RESIL4CARE

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RESIL4CARE PR1: A1 - Methodology framework and preparatory analysis

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EXECUTIVE SUMMARY

RESIL4CARE partnership uses a methodology based on an empirical investigation of the coping skills that lead to resilience attitude by considering real-life context. This method will facilitate the production of the training materials that reflect existing problems.

To achieve this target, first comes the analysis of the main issues (barriers, facilitators, determinants) that literature review will define as the main relevant ones to promote the positive attitudes and the right mind-set adoption on behalf of the informal carers that will support them in tackling everyday care life. Furthermore, this literature review will contribute to the analysis of the factors that shape the ecology of informal care, in terms of certain requirements that affect these determinants and that are relevant for the pedagogical contents training preparation: The potential for creating a qualification framework, that will allow informal carers to develop coping strategies and methods for alleviating their overload. Such a framework is even more needed since most informal carers do not dispose of any prior or relevant training or qualification, while at the same time the prioritization of home care and avoidance of hospitalization for long term care patients, obliges them to assume more responsibilities.

The impact will be to RESIL4CARE to empower informal caregivers in their tasks, and to lessen them from possible overloading situations by offering them various kind of information and psychological support through the use of social media platforms.

CHAPTER 1 - METHODOLOGICAL PLAN

RESIL4CARE partnership intends to use a methodology based on an empirical investigation of the skills that lead to resilience attitude by considering real-life context. This method will facilitate the production of the training materials that reflect existing problems. To detect the real needs of the project's direct target group which is informal caregivers, the partners will follow a plan that contains three consecutive steps.

Firstly, a preparatory analysis will be completed, analyzing the determinants that partners will define as the main relevant ones to promote the positive attitudes and the right mind-set adoption for informal carers that will support them in tackling everyday care life. This could improve the emotional and behavioral resilience, given time pressure, and the environmental and relationship stressors related to the caregiving process and its psycho-social context.

As a second step comes an extensive review of the relevant literature in order for the final conclusions to be supported by the scientific research.

As a third step, a qualitative and quantitative survey is planned to reflect the approach and attitudes of the informal caregivers themselves, as they experience the use of social media inside their socio-cultural context and living environment. Such a survey aims to identify what are the key elements, and to analyze the factors that shape the ecology of informal care, in terms of understanding the real determinants that allow the improvement of psychological resilience in informal carers. Knowing the determinants will help the consortium to shape the right training material to support positive attitudes of caregivers and enable the development of their skills to engage in meaningful interpersonal relationships and to share personal experiences in an inclusive empathic climate both in presential and in technology-mediated communications.

CHAPTER 2 - PREPARATORY ANALYSIS

2.1 INFORMAL CARE OVERLOAD – CAREGIVER BURDEN

Demographic ageing, lack of adequate number of formal caregivers, and an underfunded and fragmented health and social support system, have all contributed to placing the major burden of care on family members. A major part of informal care provision is directed towards the care of people in third age, so EU policies through active ageing and ageing in place, aim to empower older people to stay at home longer, instead of moving into nursing homes. In order to make this feasible, older people will have to rely on their direct network of family and friends to ensure informal care. Nevertheless, informal caregiving is the spinal cord for assisting in all disability types or chronic disease situations, of all ages, requiring serious commitment from people that they have their own personal and professional life and their own needs and aspirations. Family caregivers are relatives, friends, partners, or neighbors who provide assistance, typically unpaid, to someone who has limitations in their physical, mental, or cognitive functioning. Caregivers represent a broad and diverse group of individuals. They span all ages and are heterogeneous across multiple dimensions, including their relationship and geographical proximity to the person for whom they provide care and the nature, or duration.[1]

Informal care consists of any assistance to a person in need of care from someone in his or her direct environment. Examples of informal care activities are emotional support, administrative help, guidance in arranging appointments, transport, domestic and personal

care. It should be stressed that informal care is unpaid, results from social rather than professional relations, and entails long-term care for sick family members or friends.[2]

Family caregivers may experience considerable stress and subsequent health problems, isolation, fatigue, and frustration, sometimes leading to a sense of helplessness and exhaustion (caregiver burnout). The family members, or in general the informal caregivers taking on this responsibility, must adapt to new situations perceived as potentially overwhelming and a threat to their well-being and quality of life, which can be viewed as a chronic stress exposure paradigm. For many individuals, being exposed to and supporting a family member with disabling chronic illness is a major stressor. It is persistent, extending over months and often years. [3,4]

