they discover and what has surprised or amazed them. The facilitator asks what it would be that they would hide or would not want to share with the team in the end. Moreover, the facilitator encourages them to reflect if there is anything they would ask for help managing their emotions and, if so, whom they would ask for help.

To finish the exercise, the facilitator summarizes the discussion and encourages the participants to think about their future, taking advantage of the positive parts of themselves by getting ideas from both the ideas added by the other people and the windows of other participants. The facilitator asks the participants to see their possibilities and use them in what they are and what they can become. Finally, the facilitator can discuss anything else he/she would like to share with the group.

In the end, the facilitator allows participants some time to unload.

3. Personal Links

The facilitator asks participants to form a circle and write their names in the circle. Then the facilitator asks participants to add links associated with this circle and name each of these links. For the rings (individuals) that can be autonomous, use the color green. For those who are semi-dependent, ask them to use the color orange, while for those who are entirely dependent, let them use the color red. After taking some time to form the pattern, take a few minutes to observe the shape. What emotions does this shape create in the participants? What do they think when they observe this shape? What do the rings mean to them as they are formed? Which link would they like, if they wanted it to be absent, and why would they like it to be absent? That is, if links were lacking, what would be the benefits? What would be the shape of the rings after that? What would this new form mean for them?

4. Make my own story (Professionals, volunteers, older people)

The facilitator asks participants to make a circle. One person from the circle begins to say a phrase, completed by the next following the circular series. Participants complete the phrase according to their experience and knowledge. The story should report abuse-elder abuse. In 4 circles, our story ends. The group coordinator writes the story, which he/she reads to the participants. Everyone talks about the story they have created, stating their experience, feelings, and thoughts.

Chapter 2: Preventing elder abuse and maintaining respect

Theoretical portion

2.1 Assumptions and stereotypical thinking about elder abuse

Considering the numerous roles and needs of carers, it appears that caring is a demanding situation related to several physical and emotional challenges. These challenges place the carer in a vulnerable position and can lead to a care burden. To address the caring demands, self-care and other coping strategies are essential for informal carers. However, these challenges can still impact the carer's behavior and result in domestic violence and elder abuse.

It is hard to estimate the prevalence of elder abuse because it is often underreported. Existing studies on elder abuse estimate its prevalence to range globally between 1% and 35%. According to the WHO, around 1 in 6 people 60 years and older have experienced some form of abuse in community settings during the past year. An increase in elder abuse is expected, as many countries have rapidly aging populations. However, the WHO assumes that these figures may reflect only a small number of the actual cases, and some experts believe elder abuse is underreported by as much as 80%.

Population aging is transforming the world. All people age differently. Stereotypes and prejudices regarding age and elder abuse are widely spread and can harm many people. Stereotypes may be positive or negative, and people conceptualize these as a set of beliefs about the personal attributes and traits of a specific group and its members. For example, older people are often referred to as resistant to change, with many diseases, and unable to learn new things.

On the one hand, older adults are stereotyped as old-fashioned, greedy, senile, stubborn, dependent, and on the other hand, kind, wise, happy, and grandparents. Through repeated exposure from several sources, like family, friends, and the media, the stereotypes are internalized across the lifespan. Gradually they become thoroughly deep-rooted biases and self-activating thoughts. Even if a person has become aware of the stereotypical traits, getting rid of these is tricky. The potential to make quick judgments based on visible features, like hair color or the number of wrinkles on a face, can be, from an evolutionary viewpoint, effective utilization of one's internal capacities, for example, when facing danger. Unfortunately, stereotyping people has many disadvantages, and it can cause social, psychological, and physical distress and damage (Shepherd & Brochu, 2020). Negative beliefs regarding an older person's capabilities can adversely affect an older person's health. According to the Madrid International Plan of Action on Ageing (2002), "older women face a greater risk of physical and

psychological abuse due to discriminatory societal attitudes and the non-realization of the human rights of women."

The WHO has stated, "perhaps the most insidious form of abuse against older people lies in the negative attitudes towards, and stereotypes of older people and the process of aging itself, attitudes that are reflected in the frequent glorification of youth. As long as older people are devalued and marginalized by society, they will suffer from loss of self-identity and remain highly susceptible to discrimination and all forms of abuse" (WHO, 2002a).

Another form of patronizing treatment that older people experience is benevolent ageism. It is often accidental and can seem innocent, but it can be especially damaging. People often assume that older people are fragile and need protection. Assumptions like this might mean that family members or carers think they know what is in the best interest of the older person and that they are doing the right thing. Failing to let older people make decisions for themselves is paternalistic and a threat to older people's autonomy and independence (Stovell, 2020).

Stereotypical thinking and assumptions contribute to elder abuse remaining hidden in most cases. In the case of abuse, older persons' self-disclosure is very difficult in itself, as it involves shame and guilt. A society that "glorifies youth" and where older people are portrayed as weak makes speaking about violence against older persons even more complicated.

2.2 Forms and signs of violence against older people and gender-based violence

The definition of elder abuse developed by Action on Elder Abuse states, "*Elder abuse is a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.*" It has been adopted by the World Health Organization (WHO, 2002b) and is accepted globally.

Abuse of older people is either an act of commission or omission (usually described as "neglect"), and it may be either intentional or unintentional. The abuse may be physical, psychological (involving emotional or verbal aggression), or financial or other material ill-treatment. It does not matter what type of abuse the older person is facing. It will, without a doubt, cause needless suffering, injury, and/or pain. The abuse can also result in the loss or violation of human rights and will generally reduce the quality of life (WHO, 2002a). Violence against older women is rooted in the same norms and gender inequalities as other violence against women. In addition, due to discriminatory societal attitudes and an absence of protection for women's human rights, older women face a considerably higher risk of physical and psychological abuse than older men.

2.3 Different types of elder abuse [1]

- 💜 Physical abuse — infliction of pain or injuries on an older person, use of physical coercion, and physical or drug-induced restraint
- 💜 Psychological or emotional abuse — infliction of mental anguish on an older person
- 💜 Financial or material abuse — illegal or improper exploitation or use of an older person's funds and/or resources
- 💜 Sexual abuse — non-consensual sexual contact of any kind with an older person.
- 💜 Neglect — failure by a carer or other responsible person to protect an elder from harm; failure to meet an elder's needs for essential medical care, nutrition, hydration, hygiene, clothing, basic activities of daily living, or shelter, which results in serious risk of compromised health and safety
- 💜 Institutional abuse – repeated or regular abuse performed in any institutional environment where service users are engaged with professionals (outside their own homes)

Physical violence

Physical violence is defined as the use of physical force against an older person, which can cause bodily harm, permanent impairment, or physical pain.

Forms	Scratching, biting, slapping
	Burning
	Throwing things at a person
	Using weapons or other objects to inflict pain
	Pushing, kicking
	Choking or strangling
	Force-feeding or denying food
	Physically restraining a person
Signs	Carer/relative is overly protective or controlling, tells conflicting stories, shows delay in seeking care or reporting an injury, does not leave the older person

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[1] The following forms, signs, and consequences of different types of abuse are based on Perttu, S., Laurola, H. 2020 How to Identify and Support Older Victims of Abuse: A training curriculum for professionals, volunteers, and older people. Published by the University of Tartu within Erasmus+ Project: 'Training to Identify and Support Older Victims of Abuse (TISOVA)'. For more thorough explanations and further references, the manual is available at https://www.wave-network.org/wp-content/uploads/Tisova_Training-handbook_ENG.pdf. Since the current handbook focuses on informal caregiving, institutional abuse will not be further elaborated on.

	unattended; older person described as 'accident prone' or having a history of sustaining injuries
	Injuries in different stages of healing: broken bones, sprains, or dislocations, abrasions, welts, rashes, blisters, burns, lacerations, swelling; signs of being restrained, weight loss, hair loss, poor hygiene
	Lack of awareness, drowsiness, vagueness, confusion, sleepiness
	Cringing or acting fearful, agitation, catatonia, frequent requests for care or treatment for minor conditions, unexplained anger, fear, or shutting down behavior around the carer or relative.
	Over-sedation, reduced physical or mental activity, grogginess, or confusion
	Reduced or absent therapeutic response to prescribed treatment may be the result of under-medication or failure to fill prescriptions
	Pills scattered about may be signs of inappropriate use of drugs and/or alcohol
	Medical reports of a drug overdose, missing or not administered prescription medication, poor management of medical conditions, repeated accidents or emergency department presentation, and frequent falls.
Consequences	Bruises, wounds, abrasions, contusions, hematomas
	Dental problems
	Decreased hearing or deafness
	(Permanent) disabilities
	Increased risk of premature death
	Physical pain and soreness
	Decreased sight or blindness
	Brain injuries

Psychological violence

Psychological violence, also called emotional violence, consists of systematic, non-physical actions intended to inflict mental pain, anguish, and suffering on an older person.