In most cases, the impact on the caregiver is likely to be greater when the care recipient has a greater burden of disease and disability and more care is required. The experience of providing care over a prolonged period can be a source of chronic stress and affect not only their caregivers' daily lives and health, but also the society as a whole. [5]

Caregiving can be very rewarding, in terms of positive effects of caregiving such as increased self-esteem, the satisfaction of knowing that one's relative is being properly cared for, as well as improved mental or physical health reported [6]. Nevertheless, it contains several negative aspects, all contributing to what it is called caregiver's overload or burden.

Caregiver overload can be defined as a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual' with little opportunity for adaption, and it has the capacity to generate secondary stressors in multiple life domains. [7,8] Furthermore, it can be described as "the extent to which caregivers perceive the adverse effect that caregiving has on their emotional, social, financial, and physical functioning."[9].The concept of caregiver overload is presented in literature as a complex construct resulting from the interaction between patient risk factors (e.g., level of impairment, social support) and caregiver risk factors (e.g., poor health, length of time caregiving) [10].

It has been shown that overstrained caregivers use more healthcare services and prescribed medication than non-caregivers, indicating a decline in physical health [11]. Moreover, stressed caregivers report more feelings of depression, perceived lack of coping mechanisms, and concerns about their poor quality of life [12].

Burden is most apparent in caregivers' reporting of anxiety and depression. Depending on the caregiving profile (eg, sex, age), caregivers' prevalence of anxiety and depression can exceed general population norms, and in some cases, those reported by care recipients. Burden also has a negative impact on caregivers' physical health (eg, fatigue, pain), particularly as caregivers are often older themselves and confront the demands of their own illnesses [13].

Furthermore, authors have distinguished between objective burden regarding the physical aspects of caregiving, and subjective burden which is about the psychological consequences of being a caregiver [14]. Caregiver burden has been described as both objective-observable and subjective-perceived. Objective burden is an observable, concrete, and tangible cost to the caregiver for taking care of the recipient. Within this framework, objective stressors include measures of patient disability, cognitive impairment, and problem behaviors, as well as the type and intensity of caregiving provided.

Subjective burden refers to the perceived costs, such as the extent to which the caregiver is bothered by performing these tasks and the positive or negative feelings experienced while giving care. The association between objective and subjective burdens is complex. Findings show that although there are many tasks required in the taking care of the care recipient, the

caregiver accepts these tasks. The problem occurs with the uncooperative nature of the care recipient in allowing the caregiver to carry out the tasks. The caregiver-care recipient conflict involving excessive demands and embarrassment, is very possible to result in increased subjective burden [15].

Because of its individual perception base, the subjective burden is a state characterized by fatigue, stress, perceived limited social contact and role adjustment, and perceived altered self-esteem. This state can threaten the physical, psychological, emotional and functional health of caregivers. Subjective burden has been related to anxiety, depression, and negative effects on physical health.

For example, the degree of severity of behavioral issues displayed by a person with dementia is a key predictor of both subjective and objective burden whereas higher caregiver education is associated with higher subjective burden, but fewer caregiver hours, a measure of objective burden [16].

The caregiver's perception of the burden, rather than the perception of other family members or healthcare providers, determines the impact on his or her life. The level of perceived burden has been correlated with higher risks of depression and lower quality of life for caregivers [17].

2.2 STRESSORS – DETERMINANTS - FACTORS

In relation to the nature of objective and subjective burden, the burden or overload that may affect caregivers is motivated by the presence of certain factors – stressors divided into primary and secondary stressors that characterize the caregiving procedure. Primary stressors are all the demands and potential resources (consequences of the deterioration of the patient and the care they require) defining the caregiving role. They are mostly referred to in the literature as "objective burden". Secondary stressors are all the demands and resources caused by the primary stressors [18], causing symptoms related to changes in health, work, economy, and free time that translate into difficulties for physical, psychosocial, and family functioning [19].

In a similar approach by Pearlin [20], primary caregiving stressors refer to stress-arousing demands that are directly rooted in the caregiving situation (e.g., behavior problems of the care recipient). Secondary stressors, in contrast, are defined as stressful experiences that are triggered by primary caregiving stressors (e.g., restrictions in carrying out one's personal and recreational activities). Pearlin's traditional caregiving stress-outcome model hypothesizes that primary stressors trigger secondary stressors and that both types of stressors are linked to detrimental mental health among caregivers.

In the classification made by Bookwala and Schulz {21}, main primary stressors relate to:
- Care recipient behavior problems.
- Caregiving assistance. A sum of the number of basic and instrumental activities of daily living with which caregivers assisted the care recipient was used as an index of caregiving assistance,

while main secondary stressors relate to:
- Quality of the caregiver-care recipient relationship.
- Activity restriction. An activity-restriction scale developed by Williamson and Schulz [22] was adapted to indicate the extent to which 11 areas of activity (self-care, care of others, eating habits, sleeping habits, doing household chores, going shopping, visiting

friends, working on hobbies, sports and recreation, going to work, and maintaining friendships) were restricted by their caregiving responsibilities

Researchers have further extended basic stress-coping models to include examination of secondary stressors, such as role conflict and have applied many additional theoretical perspectives borrowed from social and clinical psychology, sociology, and the health and biological sciences, to help understand specific aspects of the caregiving situation.

The relevance of role conflict is also essential, showing not only that informal carers who combine work and care experience the highest burden [56], but also that a higher ADL dependency in combination with employment is positively related to caregiver stress [23].

Ransmayr et al. [24] found in their longitudinal study that burden also builds over time as a result of restrictions on caregivers' time for other activities and psychological distress. This could be linked to role theory, entailing both role conflict, which most likely is the case when less time is available for other activities, and role captivity or role overload, referring to psychological distress.

Furthermore, caregivers often have feelings of pronounced isolation and effectively grieve for their previous vibrant and active lifestyles. Lack of time for self-care and continued focus on the care recipient's well-being typically deplete their energy and contribute to an increased caregiver burden [25].

A basic classification of determinants for caregiver's burnout refers to:
1. Caregiver's Characteristics The first set of determinants of caregiver burnout are the caregiver's characteristics. Caregivers remain individuals with personal cognitions, emotions, and motives that should be considered when aiming at understanding informal caregiver burnout. The characteristics of the caregiver can be divided into three main groups: background and sociodemographic, psychological, and physical factors.
2. Caregiving Setting.
   - Time since start of caregiving (duration) is often considered as a central element in caregiving strain.
   - and living with the care-recipient has also been highlighted as an inconclusive stressor for subjective burden and burnout
   - The autonomy (or functional impairment) of the care-recipient is a factor often related to caregiving subjective burden and burnout
   - a mutual influence of the emotional states in the dyad
     Secondary stressors
   - having a reduced social life and the loss of friends
   - having a more disturbed daily life due to the illness, less free time and time for themselves
3. Social Environment. The caregivers' social environment can be considered in three distinct ways: informal and partner support, professional support, and the sociocultural environment.
4. Caregiver's appraisal (both positive and negative)
5. Relationship. As the caring process progresses, the relationship quality remains a core-element in the caregiving experience. Of course, relationship quality with the care-recipient is determined by many elements, such as the relationship before caregiving or attachment style, but the key is to consider the impact caregiving may have on this relationship. Poor relationship quality has been found to be related to burden [26].

People who experience caregiver stress can be vulnerable to changes in their own health. Risk factors for caregiver stress include:
- Being female
- Having fewer years of formal education
- Living with the person you are caring for
- Social isolation
- Having depression
- Financial difficulties
- Higher number of hours spent caregiving
- Lack of coping skills and difficulty solving problems
- Lack of choice in being a caregiver
- Signs of caregiver stress

As a caregiver, you may be so focused on your loved one that you don't realize that your own health and well-being are suffering. Watch for these signs of caregiver stress:
- Feeling overwhelmed or constantly worried
- Feeling tired often
- Getting too much sleep or not enough sleep
- Gaining or losing weight
- Becoming easily irritated or angry
- Losing interest in activities you used to enjoy
- Feeling sad
- Having frequent headaches, bodily pain or other physical problems
- Abusing alcohol or drugs, including prescription medications [27].