Forms	Emotional manipulation or other cruel behavior
	Denying access to services, religious and/or cultural events

	Forcing a person to participate in and follow religious rules and customs against their will
	Harassment, stalking
	Non-verbal communication hints, such as facial expressions and body gestures, meant to intimidate, degrade, manipulate or insult
	Verbal intimidation, shouting
	Insults, scolding
	Humiliation, threats, denigration
	Controlling behavior
	Abandonment
Signs	Feelings of helplessness, shame, powerlessness
	Loss of interest in self or environment
	Lack of eye contact with a practitioner, carer, or another person
	Nervousness or other changes in behavior around a carer or another person
	Paranoid behavior or confusion not associated with illness
	Display of signs of trauma, e.g., rocking back and forth
	Depression, sadness, tearfulness
	Changes in self-esteem, lack of confidence
	Unusual passivity or anger
	Agitation, disorientation
	Isolation
	Withdrawal, apathy
	Fearfulness
	Reluctance to talk openly
	Insomnia/sleep deprivation
Consequences	Long-term trauma symptoms
	Post-Traumatic Stress Disorder (PTSD)
	Increased mortality and suicide risk

	Depression and anxiety
	Dementia
	Substance abuse

Financial violence

Financial violence is "the illegal or improper exploitation or use of funds or other resources of the older person" (WHO, 2008).

Forms	Controlling the use of money and property by an older person
	Theft, use of coercion, or fraud to (try to) obtain an older person's money or possessions
	Illegal or improper use of an older person's money, property, or assets
	The exploitation of and pressure in connection with wills, property, or inheritance
	Fraud and internet scams
Signs	The individual expresses concern that they do not have enough money to cover their basic needs
	The individual is confused about funds missing from their accounts
	Confusion regarding assets, property, and income
	Individual reports that furniture, jewelry, credit cards, documents, or other items are missing
	Numerous unpaid bills or overdue rent that an older person should be able to afford or that someone else is expected to pay
	Lack of amenities, e.g., a TV or appropriate clothing that an older person should be able to afford
	A recently signed will, or changes in a will, when an older person is incapable of drafting or signing it
	An older person 'voluntarily' giving inappropriate financial reimbursement for needed care and companionship
	Loans or mortgages obtained by an older person
	Being accompanied by another person when attending financial institutions or using ATM, and the other person is reluctant to allow a conversation with the older person regarding transactions

Sexual violence

Sexual violence of an older person occurs when a perpetrator engages in sexual behavior towards them, including physical contact of a sexual nature, without their consent.

Forms	Unwanted sexual contact, e.g., inappropriate touching, sexualized kissing
	Forcing an older person to watch sexual acts or pornographic material
	Forcing an older person to undress against their will, coerced nudity
	Cleaning or treating an older person's genital area roughly or inappropriately
	Sexual assault and battery
	Forcing an older person to perform a sexual act
	Forced intercourse/rape
	Explicitly sexual photography
	Sexual remarks/suggestions
Signs	Urinary tract infections
	Fear of being touched
	Unexplained venereal disease
	Increased sexual or aggressive behavior
	Depression or withdrawal
	Insomnia
	Anxiety or excessive fear around a carer
	Increased interest in sexual matters
	Unexplained incontinence (bladder or bowel)
	Difficulty walking or sitting, or pain when toileting
	Bleeding, bruising, abrasions, infection, tenderness of the anogenital area, thighs, and breasts
Consequences	Fear and unwillingness to live at home
	Inability to sleep at night (e.g., having nightmares or flashbacks)
	Severe psychological trauma, shame, guilt, self-blame

	Chronic pain, long-term physical and health problems
	Depression, anxiety, nervousness
	Increased use of alcohol and other substances
	Distrust of others
	Suicidal thoughts, attempted or committed suicide

Neglect

Neglect is defined as a failure by responsible persons to satisfy the essential basic needs of an older person.

Forms	The person is abandoned, left unattended for long periods, or locked in the house alone
	Inadequate or inappropriate use of medication; the person is over-sedated in the middle of the day
	The person is not provided with necessary aids, e.g., glasses, hearing or walking aids
	Immobility, the person stays in bed almost all the time
	Inadequate food and drink
	Isolation; lack of mental, physical, and social contacts
	Lack of clean, appropriate clothing
	Restraints; the person is tied up to the chair or bed
	Inadequate medical or dental care
	Exposure to unsafe, unhealthy, unsanitary conditions
Signs	Pain, discomfort, multiple large bedsores
	Unexplained weight loss, malnutrition, dehydration, constipation
	Poor hygiene, unkempt appearance; an older person is dirty, smells strongly of urine
	Poor or nervous interactions between an older person and carers/family
	Under- or over-medication
	Hypothermia or overheating

	Signs of withdrawal, depression, passivity
	Absence of required assistive technologies
	Lack of concern on the part of carers/family or overly attentive behavior in the company of others
Consequences	Depression
	Emotional suffering
	Infectious illnesses
	Premature mortality

2.4. Neglect, intentional or unintentional abuse

Neglect of older people is the most common type of elder abuse (Ananias & Strydom, 2014). Failure to provide proper nutrition, clothing, and hygiene care to bedridden older people and leaving an injured older person unsupervised is considered neglect. Unintentional neglect means that the carer does not have the necessary skills and knowledge to care for a person who cannot satisfy their needs without help (Lin, 2020). Neglect is considered intentional when an older person is intentionally harmed and abandoned or when others are not allowed to provide adequate care to an older person.

It has already been explained that neglect has certain forms, signs, and consequences. However, no mention is made of a subtype of emotional abuse called communication neglect. It is a psychological insult inflicted on another individual (Sorenson, 2006, as cited in Lin, 2020). Unintentional communication neglect occurs when informal carers give little attention to the older person due to the multiple tasks they are responsible for and when they try to minimize irritations for both sides due to communication barriers. On the other hand, in intentional communication neglect, informal carers try to avoid physical and emotional connection with the older people on purpose, as they see communication neglect as a possible treatment to respond to repeated frustration when trying to provide help to the older people (Lin, 2020).

Even though communication neglect is not officially recognized as a form of elder abuse, its presence is acknowledged (Lin, 2020). Unlike other forms of neglect, informal carers who engage in communication neglect continue to meet the daily needs of older people, but communication is absent. For instance, informal carers may avoid or ignore older adults' needs for relationships or social interactions. Reducing or keeping the conversation to its minimum, informal carers' communication neglect may leave older adults feeling isolated. Whether in institutional or home settings or as a result of aging-related diseases or other health issues, older adults may not be able to communicate effectively. A possible response could be to minimize conversation or to attempt to engage in meaningful conversations. While it has been conceptualized and discussed in the literature, the role and influence of communication neglect have not been empirically tested extensively in the informal caring context (Lin, 2018).

Evidently, there continues to be a need for effective interventions regarding elder abuse and neglect (Ananias & Strydom, 2014). Specifically, offering social and emotional support, respite, and daycare must be designed and implemented to help carers reduce stress. Additionally, the development of support group interventions with carers can reduce the caring burden and social isolation and, in addition, offer psychosocial support, problem-solving skills, and coping strategies among carers. That way, elder abuse, and neglect risk factors can be addressed appropriately (Ananias & Strydom, 2014).

2.5 Complexity of violence against older people

When describing the phenomenon of violence against older adults, the common term used is 'elder abuse.' There are debates about the field the term belongs to and whether violence against older people should be considered a separate field or a type of domestic violence because it is similar to and different from other types of domestic violence.

Besides providing adequate age- and sex-disaggregated data, one of the main challenges is that violence against older people is a susceptible and often taboo subject. Its practice and denial involve people in positions of trust – family members, officials, and the wider community. Moreover, older people often do not want to speak about such experiences because they are seen as a threat to the family's prestige or are ashamed of being subjected to violence and exploited by their children or other relatives. Also, older people may not recognize that they are a subject of abuse or neglect.