Apart from the above mentioned list of specific factors that are related to caregiver burden, the duration of caregiving tasks, usually caused by the progression of the care recipient's physical or mental condition, is the strongest determinant of burden. In relevant studies, caregiver burden increased non-linearly over time, as perceived burden increased at a steeper rate as time progressed. However, it can also be hypothesized that duration has a more direct effect on caregiver burden, independent of disease progression; the burden becomes heavier the longer caring tasks are performed.

Furthermore, these studies considered the patient's functional status in terms of dependency level in activities of daily living (henceforth shortened to ADL) as one of the strongest predictors of perceived caregiver burden. Another factor that influenced informal caregiver burden is the specific illness of the patient. Finally, the care recipient's mental state – behaviour and cognitive capacity – appeared to be relevant [28].

2.3 COPING STRATEGIES

There is a declared lack of knowledge on common determinants that may hamper the development of effective policies and interventions that aim to relieve caregiver burden. Current interventions generally focus on providing caregivers with both direct and indirect support, such as emotional support, advice on coping, and respite services to reduce the amount of care burden [29].

However, the response of caregivers can be positive or negative depending on various factors, such as the coping strategies of caregivers.

Coping may be defined as a process of adaptation to stressful situations, which includes the allocation of cognitive and behavioral efforts to manage demands perceived as taxing or exceeding the resources of an individual, has been classified according to various criteria [30].

Effective and adaptive coping strategies may play a protective role in reducing the caregiver's stress. According to Lazarus and Folkman et al. [31], coping is a process that addresses how people respond and act both when experiencing stress and when the level of exposure to stress rises.

Coping strategies have been conceptualized in a variety of ways in the literature, however more broadly, they have been considered to fall into two main categories: problem-focused and emotion-focused [32]. Problem-focused coping strategies aim to change the situation and take control of the source of stress. They involve evaluating the source of stress and actively considering and implementing potential solutions to actively perform a task that will remove the problem or make the problem better; typically, if the frequency of task-focused coping increases, the distress decreases. On the other hand, emotion- based coping involves emotional response to stressors. Emotion-focused coping strategies can also entail enlisting emotional support from others.

Problem focused coping strategies , including active coping, instrumental support, and planning; aim to change the situation and take control of the source of stress. Problem-focused coping is oriented toward resolving challenges, while emotion-focused coping towards managing emotions [33]. They involve evaluating the source of stress and actively considering and implementing potential solutions to reduce the aversive effects of the stressor.

On the other hand, emotion-based coping involves emotional response to stressors. Emotion-focused coping including acceptance, emotional support, humor, positive reframing, and religion; seek to regulate distressing emotions and can include emotional expression, fantasizing, and reflecting on positive or negative thoughts [34]. Emotion-focused coping strategies can also entail enlisting emotional support from others [35].

Additionally, using fewer coping strategies was associated with higher reports of caregiving burden among caregivers [36]. In their review, caregivers that experienced higher levels of burden tended to be less likely to engage in self-care, and may experience weight loss, anxiety, and sleep deprivation (particularly in caregivers of partners with dementia).

Under this classification, coping strategies are the cognitive and behavioral efforts of individuals to interpret and overcome problems and challenges.

Effective interventions for caregivers include emotional support, counseling, respite (time away), and practical assistance with care tasks. Caregivers can often obtain reassurance or learn helpful information or strategies for caregiving from doctors, nurses, social workers, or case managers. Caregivers can also take the following measures to prepare themselves for caregiving and to avoid caregiver burnout:

- Attending to their own physical, emotional, recreational, spiritual, and financial needs
- When appropriate, asking for help with caregiving or psychologic support from other family members and friends

- Investigating outside groups that can offer psychologic support (such as support groups) or that can help with caregiving (such as counseling, home health care, adult day care, meals programs, and respite care)
- Avoiding taking the person's difficult behavior or hostility (if they occur) personally [37].

2.4 RESILIENCE

Resilience is defined as 'positive adaptation to face adversity, flexibility, psychological well-being, strength, healthy life, burden, social network, and satisfaction with social support' [38] Resilience in the context of caregiving is a psychological factor that modulates active coping, including emotion, problem, and meaning-centered strategies. It has a positive impact on adaptation and reduces risk factors for families and informal caregivers related to emotional distress, burden, fatigue, and stress and improved patient care. These results point out the need to develop interventions aiming at promoting and improving resilient coping style in informal caregivers. They should focus on the identification of active coping strategies that improve adaptation to illness and on increasing awareness about the positive aspects of caregiving, while encouraging the search for personal meaning within the experience of illness [39].