Violence and neglect have emotional and physical effects on older people. When someone they trust is hurting or taking advantage of them, the older person may feel guilty, shocked, embarrassed, or ashamed. Sometimes, older adults may feel they must help and keep their spouse or children safe, even if they are violent or abusive. The older generation also may not think about the consequences or effects of violence on themselves (Perttu, 2018).

The structure of our society favors young people, and older adults are often rejected, ignored, and lost in the hustle and bustle of life (Shepherd & Brochu, 2020). Isolation is the most significant factor contributing to the vulnerability of older people. Isolated, more aged people are left without access to information or services and placed at heightened risk of violence, including sexual and domestic abuse, exploitation, and discrimination (UNFPA, 2012).

Violence against older people is not only a social problem. Another critical issue that must be raised concerns illiteracy and digital illiteracy (Vágvölgyi et al., 2016). In particular, that illiteracy characterizes the informal carers population, and it can be considered a possible barrier to accessing information (on paper and digital), such as the rights of carers and caretakers regarding diseases, medication, and food. Since one segment of the whole population is exclusively vulnerable to this abuse, it can be a human rights violation. Therefore, it is necessary to put in place special measures to ensure that this group is not more at risk of violence than other groups.

The claim that older people are always cared for by their extended families and relatives is incorrect. Violence and abuse take various forms in different political, economic, social, and cultural contexts and are not restricted to any specific context or region. Older people can be more vulnerable to violence, abuse, and neglect due to increased dependence, isolation, and frailty. Physical abuse, including sexual abuse, is considered the most serious and the least frequently reported by either victims or service systems. At the same time, the most prevalent types of self-reported abuse are psychological and financial.

The communities need a deeper understanding of the complexity of elder abuse by considering the interactions that occur across several interrelated systems and the multiple risk factors that contribute to elder abuse and neglect. For example, many older people still live in extended, multigenerational households and receive informal care from their adult children, partners, and other family members. However, family structures are also undergoing significant changes since adult children no longer live in the same towns as their old parents because of the current socio-economic climate, high living costs, and pressure to find employment.

Children of older people have their own children to care for and provide. There are no means and resources to care for generations up and down and support both their parents and their children, whether financially, physically, or emotionally (a so-called sandwich generation). Members of the sandwich generation are middle-aged adults with a living parent at age 60 or older and a child under 18 or a child over 18 who requires support. They are literally "caught in the middle" and are pulled in many directions, which can lead to unintentional violence by the informal carer.

2.6. Domestic violence in a caring relationship: change in the power dynamic, risk

Caring often arises from a long-standing familial relationship (Gimeno, Val, & Cardoso Moreno, 2021). Caregiving relationships bring about many life-changing impacts on the carer's life, including considerable negative impacts. As these long-term impacts become apparent, the dynamics usually change as the social environment continues with their ordinary lives, leaving those in the caring role increasingly isolated and with a life dominated by caring. Despite this possible cost, it is out of the question for most carers to contemplate not taking over the role due to their relationship with that person (Lin, 2020). Nevertheless, it is worth highlighting that practices of power in adult relationships are complicated and subtle, and power is continuously negotiated and mediated. Disrupted power relationships are probable throughout times of change in long-term intimate and family adult relationships (Isham, Hewison, & Bradbury-Jones, 2019).

The main motives for adopting a caring role must be seen within the broader family and societal context (Gimeno et al., 2021). Caring for older adults usually arises out of the continuation of the relationship and the carer's will to monitor and safeguard the older person's health as they possess an in-depth knowledge of that person, which allows them to be in the best position to provide the care. Often, caring results from a sense of duty and commitment to the older person. It reflects the expectations of society that the carer has internalized and their doubts

about the quality of institutional care. However, it is of particular importance to take into account the distinction between assisting with carer tasks, such as taking on extra family responsibilities, and being a primary carer, meaning feeling responsible for that person's well-being (Mendes, Mestre, Santana, Reis, & Lopes, 2019).

The relationship between carer and recipient is a dynamic and evolving entity since the people concerned move through life phases, and the older adult's possible illness takes its course (Isham et al., 2019). This dynamic process is unstable and lacks resilience, as the challenges of caring and illness are intense and complex for most families and may result in a state of unpredictability and uncertainty within the relationship. The process becomes more complicated for carers of elders whose health is deteriorating due to the loss and mourning of the previous relationship. Caring demands become more significant, and considering more pressing alternatives may lead to stress and burden, which will probably affect both parties. Stress is an integral part of a caregiving relationship that can make some caregiving situations tense and full of disagreements. Therefore, caring for an older person may negatively affect the physical, psychological, psychosocial, social, and financial health of her/his informal carer, which, in turn, may result in domestic violence and elder abuse (Isham et al., 2019).

According to the social representations of Portuguese and Brazilian carers (Mendes et al., 2019), violence against older people is based on disrespectful behavior and humiliation, and the portrayal of violence reflects, in essence, the dominant social attitude towards aging. Potentially harmful carer behavior may be seen as a warning sign or precursor to intentional or unintentional abuse (Beach et al., 2005).

Many commonly accepted theoretical approaches have tried to explain the causes of elder abuse. However, the one that offers a more comprehensive explanation of this complex problem is the ecological theory (Ananias & Strydom, 2014). As stated in this approach, certain potential risk factors for elder abuse concern the older victim/recipient, the perpetrator/carer, the context of caring, and the broader societal context. Regarding the individual characteristics of the older victim of abuse, the variables of gender, chronological age, marital status, severe chronic health problems, presence of cognitive disorders, presence of mental or emotional illness, substance use, problematic behavior, social isolation, and loneliness are related to elder abuse. More specifically, the victim is more likely to be an older male or female of advanced age who abuses alcohol, displays difficult behavior, and suffers from a severe physical, cognitive or mental disorder (Ananias & Strydom, 2014). In relation to the individual characteristics of the carer, gender, chronological age, psychological and emotional problems, and substance abuse are associated with elder abuse (Pillemer & Suitor, 1992). Thus, the perpetrator of elder abuse is more likely to be a male or female carer who suffers from a psychological or emotional problem and is a substance abuser.

Furthermore, the interaction between the older person and the carer within the caring context implies risk factors (Pillemer & Suitor, 1992). Lack of carer experience and reluctance, lack of support, past relationships between older person and carer, dependency, carer stress, financial difficulties, and living arrangements are some variables relating to elder abuse. Therefore, an inexperienced or reluctant carer, an insufficient support system, a history of

dysfunctional relationships, interdependency, and co-residence between the carer and the older person are contextual characteristics that provide a breeding ground for abusive behaviors (Pillemer & Suitor, 1992). Its also worth noting that broader societal factors, such as ageism and historical disadvantages, can make older people vulnerable to elder abuse (Ananias & Strydom, 2014).

Besides risk factors, there are factors within the family and society that can decrease elder abuse incidents (Ananias & Strydom, 2014). In particular, carers who maintain good mental and physical health and receive sufficient remuneration, support, and some form of training to deal with the stress of the caregiving situation are less likely they become abusive towards older people. Moreover, in terms of society, communities characterized by a strong sense of community, spirituality and resilience, loyalty to family, the value of motherhood, and appreciation of older people are considered protective factors against elder abuse (Ananias & Strydom, 2014).

2.7. Identifying risk factors and warning signs of elder abuse when working with carers

As mentioned above, several risk factors can harm a carer's general health and increase the older person's chances of being abused and neglected. The lack of carer experience, reluctance, formal or informal support systems, and the unhealthy past relationships between carer and recipient can result in emotional exhaustion and elder abuse (Pillemer & Suitor, 1992). Furthermore, the dependency of older people, financial difficulties, and co-residence can lead to an absence of personal time, which can cause physical and behavioral problems. Therefore, practitioners must understand not only the risk factors but also the warning signs associated with caregiving to maintain self-care and identify, prevent and minimize the effects that could result in abusive behaviors. To clearly understand the effects of caregiving on informal carers, it is necessary to know the immediate effects of trauma and stress reactions on older people (Van Durme, Macq, Jeanmart, & Gobert, 2012).