Inspired by ecological systems theory, Windle and Bennett [40] developed a theoretical resilience framework for caregivers.

This recognizes that caregivers will draw on individual resources, but also interact with their environment by drawing on community and societal resources which may facilitate or hinder resilience. Caregivers who have low resilience would experience high burden even in the presence of low care demand from a care-recipient. On the contrary, caregivers who have high resilience would experience low burden even when they experience high care demand. This perceived low burden could be attributed to effective coping strategies where resilience was associated with problem- and emotion-focused coping strategies and sense of self-efficacy. Therefore, considering this framework, resilience can be described as 'the process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and "bouncing back" in the face of adversity'. Resilience is generally understood as a positive outcome despite exposure to an adversity or risk and focuses on strengths rather than weaknesses [41,42].

Resilient caregivers are proactive towards maintaining harmonious relationships with health care professionals, aggregate information and resources, and developing social networks [43]. Caregivers, who face the challenges of taking care of their beloved ones, express their feelings relying on their social support networks to help them deal with their life situations [44].

This emphasizes the fact that resilience is a complex, multifaceted phenomenon that merits further clarification within the caregiving sphere with respect to whether it is a trait, process or a hybrid of the two. Collective findings demonstrate that resilience is associated with better overall health and psychological well-being, and contributes to optimal stress management among family caregivers. The ideal context in which resilience develops and how that process varies cross-culturally has yet to be determined, though this represents a useful direction for future research and complements newfound socio-ecological resilience theories [45].

It is obvious the need to determine the "predictors" or "favoring" factors of resilience, specifying characteristics such as being a relative of the patient, the least degree of cognitive deterioration, the presence of social and family support, faith, humor, positivity and optimism,

adequate information about the disease, and feelings of closeness and love towards the sick relative as the factors that are repeated the most in previous investigations. The consequences of this capacity or personality trait in the primary caregiver are less specific [46]. If we try to delineate the ecosystem of reslilience, at first we should emphasize the psychological well being as a crucial factor that determines the fluctuation of the resilience capacity of the caregivers. So we have,

High resilience:

- high care demands
- good psychological well-being

Low resilience:

- high care demands
- poor psychological well-being

The resilience is also shaped by the

1. Individual resources:
   - Sociodemographics: Age, gender, educational level, and employment status of the caregiver; age and gender of the person with dementia
   - Carer's inner psychological attributes: Sense of competence, coping styles, mastery, feelings of guilt
2. Context of care: Cohabiting, type and quality of the carer-patient relationship, duration of care, care burden
3. Social and community resources: Loneliness, social support, regular help from family/friends, use of services [47].

Subsequently, resilience positively affects physical health, improves survival, and mental health, while significantly reducing the risk of developing depression, anxiety, and stress. Recent studies have shown that resilience can reduce anxiety, depression, perception of pain, and emotional distress as well as it enables adaptation promoting effective coping strategies and positive affect in the context of oncological illness. The identification and development of resilience and its associated psychological factors could help reduce stress and burden and promote well-being. This could indirectly impact on how caregivers cope with and manage challenging clinical situations that require early identification and treatment of the emotional and physical needs of patients. Increasing caregiver's resilience capacity improves both the patient's and caregiver's emotional well-being. Psychological interventions should be addressed early on to improve resilience mechanisms or resources in the caregiver [48].

2.5 SOCIAL SUPPORT

Social support can be defined as "the existence or availability of people on whom we can rely, people who let us know that they care about, value and love us" [49]. Classically, this construct has been classified in two dimensions: structural and functional. The structural dimension refers to the size, composition and complexity of the social network [50,51].

Support is needed to enable informal caregivers to continue in their role as long as possible, without compromising their physical or mental health.

Seeking social support is a commonly used as a resultful coping strategy for sharing feelings and thoughts, for receiving information and guidance, for receiving emotional support from others. Caregivers may seek social support from family or friends, or elicit information from professionals which can be a form of social support as well [52].

2.6 SOCIAL MEDIA USE

A. What to know:

Find a chat group online whose members are dealing with caregiver stress issues similar to your own. Read a few posts to get a sense of how candid the group's posters are — most boards welcome honesty.

Actions to find a conversation board that's right for you:

- Check the Web sites of major organizations that deal with your specific situation (e.g., Alzheimer's Association, Arthritis Foundation).
- Look for Web sites that offer forums on a variety of caregiving topics (e.g., Caring.com, Caregiver Action Network, Facebook, Yahoo).
- Search words like "discussion group" or "forum" and the condition you're interested in (e.g., incontinence, arthritis, diabetes).
- Start a blog or try Twitter.

A large body of research shows that writing about difficult experiences can boost immune function and curb stress, potentially fending off caregiver burnout. Blogging, in particular, has been shown to improve coping for students and new moms, two groups that, like caregivers, live pressure-cooker lives. Unlike diaries, many blogs allow comments, which help the writer feel more connected and supported.

Choose your level of anonymity.

If you're concerned about the person in your care or other family members being upset by what you say publicly, use a persona on the Web. Chat groups often allow you to choose a nickname or avatar. On Twitter, you can pick a name that reflects your interests.

B. How Caregivers Can Find Support on Social Media

One of the greatest things about social media is that it makes it easy for people to connect to virtually whomever they want, from wherever they are, at any time of the day or night. Did you know that 41% of caregivers find support online through social media and other forums? Social media is a great place for those who are caring for a loved one to connect with other caregivers who can empathize, share personal stories, and offer helpful first-hand advice. If you're a caregiver who is interested in utilizing social media to find support and get connected with resources, here are some suggestions for how to get started, as well as some safety concerns to be aware of.

C. Social Media Support Groups for Caregivers

Facebook

Sites like Facebook allow individuals to create profile pages where both photos and thoughts can be shared via "status updates." Additionally, connections with others can be made by establishing a network of friends with whom you can share your photos and experiences. On a rough day, comments from friends may be just what you need to keep going. To find a group on Facebook, use the search bar at the top. Facebook will serve up a list of suggested groups based on the keywords you've entered. You can also select the "Groups" tab to the left of your

feed. Here, under the "Discover" tab, Facebook will make suggestions of groups to join based off of your interests and demographics.

Twitter

Twitter is a great place to connect with caregiving experts. It is a great way to ask questions, get important information quickly, and engage with others in the caregiving community. There are also frequent caregiving-related twitter chats where you can tune in and discuss relevant topics in real-time. With posts limited to 140 characters, Twitter offers quick bursts of information. Users can follow their own personal friends, as well as experts in any industry. By following senior care experts, family caregivers can receive notice of current elder care trends, while simultaneously following their favorite comedians to receive mid-day laughs. Also beneficial is the ability to share your own thoughts via tweets and receive feedback from other followers.

Blogs

Caregiving blogs and podcast, published/recorded by past or present caregivers and/or industry professionals, can be a great resource as you navigate your caregiving journey. A number of caregiving-centered sites provide forums where family caregivers can participate in online conversations. After establishing a profile, users can browse these forums, post topics, respond to topics posted by others or simply read about the experiences and advice of others. Acting as a virtual support group, online forums give caregivers who may not have time to attend a support group in person an online source of inspiration and guidance.

Yelp, Pinterest, and More

Time-strapped caregivers can utilize review and recommendation sites to help reduce the amount of research time needed. For instance, finding supplies for caregiving can sometimes turn into a monumental task. You can use Pinterest to save items that you have found to be helpful, and you can browse other user's pinboards to see what others have found helpful. If you need to find a service or certain type of store, Yelp provides user reviews to help you save time and choose more highly-rated businesses. Social media is an effective tool for time strapped family caregivers to both garner important information, and find time to interact with friends and keep up on current events.

D. Social Media Safety

When spending time on social media be aware of:

- Scammers: people looking to anonymously take advantage of your vulnerabilities to get information from or scam you.
- False or Misleading Information: finding information online may seem right, but make sure to always validate any health or medical recommendations with a physician.
- Disengaging from in-person interaction: Social media is social, but don't forget the importance of getting out there and engaging with friends and family in person from time to time

References

1. Schulz et al. Family caregiving for older adults. Annu Rev Psychol. 2020 January 04; 71: 635–659

2. Lindt, N., van Berkel, J. & Mulder, B.C. Determinants of overburdening among informal carers: a systematic review. BMC Geriatr 20, 304 (2020).