When working with informal carers, many physical, behavioral, and psychological warning signs of burnout can help practitioners identify potential violence against older people (Van Durme et al., 2012). In terms of physical warning signs, exhaustion, insomnia, headaches, increased susceptibility to illness, sore back and neck, irritable bowel, gastrointestinal distress, rashes, skin breakouts, grinding one's teeth at night, heart palpitations, and hypochondria are the most frequent. We also need to pay increased attention to a carer's increased use of alcohol and drugs, avoidance of the recipient, lack of entertainment, avoiding friends and family gatherings at social events, impaired ability to make decisions, problems in personal relationships, difficulties with sex and intimacy, compromised care for the older person, impaired appetite or binge eating and thinking of resigning from a job. On a psychological level, the challenges and difficulties of the caregiving role can have adverse effects and self-image related to caregiving stress, helplessness, blaming oneself, and possibly elder abuse and neglect. These negative emotions can be a significant source of depressive symptomatology and carer burden, leading to an increased risk of becoming violent against older people (D' Aust, Brewster, & Rowe,

2015). It has been found that the most frequently cited emotion is carer depression, followed by anger, anxiety, resentment, irritability, hostility, and suicidal thoughts (Lin, 2020).

Interestingly, in a study with patients with dementia and their carers (Gimeno et al., 2021), it seemed that the presence of behavioral disorders, like aggression and irritability at the middle stage of the disease, could also be associated with the carer burden and elder abuse. Other identifiable warning signs when working with informal carers who may become violent are related to the carer's cognitive functions as there are carers who face difficulties in concentrating on specific tasks, feel discouraged about the world and the future, hopelessness, and intrusive imagery. Furthermore, both high caregiving extent and low social resources are associated with low levels of life satisfaction. It is essential to mention that low life satisfaction can lead to potentially harmful carer behavior, which may be considered an early warning sign of elder abuse or neglect (Borg & Hallberg, 2006).

Therefore, caring may harm the quality of life of the informal carer on several levels and lead to violent and aggressive behaviors. In particular, caring for an older adult is likely to provoke carers' suffering, ill-health, and potentially harmful behavior towards the recipients. Caring demands are accompanied by major emotional, financial, and social strains. According to research on stroke patients (Oliva-Moreno et al., 2018; Bugge, Alexander, & Hagen, 1999), strain is, without a doubt, a complex concept that affects a carer's health and behavior. Though the strain was not related to the recipient's residence and the offering of services, it was found that grand proportions of time spent assisting the older person, the severity of the stroke, and poor physical and mental health of carers increase the risk of elder abuse and neglect (Pinquart & Sörensen, 2007). It is therefore important to consider how much strain the carers experience in caring for older adults.

2.8 Adult safeguarding

Adult Safeguarding means protecting an adult person's right to live safely, free from abuse and neglect. To prevent these types of situations, institutions and professionals need to have a clear understanding of their role in safeguarding adults, whether this is in a proactive or reactive role. There are people who, due to their needs, are more at risk of being victims of abuse or neglect, namely, people with care and support needs, such as older people or people with disabilities and people with communication difficulties. In both cases, these people's vulnerability may prevent them from identifying abusive behaviors and reporting them. Sometimes people may not even be aware that they are being abused, especially if they have a cognitive impairment (Stevens, 2013).

Some personal characteristics or life circumstances increase the chance of someone being a victim of abuse or neglect (Pillemer, Burnes, Riffin & Lachs, 2016). Personal characteristics may include age, physical or mental disabilities, special educational needs, and any mental or physical illness. Their circumstances may include isolation or loneliness, finances, work, and living conditions.

The aims of adult safeguarding are to (Somerset Safeguarding Adults Board):

- 💜 Prevent harm and reduce the risk of abuse or neglect to adults with care and support needs.
- 💜 Stop abuse or neglect wherever possible.
- 💜 Safeguard adults in a way that supports them in making choices and controlling how they want to live.
- 💜 Promote an approach that concentrates on improving life for the adults concerned.
- 💜 Raise public awareness so that communities as a whole, alongside professionals, play their part in preventing, identifying, and responding to abuse and neglect.
- 💜 Provide information and support in accessible ways to help people understand the different types of abuse, how to stay safe and what to do to raise a concern about the safety or well-being of an adult.
- 💜 Address what has caused the abuse or neglect.

Unfortunately, abuse can take place in any context: caring situations, within nursing, residential, or daycare settings, in hospitals and custodial situations, support services in people's own homes, and other places such as public places or places previously assumed as safe (Department of Health, 2000). Many adults in a generally aging European population face limitations due to disability or insufficient personal capacities. Vulnerable adults face challenges and difficulties in protecting their rights, defending their interests, and accessing justice. In this sense, taking initiatives that guarantee the protection of these people is crucial.

2.9 Domestic violence support and existing carer's support

Victim support

When helping older victims, their safety must always be a priority. Intervention should not worsen the situation. However, if the situation is life-threatening, professionals must take action immediately to protect the victim. It is essential to remember that mentally competent older people have the right to make choices that may seem thoughtless or harmful to others. Such decisions do not imply that the older person lacks mental capacity.

An important aspect to consider is cultural sensitivity which is vital to building trust between a victim and a professional; it contributes to communication and acceptance of an intervention. Professionals should be conscious of their beliefs, values, and prejudices to comprehend other people's ways of life. Nevertheless, cultural or religious beliefs can never justify illegal behaviors. Finally, all interventions must focus on the client's needs, even if the abuse is unintentional or the client is an abuser.

Different aspects of the client's situation must be analyzed and addressed. Professionals must respect older people's right to confidentiality. Still, it should not be a barrier to taking action. Confidentiality must be balanced against the possible consequences of inaction and the

potential risks. Professionals cannot use confidentiality to justify failure to respond to abuse. However, sharing relevant information with colleagues can be justifiable to help them better carry out their duties.

If the older person discloses an abusive circumstance or occasion, the professionals should try to gather as much information as possible to obtain an overview of what had happened. They should use the following questions (Perttu & Laurola, 2020):

- 💚 Explore abuse or neglect: what, how, when, how often?
- 💚 Who is/are the perpetrator(s)?
- 💚 Has the older person sought help for the situation? If yes, what happened?
- 💚 Does the older person have someone they trust and can contact if the abusive situation re-occurs?
- 💚 How does the older person see the situation: do they want to change and help? If yes, what kind?
- 💚 What would make them feel safer in the current situation?
- 💚 Do they require a safety plan?

Support for the informal carer

The stress of dedicating time and energy to someone else's well-being can be physically or mentally demanding, and caring can be an isolating experience regardless of age. However, the main contributor to burnout and depression is the feeling of powerlessness. To support informal carers, the people around them must be sensitive and understanding. As taking care of a loved one can be very rewarding, the carer should not forget about his or her own needs. Encouraging carers to take time for themselves and prioritize their health is crucial. Carers often face all the challenges independently and are reluctant to help and claim that everything is under control. At the same time, stress levels increase, and the feeling of helplessness deepens. Therefore, it is essential to encourage them to seek out additional support.

When providing support to a family carer, it is necessary to understand that what an outsider considers help might not actually be helpful. So again, though well-intended, there are limits on the number of precooked meals or pamphlets with relevant information the carer needs. According to Jacobs (2017), "logistical, financial and especially emotional support is vital to bolstering carers who are struggling with extended caring. However, in order to make a genuine difference, these efforts need to be carefully tailored to the particular carer's circumstances, personality and preferences. That requires prospective helpers to inquire sensitively about carers' needs and to respond flexibly to their wants."

1. The critical incident technique (The technique of Flanagan critical events, 1957)

Description: The group facilitator reads a story of elder abuse to participants. Then the facilitator asks participants to break into small groups and decide which role (indirect or direct, involved or not) they would like to play later in the game. The facilitator asks the participants to express their thoughts, opinions, and feelings about the incident that was read to them. The facilitator asks them to express all their thoughts, pointing out that there are no wrong thoughts, and it is safe within the group to express that they feel exactly as they would on their own.

Note: The facilitator should not tell participants that the story is about existing abuse. He/she allows participants to name how they feel about the story presented to them, the behaviors that exist in them, the forms of violence, or perhaps to express some personal experience. At the end of the exercise, the facilitator proceeds to open dialogue among participants stating the whole theoretical framework.

Theoretical framework (speak about):

- What is violence?
- Forms of violence & abuse
- Signs of violence & abuse
- Victims' rights
- Rights & obligations of professionals in disclosure of incidents of violence and abuse
- Ways of treatment & protection
- Multiple risks of elder abuse

2. Gender stereotypes & truths in old age

Description: The exercise is performed in groups (4-5 people). The facilitator gives each group a phrase, a common and stereotypical understanding of gender roles (it is at the disposal of each organization to use examples that are common in the country, e.g., older peoples' abuse mainly affects old women, old men have worked much harder than men today, men of the "old" years had higher values, old women knew how to support their family, abuse did not exist in the past. etc.).