3. Rodríguez-Pérez et al. Coping strategies and quality of life in caregivers of dependent elderly relatives. Health and Quality of Life Outcomes (2017) 15:71

4. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist. 1980;20:649–654.

5. Ong et al. Resilience and burden in caregivers of older adults: moderating and mediating effects of perceived social support. BMC Psychiatry (2018) 18:27

6. Beach SR, Schulz R, Yee JL, Jackson S. 2000 Negative and positive health effects of caring for a disabled spouse: longitudinal findings from the Caregiver Health Effects Study. Psychol. Aging 15:259–71

7. Kazemi et al. Caregiver burden and coping strategies in caregivers of older patients with stroke. BMC Psychol (2021) 9:51

8. Kim H, Chang M, Rose K, Kim S. Predictors of caregiver burden in caregivers of individuals with dementia. J Adv Nurs. 2012:68(4):846–55.

9. Zarit SH, Reever KE, Back-Peterson J: Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 20(6):649–655, 1980.

10. Adelman, R., Tmanova, L., Delgado, D., Dion, S., & Lachsm, M. (2014). Caregiver burden: A clinical review. Journal of the American Medical Association, 311(10), 1052–1059.

11. Serrano-Aguilar PG, Lopez-Bastida J, Yanes-Lopez V. Impact on health-related quality of life and perceived burden of informal caregivers of individuals with Alzheimer's disease. Neuro-epidemiology. 2006:27(3):136–42.

12. Molyneux GJ, McCarthy GM, McEniff S, Cryan M, Conroy RM. Prevalence and predictors of carer burden and depression in carers of patients referred to an old age psychiatric service. Int Psychogeriatr. 2008:20(6):1193–1202.

13. Lambert SD, Bowe SJ, Livingston PM, et al. Impact of informal caregiving on older adults' physical and mental health in low-income and middle-income countries: a cross-sectional, secondary analysis based on the WHO's Study on global AGEing and adult health (SAGE). BMJ Open 2017;7:e017236

14. Van Der Lee, J., Bakker, T., Duivenvoorden, H., & Dröes, A. (2014). Multivariate models of subjective caregiver burden in dementia: A systematic review. Ageing Research Reviews, 15, 76–93.

15. Jones SL. The association between objective and subjective caregiver burden. Arch Psychiatr Nurs. 1996 Apr;10(2):77-84.

16. Joanna Lloyd, Jane Muers, Tom G Patterson & Magdalena Marczak (2018): Self-Compassion, Coping Strategies, and Caregiver Burden in Caregivers of People with Dementia, Clinical Gerontologist

17. Aronson, K. (1997). Quality of life among persons with multiple sclerosis and their caregivers. Neurology, 48(1), 74–80

18. Gérain P and Zech E (2019). Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving.Front. Psychol. 10:1748.

19. National Collaborating Centre for Mental Health. Dementia: The NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care; The British Psychological Society & The Royal College of Psychiatrists: London, UK, 2007

20. Pearlin, L. 1. (1994). Conceptual strategies for the study of caregiver stress. In E. Light, G. Niederehe, & B. D. Lebowitz (Eds.), Stress effects on family caregivers of Alzheimer's patients: Research and interventions (pp. 3-21). New York: Springer

21. Bookwala, J., & Schulz, R. (2000). A comparison of primary stressors, secondary stressors, and depressive symptoms between elderly caregiving husbands and wives: The caregiver health effects study. Psychology and Aging, 15(4), 607–616

22. Williamson, G. M., & Schulz, R. (1992). Pain, activity restriction, and symptoms of depression among community-residing elderly adults. Journal of Gerontology: Psychological Sciences, 47, P367-P372

23. Lindt, N., van Berkel, J. & Mulder, B.C. Determinants of overburdening among informal carers: a systematic review. BMC Geriatr 20, 304 (2020).