The group has 15 minutes to think about the phrase given to them and make arguments to support this position, even if they disagree. The facilitator encourages the participants to make arguments based on what is prevalent in public and evidence supporting this phrase. The participants then have 5 minutes to express their argument to the large group (all participants) and support their position. Participants are then again divided into groups and given 20 minutes to make arguments that challenge the phrase given to them while at the same time formulating at least one argument as disagreeing with each of the other phrases supported by the other

groups in the big team. After the end of this group work, all participants join the big team again. They have 10' to present their thoughts. In the large group (all participants together), discuss everything that has been said. Participants must support their views and decide their final position and whether their final position has changed with what has been said throughout the group work and discussion.

3. Role-play

Description: The facilitator asks volunteers to take on the roles according to the script (the case will be about neglect-abuse in old age), which the facilitator will read to them. The first volunteer will play the older person's beneficiary, the second the carer, and the rest of the participants will observe the interaction between them. The facilitator informs the actors, reads the script to them, and they play the role they have taken on. After they finish reading the script, ask the observers to express their thoughts, talking about how this beneficiary-carer relationship seemed to them, how they would characterize this relationship and their communication, and what signs of abuse or neglect they observed. The facilitator asks them how they would react if each participant were in the position. Finally, the facilitator asks the protagonists to express how they felt while playing their roles and what their dominant emotions are.

The protagonists also try to answer the following questions:

- How could this relationship be characterized?
- What are the main features of this interaction/communication? Write them down.
- What should the carer do? What actions is the carer taking now, or what actions are the carer not taking?
- What are the challenges or difficulties the carer faces?
- How do these challenges or difficulties affect the exercise of the carer's professional role?
- How could the beneficiary react?
- To which Agency/Organization/Body or other professionals could one turn for help and support?
- How could the relationship between the beneficiary and carer be improved?

The possible scripts for the role play:

First script:

Discussion during the feeding procedure of an older person by their carer:

Older person: I find it difficult to eat this food. My teeth hurt.

Carer: This is what I have prepared for today. Serve yourself.

Older person: It does not matter; I don't like it.

Carer: I am not going to throw away the food. I did not cook in vain. You have to eat it!

Older person: I am not going to eat anything. I told you I cannot chew solid food.

Carer: I don't care. Either you eat it, or you go hungry.

The carer, while the older woman eats the food with extreme difficulty, leaves the medicine bottles abruptly on the table without paying attention to whether the older woman took the proper dosages or not. She continues to do various other chores around the house.

Carer: I'm tired of you! You keep complaining about everything! As soon as I find something else, I will leave! You are incapable of doing anything by yourself! Let's see what you'll do without me!

The frightened older woman responds to her carer's muttering by eating her food silently. She feels very sad but doesn't comment on anything. Under the constant threat of abandonment, the older woman keeps justifying the carer.

Older person: I am sorry, my child. It is my fault! I am old enough, and sometimes I act like I don't respect your efforts. Please, don't leave me.

Second script:

Mrs. Maria is 73 years old. One month ago, while cleaning the garden, she fell and hit her hip. Since then, she has had to hire a woman to take care of her and help her as she can't even get out of bed alone. The carer often speaks abruptly or neglects Mrs. Maria.

The old woman is sitting on her chair watching TV while the caretaker is busy with her cell phone.

Older person: I want some water.

Carer: You have next to you. Drink.

Older person: I cannot reach the glass.

Carer: Try. It's close enough. Don't expect me to provide you with everything in hand.

The old woman tries to reach the glass from the table near her. The table falls, and the things on it fall onto the floor.

Carer: You are completely useless! You can do nothing alone. I can't pick up your shit all the time.

Older person: Sorry, sorry.

Carer: Don't talk anymore. I can't give you everything. I am here to help you do things; I'm not your servant!

Older person: Please, I'm thirsty. Can you bring me some water?

Carer: I don't even want to hear your voice! You'll have to wait until I clean up.

The old woman is thirsty but remains silent and continues to apologize to the carer.

Third script:

Mrs. Mania is 66 years old. She has been showing signs of dementia for some years. She is pretty independent and does things on her own, but often has difficulty and needs help. Because of this, her children hired a carer to visit her a few times during the day to check if she needed anything and that everything was okay. However, the carer often doesn't go, providing her children with false information and telling them everything is fine, even if he has not even visited Mrs. Mania's house. He often tries to convince Mrs. Mania that he has already visited her, and she just doesn't remember well.

Older person: Can you check if I took my medicine at noon? I do not remember if I got them. I was waiting for you at noon, but you didn't come. Did something happen to you?

Carer (without even checking the medicine box): Mrs. Mania, you took your medicine at noon. I gave them to you after we finished eating.

Older person: Did you give them to me? But you were not here at noon.

Carer: Mrs. Mania, you probably don't remember it at the moment. At noon we sat together for a long time.

Older person: I don't remember anything like that.

Carer: It doesn't matter, Mrs. Mania. Don't worry. Sometimes this happens. That's why I'm reminding you. Don't worry.

Older person: Please don't tell my children. They will be very worried about me, and I don't want to upset them even more.

Carer: Don't worry. I will not tell them anything this time, but I may need to let them know in the future.

Older person: Thank God I have you in my life.

The carer often receives small amounts of money from Mrs. Mania. He informs her children, telling them that children from the neighborhood, knowing the situation of Mrs. Mania, visit her and ask her for money. He even convinces them that her condition is worsening, making it necessary to visit her more often to protect her from similar behaviors. Due to the increased frequency of visits, he also requests an increase in his salary. The children fully trust the carer because he has good recommendations from previous families that he has worked with and agrees to whatever he suggests. Additionally, the ostensibly great bond he created with their mother significantly influenced them to accept whatever he asked for.

4. Recognize abuse in the beneficiary-carer relationship & create a security plan

Description: The facilitator reads to the participants a case study concerning the abuse of an older person by a carer (It is good to use several case studies that report different forms of violence against the beneficiaries, e.g., physical, psychological, financial, neglect, or excessive care). The facilitator asks the participants to report all the signs of abuse as well as forms of abuse. The facilitator then asks the participants to formulate the personal safety plan for the beneficiary, considering their role as carers. More specifically, the facilitator asks the participants, for each sign of abuse and violence, to suggest the ways of treatment and the actions that must be taken to ensure the protection and safety of the victim.

Questions to be answered:

- What kind of violence is used?
- Who is the victim, and who is the perpetrator?
- What causes violence to the victim?
- How does the victim react to the violence?
- How does the perpetrator react to the violence? Does the perpetrator recognize the violence as it is? Does the perpetrator name the violence as it is? Is the violence indirect or unintentional?
- How does the violence affect everyone involved?
- Is there anyone who can ask for help?
- What are the actions taken to protect against violence when violence is exercised?
- How can violence be prevented in the future?

The cases studies are as follows:

Dimitra's Case

Mrs. Dimitra is an 81-year-old woman who is left alone after the death of her husband, and she takes care of herself. She has good physical and mental health. Her children stay away because they work in different cities. They visit her as often as they can. She is active and has several hobbies to fill her time happily and constructively. She has been joining the Open Day Care Centre of the municipality for many years. She loves spending her mornings there, doing activities with other seniors and the center staff. Recently, a new social worker who is stricter and distant from the beneficiaries has come to the center. He speaks rudely to them, treats them impatiently, and insults them several times. One day, while the social worker was talking abruptly to a friend of Mrs. Dimitra's, Mrs. Dimitra reacted and told him that his behavior was unpleasant and that she would make sure to talk to the mayor. The social worker replied that he didn't care, even if Dimitra would talk to someone superior. During all this time, the rest of the daycare center staff observed the social worker's behavior but did nothing. Mrs. Dimitra looked for the mayor for several days, but as many times as she tried to talk to her, she could not contact her.

Helmi's Case

Helmi is 68 years old and lives in a small town, in her house with a lovely flower garden. Her husband passed away a few years ago. They had a happy marriage and two children. Both have their own families and live 200 km away in the capital. They try to visit their mother as often as possible, but with the long distance and full-time jobs and kids, it's mostly on birthdays and holidays. Helmi seems a little forgetful; she misplaces her things (glasses, phone, and books). After a few times when the children could not reach her by phone, they hired a caretaker to check upon Helmi once a week. They met and hired Taivo, 42, through the local nursing home. Taivo was responsible for visiting Helmi once a week, bringing her groceries and other necessities.

A few weeks pass, and the otherwise always cheerful Helmi seems unhappy and distracted on the phone when talking with her children.The daughter, who occasionally visits Helmi, notices that she is not as talkative, seems tired, and her flowerbeds, usually her pride and joy, are unattended. She tries to talk to Helmi, but she claims that she is just tired. When asked about Taivo's assistance, she avoided eye contact and changed the subject. A few weeks later, Helmi's daughter was very concerned because she had not answered her calls for two days. Then she goes to Helmi's house. Nobody answers the door, but it is unlocked, so she steps in. She calls out for her, and though no one answers, she realizes that somebody is in the kitchen. Helmi sits by the kitchen table, and an empty bottle of vodka is beside her -- she is drunk. She is utterly surprised because she knows Helmi does not drink alcohol, perhaps only a little champagne at celebrations. The daughter helps Helmi to her bedroom and notices that the bed linen is a mess, and traces of blood are also visible. Helmi sobers up and starts crying and apologizing for the mess. The daughter tries to calm her down, makes some coffee, and asks Helmi to explain what happened. Helmi is very reluctant to say anything but finally admits that the caretaker, Taivo, has been abusive towards her. It started with accidental touches. Then he insisted that he had to help her to shower, though she was very capable of doing it herself. And then, finally, last night, he forced himself on her.

Anna's Case

Mrs. Anna is 67 years old and lives alone in a house in the village. She has two children who work and have their own families. They work long hours and have minimal time to visit their mother. They talk pretty often on the phone. For the last three years, she has started to forget things more and more often. Two months ago, she had forgotten to turn on the kitchen light and almost set the house on fire. Fortunately, a relative of Mrs. Anna was passing by the house and saw her sitting in the garden and smoke coming from the kitchen. The relative informed her children, and they decided to hire someone to take care of their mother. So, they decided to hire a cousin from the village to take care of her. Mrs. Anna also knew her cousin well and agreed with this decision. This woman did not know about caring for the older person. She often spoke abruptly to Mrs. Anna, shouted at her when she had said something to her many times, and she forgot or got confused and left Mrs. Anna to take her medication on her own,

sometimes taking it more than once. The children visited her doctor with their mother, who informed them that the mother's examinations were not good and the reason needed to be investigated.

Lena's Case

Mrs. Lena is 72 years old. Since the death of her husband, she has been left alone for the last four years. Mrs. Lena is wealthy. She has no children, and her closest relatives live far away. In the last year, she has found it very difficult to take care of herself, and for this, through an advertisement she published, she hired a woman to take care of her with the housework and her daily shopping and to help her go for walks or walks. For the first four months, their relationship was perfect -- she even began to care for the carer as her daughter.

Ms. Lena has recently noticed an inexplicable increase in money markets. Dimitra, the woman who takes care of her, told her that all the products had increased in price and were more expensive. In addition, Dimitra, who stays at Mrs. Lena's house some nights, often invites her friends to the house and has a party. At first, Mrs. Lena felt good that the house was alive. However, then she started to get very tired and asked Dimitra not to bring friends home so often. Dimitra did not listen to what Mrs. Lena asked her and continued to invite people to her house. At the same time, Mrs. Lena's money was constantly decreasing. Also, Dimitra started to answer with agitation whenever Mrs. Lena asked her something or told her to do something different from what she wanted. In addition, Dimitra often tells Mrs. Lena that she is an old woman, alone, and that she is the only thing she has, and for that reason, she should let her do what she wants because otherwise, she will leave her to die alone and no one will cry for her. Other times she threatens her, telling her that if he chases her, she will hurt her or throw drugs at her, and she will not even be able to move. Mrs. Lena is very disappointed and does not know what to do.

5. Outline of the basic rules of work

Description: The facilitator encourages them to think and create the "ideal carer." The facilitator asks team members to describe and record the behavioral patterns, basic working principles, service rules, difficulties, and challenges they face at work. Through this exercise, it will be possible to explore the norms and stereotypes inherent in carers of older people, to examine "critically" the perceptions of the responsibilities and obligations of carers, and the difficulty in forming and developing a relationship of trust between carers and beneficiaries of care. They will also be able to explore and focus on appropriate ways and methods of caring for and protecting older people by avoiding behaviors and practices that involve methods that adversely affect forming a healthy relationship and lead to abusive behaviors.

6. Projective techniques: Perception of oneself as an informal carer (Variation of Machover's 'Draw a person' projection test)

Description: The facilitator helps participants discover their role and how to play it, asking them to perceive themselves as a carer. Then ask them to answer some questions in writing or orally:

- 💜 Where is the carer?
- 💜 What are the responsibilities of the carer? What is she/he doing?
- 💜 What should the carer and should not do?
- 💜 How does the carer feel?
- 💜 What is the environment like?
- 💜 Who else is with the carer?
- 💜 How does the carer feel about others?
- 💜 How does she/he experience her/his contact with others, and how would she/he like to experience it ideally?

The facilitator asks the participants if there is anything else they would like to mention.

7. Statements of practices & values

Description: The facilitator reads the following suggestions to the participants and asks them to agree or disagree with them (using the Likert scale). Once the facilitator has finished reading the sentences, he/she discusses the answers with the whole group.

	Statements	True	False	Depends on the case
1	Unconscious abuse is abuse.			
2	Abuse in a relationship can start at an older age.			
3	Women and men can be abused at an older age, especially if they have a disability or depend on others.			
4	Abusing older people is a crime.			

5	Psychological / emotional abuse is not as important as physical abuse.			
6	Older people's abuse and neglect are rare.			
7	Aggressive behavior of an older person with dementia or other disorders towards the social carer is an abuse of the carer.			
8	Older people's abuse is always associated with substance use or mental disorders.			
9	Older women are more vulnerable to abuse than older men.			
10	Abuse can cause premature mortality in older victims.			
11	There are cases where the restriction of an older person's freedom and / or rights is necessary and cannot be considered abuse.			
12	When the older person does not say something is bothering them, it means they do not feel any discomfort, and certainly, this is not abusive behavior.			
13	Teasing or frequently referring to an older person's weaknesses or difficulties is a joke and creates an intimate relationship between a carer and an older person.			
14	It is easy for an older person to express their feelings and acknowledge that they are being abused.			

15	Many times the abuse older carers receive is greater than the abuse they inflict.				
16	It is normal for carers to react more aggressively at some point when they have older people constantly responding negatively and misbehaving.				
17	A carer may be better aware of an older person's needs, so sometimes, it is necessary to impose.				
18	By hiding things or restricting direct access to the goods of the older person, it is possible to protect them from potential dangers.				

Chapter 3: Lessons learned from "Listen to my story."

Theoretical portion

At this point, it is essential to note that a narrative-based workshop for informal carers was coordinated by the Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas) in close cooperation with the partners of the 'S.IN.CA.L.A. II – Supporting Informal Carers: A Whole-Family & Lifecourse Approach project. Three dedicated programs of workshops were developed: one for spouses, one for adult children, and one for grandchildren/young carers. Each workshop considered the targeted group's issues regarding age and kinship with the person they care for. Each of the three workshops was based on 3 to 5 sessions of approximately 90 minutes each and tested with carers. The "Listen to my story" workshop was piloted between September and November 2021 in Estonia, Greece, Italy, Portugal, and Slovenia. Overall, we involved 68 participants: 22 spouses, 32 children, eight grandchildren, and six other carers of people with chronic diseases. The participants received and grasped the narrative-based approach in all countries very well. The approach was conducted only online at some piloting places (due to covid-19 pandemic and restrictions). Both modalities (i.e., online and face-to-face) have pros and cons. While online modality is an effective solution for overcoming the issues related to the COVID-19 pandemic, time management, and decentralization of the intervention, face-to-face modality enables greater involvement and participation. The children's group was the most approachable and confident to participate in the session.

In contrast, the spouses and grandchildren groups required more time to accept the approach and to open themselves about their feelings and experiences. In Italy, gender differences were recognized; the children's group was composed only of female participants. In the spouses' group, males and females were equally represented.

3.1 Examples of issues raised in workshops and potential solutions

In most countries, the participants were initially reluctant to share their views and feelings. Consequently, they needed to be motivated and guided. The latter was achieved through the trainers sharing their views and insights with others which later motivated participants to do the same. The main factors recognized by trainers that had contributed to initial solid people's motivation for participation were an aspect of "peer experience" and the people's ability for empathy.

In general, commonly addressed topics in all countries were: feelings of guilt, anger and loneliness, lack of support and the need to ask for help, the need to share feelings with others, the impact of caretaking on the caretaker's identity, and the overcoming of health

problems/difficulties associated with dementia. The main topics discussed with children were the obligation to care for a person, neglect of a person towards them (also verbal mistreatment), denial, incontinence of a caretaker, behavioral outbursts when taking care of hygiene, difficulties managing work and care obligations, financial struggles, concerns about health deterioration of the caretaker, feeling guilt, and low self-image. Spouses discussed love that changed, changes in the relationship, poor quality of sleep due to caring tasks, fear of the future and the progression of the disease of the caretaker, institutionalized care, and personal struggles concerning the caretaker's wishes to stay at home, and agreement with other family members about the decisions. Grandchildren were also discussing social life, not being confident to solve situations with the caretaker, behavioral changes, and changes in the relationship with a person.

The stimuli used in the groups were: Poem to Friends (Borges), You Learn (Borges), The Little Prince (De Saint-Exupéry), Old Man and the Sea (Hemingway), Moby Dick (Melville) – Chapter 82 / The Symphony (Tone Pavček), Simple Words (Ivana Malkoč), Shadow (Božo Rustija), Stories for Conversation: Monster in the Field (Tone Pavček), Being in the Moment and Greek Mythology, Theseus Story (The Death of Aegeus). 71% of the participants were satisfied with the selected literature and said it appealed to them. However, as mentioned in the sections above, some (29%) stated it was adequate.

The raised topics were:

- Difficulties developing real friendships and perceiving friendship as something different from the one described in the stimulus poem (considered unrealistic). Some people referred to having lost friends because of the caring role but having found new ones (for example, in peer-support groups for carers).
- Challenges of getting older, coming to terms with one's life, and failing to reach some of one's goals. Participants also reflected on their older care recipients and how they might still have goals and ambitions for their life, despite their age. The text also reflected on the idea of struggles and how sometimes the struggles in life shape our identities.
- The importance of others, as mirrors and listeners – how much we need other human beings in our life. The fact that often we dedicate our lives to something, but maybe then we realize that this was not what we wanted to do. For example, some people were forced by circumstances to become a carer and have to give up other aims to assume this role.
- The risk of isolation experienced by carers is related to the fear of judgment from other people who are not in the same situation and can have difficulties understanding their feelings. At the same time, they underlined the importance of closeness, to have someone with whom they feel free to share their emotions and thoughts. All participants agreed they found difficulties sharing their suffering; they are not used to it.

- 💜 The difficulty in accepting the disease of their loved ones and the changes that this entails. This aspect deals with the sense of helplessness they experienced during their caring activity. A carer said: "it's very hard to see the person you love plummet."
- 💜 Forgiveness, mainly, how hard it seems to forgive themselves. Carers tend to be critical of themselves, focusing on what they did not manage and neglecting all the daily tasks they perform. This topic led to a conversation about anger and granting themselves the right to be angry without feeling guilty.

3.2 How specifically to deal with potential instances of violence/carer burnout identified and cultural differences

As mentioned above, informal carers usually deal with the consequences of the caring situation, leading to elder abuse and carer burnout. It is worth mentioning that there are various ways to deal with potential instances of such cases when working with informal carers. The training of informal carers should be a high priority for professionals working with them. Educational background demonstrates the knowledge about the care provided by informal carers. It contributes toward understanding the disease and learning better ways of dealing with the process and its consequences on informal carers' quality of life (Souza Alves et al., 2019).

Considering the crucial role of coping strategies in caregiving stress regulation and subsequent burden, dealing with these instances should include training on several coping methods (Gérain & Zech, 2019). In general, using a more comprehensive range of coping strategies appears to lead to a less subjective burden, and carers with such strategies as confident and optimistic approaches or positive reappraisal and active coping appear less prone to carer burnout. Furthermore, professionals should identify the psychological processes involved in informal carer burnout to identify those with the most significant impact and those most promising for interventions. While some psychological factors are more related to trait elements (e.g., personality) that would be hard to modify, others could be targeted by interventions to help exhausted carers or prevent future problems. Therefore, professionals should deal with informal carers' cognitions, dysfunctional thoughts, and perceived competence, which play an important role in the caregiving experience and are predictors of burden and burnout (Gérain & Zech, 2019).
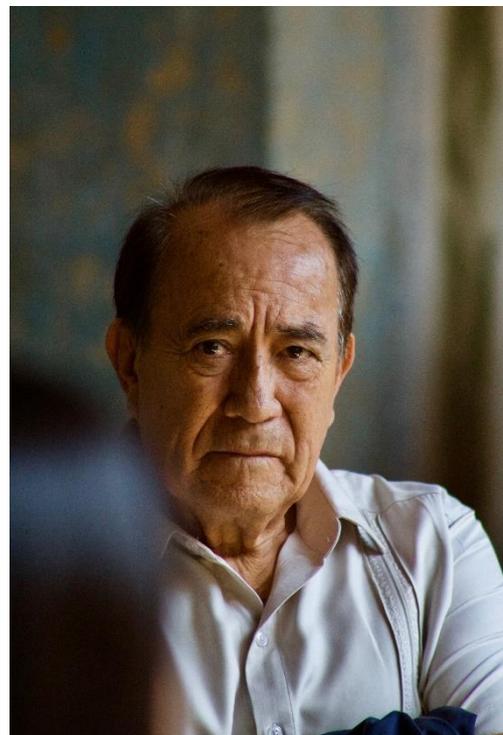
Professionals should also focus on developing a deeper understanding of how relationship quality affects carer burnout and the relationship between appraisal and relationship quality. If positive relationships could alleviate part of the subjective burden, other elements such as perceived fairness, unfairness, or role modifications could also impact the carer's appraisal (Souza Alves et al., 2019). So, given the close interrelationship between carer burden and elder abuse, it seems reasonable that professionals make more efforts to relieve the carer burden and adopt early interventions to deal with their emotional problems (Tan et al., 2018). For this reason, improvement of symptom management and psychological well-being in care recipients can positively ease informal carer burden and emotional distress. Moreover, family-based or partner-centered interventions with specific symptom management components and emotional support could be an option offered to both patients and their carers. As it seems, all these strategies can be implemented effectively in different cultural contexts.

Practical elements

The facilitator uses case studies (audio and not in writing given the difficulties in old age), audio-visual material & movies (e.g., diary - the notebook, rain man, love from the beginning) to discuss specific topics of the chapter.

The facilitator exercises lifeline with emphasis on points that have been more emotionally painful for the participants

Description:

A) Participants are asked to write on paper two parallel lines in which they will mark important points in their lives and events that have been etched in their memory and have played an important role in their lives. At the top line, they will note the events in chronological order, while at the second, they will note the events, starting with those that were most important for their course (regardless of chronology).

B) Ask the participants to think and record all the thoughts that come to them by doing this flashback. Which emotions are the ones that dominate? What emotions do they feel still exist in their lives, and what are they sick of? For example, what emotions do they feel to a lesser degree now? Why do they feel like that today? What important life events or situations contributed to this change in their emotions/feelings? How has this change affected their lives and careers or their professional experience?

Chapter 4: European context

4.1 Population aging in the EU, implications on societies

The aging process presents new requirements, challenges, and changes in everyday life for individuals. Experts cite various aging theories, including biological, sociological, and psychological (Jylhävä J et al., 2017; Wurm et al., 2010). The percentage of older adults in more developed countries is continuously increasing, so the aging process will be more intense in the future. In order to understand the aging process, we need to consider it in terms of the aging of human cells, which in turn brings about physical and cognitive changes and life adjustments in the individual.

Demographic changes in the EU

The population of the EU-27 is aging: indeed, on 1 January 2019, it was estimated at 446.8 million, of which young people (0 to 14 years old) made up 15.2 %, while persons considered to be of working age (15 to 64 years old) accounted for 64.6 % of the population. Older persons (aged 65 or over) had a 20.3 % share, representing an increase of 0.3% compared with the previous year and 2.9% compared with ten years earlier. In this context, regarding the share of persons aged 65 or older in the total population, Italy (22.8 %), Greece (22.0 %), Portugal, and Finland (both 21.8 %) had the highest shares. In contrast, Ireland (14.1 %) and Luxembourg (14.4 %) had the lowest shares.

Another demographic aspect being considered is dependency. The old-age dependency ratio is used to study the level of support given to older adults by the working-age population; this ratio is expressed in terms of the relative size of older populations compared with the working-age population. For the EU-27, it was 31.4% on 1 January 2019. As such, there were just over three working-age persons for every person aged 65 or over, versus a world average of 14%.

The growth in the relative share of older people may be explained by increased longevity, a pattern that has been apparent for several decades as life expectancy has risen. On the other hand, consistently low fertility levels over many years have contributed to population aging, with fewer births leading to a decline in the proportion of young people in the total population. According to Eurostat projections for 2100, the EU-27 population is projected to continue aging. In the coming decades, the number of older people will increase significantly.

Another aspect of population aging is the progressive aging of the older population itself, as the relative significance of the very old is growing faster than any other age segment of the EU-27 population. The share of those aged at least 80 years in the EU-27 population is projected to have a two a half fold increase between 2019 and 2100, from 5.8 % to 14.6 %. (Eurostat, 2021).

Implications of demographic changes

Demographic change in Europe involves not only radical shifts in the age composition of European populations, characterized by population and labor force aging and a shrinking working-age population, but also impacts on intergenerational relationships. Families are becoming smaller (with fewer siblings), increasingly de-institutionalized (non-marital unions), and non-co-resident, with new kinship networks. In addition, family dissolution and reconstitution patterns make families and kinship increasingly complex, diversified, and fluid.

Studies on intergenerational relationships and family well-being, performed in the context of population aging, show that vertically extended families with more than three generations are not frequent yet; however, the expected 'double aging' in the near future might change the picture. Moreover, studies clearly show that the aging process cannot be reduced to shifts in the age composition. Such age shifts impose changes in family and social structures that influence individuals' economic and subjective well-being, for example, when balancing work obligations and care responsibilities. This could lead to a greater supply of care provided by those at work and a greater labor supply of people who would otherwise have to give up work to be carers (European Union, 2014).

Particular challenges stem from the rapid increase in the share of the oldest-old. This group is likely to require more care and to be at a higher risk of social exclusion than the younger old. In most European countries, we can observe a shift in care provision from the institutional setting to home care services, with institutional care being postponed to a later age (CEB, 2014) and demand for informal care projected to increase. Population aging in Europe impacts the demand for informal care and the supply, with the proportion of informal carers increasing with age. While the prevalence of informal caring within Europe's adult population is 17.0%, in the over 50's age group, the same rate ranges between 13.5 and 25.6%. (Tur-Sinai et al., 2020).

According to research, there is a projected increase in care by spouses or partners, primarily due to projected reductions in male mortality rates and a likely fall in the number of widows. Care for older people from their adult children may be affected by the future availability, ability, or willingness of children to provide care. This can be affected by demographic and socio-economic factors such as the projected decline in people with no surviving children, the decline in co-residence of older people with their children, and the continuing rise in labor market participation by mid-life women. The 'care gap' (availability vs. demand for informal carers) is projected to grow because of underlying demographic trends. The number of older people, especially the oldest old, is rising faster than the number of the younger generation (Pickard, 2015).

4.2 European policies to respond to population aging

The European Union has been tackling the issue of demographic aging through various policies, mainly focusing on the impact of aging on the labor market and health and long-term care. Particularly relevant for the scope of this report are:

The EU Work-life Balance Directive entered into force in August 2019. The Directive introduces a set of legislative actions designed to modernize the existing EU legal and policy frameworks, with the aim – among others - of better supporting a work-life balance for carers, introducing the entitlement for workers providing personal care or support to a relative of five days of leave per year and extending the right to request flexible working arrangements.

The approval of the European Pillar of Social Rights in 2017 sets out 20 fundamental principles representing the beacon of a strong social Europe. Among those, it is relevant to mention Chapter III, which includes principles referring to the following: the right of old age income, the right to timely access to affordable, preventive and curative health care of good quality, the right to inclusion for people with disabilities and the right to affordable long-term care services of good quality, in particular homecare and community-based services.

The launch of a new Green Paper on the challenges and opportunities of Europe's aging society started in January 2021 and aims to take a life-cycle approach, reflecting the universal impact of aging on all generations and stages in life. In doing so, it highlights the importance of striking the right balance between sustainable solutions for our welfare systems and strengthening intergenerational solidarity.

4.3 Best practices, networks, psychosocial interventions & other useful tools

Psychosocial interventions to support carers of older persons

Psychosocial interventions emphasize psychological or social factors rather than biological ones. Therefore, they can include psychological therapies, health education, and interventions focusing on social aspects, such as social support and networking. Although not always evidence-based, psychosocial interventions are widely used to support carers of older persons. In this chapter, we will present some of the most common.

Psychoeducation

The term psychoeducation encompasses a range of interventions, usually carried out in a group setting, that combine educational activities with other supportive actions to help patients and their families better understand and cope with the consequences of a disease. Though this tool originated in the psychiatric field, particularly in schizophrenic patients, this tool is now used for various illnesses, including psychiatric disease, dementia, cancer, etc.

The models used vary significantly in duration, content, and techniques. According to Bhattacharjee et al. (2011), they can be classified into informational, skills-based, supportive, and blended. The first model focuses on informing patients and family members about the disease and its management. This model is close to that of therapeutic education. The skills-based model aims at getting users to develop specific behaviors that enable them to cope better with the consequences of the disease. The third model is based on support groups that share emotions and experiences. The purpose of this model is primarily to support participants so that they acquire tools to better cope with the condition experienced from an emotional point of view. This is a model akin to that of mutual-help groups. Finally, the blended model combines elements of all three previous models.

Therapeutic education

The purpose of therapeutic education, as defined by the WHO (1998), is "to help patients and families understand disease and treatment, cooperate with health care providers, live healthy lives, and improve or maintain quality of life." It is a recommended pathway for a long list of chronic conditions from cancer to mental disorders, diabetes, musculoskeletal conditions such as rheumatoid arthritis, etc.

Therapeutic education differs substantially from psychoeducation because it is more oriented to informing and training the patient and/or his carer concerning how to manage the disease from a health point of view in the context of home (use of drugs, the performance of care practices, etc.). However, it is still kept in mind that the patient must handle the disease in the context of the home, and the psychological and emotional aspects are also considered.

According to Lagger et al. (2008), the focus of this model is an accurate transfer of skills from the health care professional to the patient. It should be emphasized that the trainers in the case of therapeutic education are mostly health professionals. However, the same authors point out that these professionals often lack the pedagogical skills to structure an appropriate training intervention.

The need for the carer for this type of intervention is related to the concern and anxiety concerning the patient's well-being and the lack of the skills necessary to provide the appropriate care (Robinson et al., 1998). In fact, not having the necessary skills to provide care for one's family member properly has consequences for both the patient's and the carer's health.

Mutual aid groups

Born in the 1930s in the United States with the experience of Alcoholics Anonymous, Mutual Aid Groups (MAGs) are groups of people who come together to secure mutual support to overcome a common problem. Today, there are MAGs dedicated to various issues: disability, addiction, chronic illness, and family care. The intervention is based on the idea that mutual help begins with self-help, the moment the person recognizes the existence of a problem and takes action to seek some form of support. Mutual aid occurs when there is an experience of

sharing between those who help and those who are helped with respect to facts, experiences, and emotions of a common problem.

The benefit brought by self-help groups to their participants is primarily emotional. Sharing experiences with one's peers facilitates coping. It decreases negative emotions, helps to realize that one is not alone in a given situation, and therefore reduces the perception of stigma, makes one feel understood, helps to create social ties, and also allows one to identify positive role models to aspire to (Reay-Young, 2001).

Variation of the life course shape:

Description: The facilitator asks participants to form a life course, which will include all the important events, experiences, and memories regarding issues related to aging and how to approach them (practices, policies, care services, etc.) and about which the participants are aware. The facilitator is aware of important turning points and historical changes that she/he will add to this work. Then the facilitator discusses these changes with the participants and how they have been incorporated and used in their lives (e.g., if or how they have used them in case of a law or a service provided).

Objectives learnings/goals:

- Recognition of forms of gender-based violence in old age
- Recognition of involuntary violence that may occur in old age
- Signs & recognition of violence in old age
- Increasing the knowledge and awareness of carers about gender-based violence in old age regarding its causes and effects
- Recognition of the role of the individual as a carer
- Identify the challenges & difficulties in providing care for older people (carer & carer recipients)
- Enhance the carer's ability to enter into a healthy relationship between carer & care recipient

Chapter 5: National context – all partners

5.1 Policies & legislation

5.2 Informal carers support framework

5.3 Violence in informal caregiving relationships

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