24. Ransmayr G, Hermann P, Sallinger K, Benke T, Seiler S, Dal-Bianco P, et al. Caregiving and caregiver burden in dementia home care: results from the prospective dementia registry (PRODEM) of the Austrian Alzheimer Society. J Alzheimer's Dis. 2018:63(1):103–14.

25. McLaughlin, D., Hasson, F., Kernohan, W. G., et al. (2011). Living and coping with Parkinson's disease: Perceptions of informal carers. Palliative Medicine, 25(2), 177–182.

26. Gérain P and Zech E (2019). Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving.Front. Psychol. 10:1748.

27. https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/caregiver-stress/art-20044784

28. Lindt, N., van Berkel, J. & Mulder, B.C. Determinants of overburdening among informal carers: a systematic review. BMC Geriatr 20, 304 (2020).

29. Allen RS, M. MH, Ege MA, Shuster JL, Burgio LD. Legacy activities as interventions approaching the end of life. J Palliat Med. 2008:11(7):1029–38.

30. Rodríguez-Pérez et al. Coping strategies and quality of life in caregivers of dependent elderly relatives. Health and Quality of Life Outcomes (2017) 15:71

31. Folkman S, Lazarus RS. Stress, appraisal, and coping. New York: Springer; 1984.

32. Fink G. Stress: Concepts, cognition, emotion, and behavior: handbook of stress series, Volume 1: Academic Press; 2016.

33. Rodríguez-Pérez et al. Coping strategies and quality of life in caregivers of dependent elderly relatives. Health and Quality of Life Outcomes (2017) 15:71

34. Iavarone et al. Coping strategies in caregivers of AD patients. Neuropsychiatric Disease and Treatment 2014:10

35. Kazemi et al. Caregiver burden and coping strategies in caregivers of older patients with stroke. BMC Psychol (2021) 9:51

36. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. Jama. 2014;311(10):1052–60.

37. https://www.msdmanuals.com/professional/geriatrics/social-issues-in-older-adults/family-caregiving-for-older-adults

38. Dias R, Santos RL, Sousa MF, Nogueira MM, Torres B, Belfort T, et al. Resilience of caregivers of people with dementia: a systematic review of biological and psychosocial determinants. Trends Psychiatry Psychother. 2015;37:12–9.

39. Palacio G et al. Resilience in Caregivers: A Systematic Review American Journal of Hospice & Palliative Medicine, 2019, 1-11

40. Windle G, Bennett KM: Caring relationships: how to promote resilience in challenging times; in Ungar M (ed): The Social Ecology of Resilience: A Handbook of Theory and Practice. New York, Springer, 2011, pp 219–231.

41. Windle, G., & Bennett, K. M. (2011). Caring Relationships: How to Promote Resilience in Challenging Times. The Social Ecology of Resilience, 219–231.

42. Tugade MM, Fredrickson BL. Resilient individuals use positive emotions to bounce back from negative emotional experiences. J Pers Soc Psychol. 2004;86:320–33.

43. Lin, F. Y., Rong, J. R., & Lee, T. Y. (2013). Resilience among caregivers of children with chronic conditions: A concept analysis. Journal of Multidisciplinary Healthcare, 6, 323–333.

44. Garcia-Dia, M. J., DiNapoli, J. M., Garcia-Ona, L., Jakubowski, R., & O'Flaherty, D. (2013). Concept analysis: Resilience. Archives of Psychiatric Nursing, 27, 264–270.

45. Schulz et al. Family caregiving for older adults. Annu Rev Psychol. 2020 January 04; 71: 635–659

46. Gómez-Trinidad et al. Resilience, Emotional Intelligence, and Occupational Performance in Family Members. Who Are the Caretakers of Patients with Dementia in Spain: A Cross-Sectional, Analytical, and Descriptive Study. J. Clin. Med. 2021, 10, 4262.

47. Joling et al.: Factors of Resilience in Informal Caregivers of People with Dementia from Integrative International Data Analysis, Dement Geriatr Cogn Disord 2016;42:198–214

48. Palacio G et al. Resilience in Caregivers: A Systematic Review American Journal of Hospice & Palliative Medicine, 2019, 1-11

49. 1. Sarason IG, Levine HM, Basham RB, Sarason BR (1983) Assessing social support: The social support questionnaire. Journal of personality and Social Psychology 44: 127.

50. Thompson EH, Futterman AM, Gallagher-Thompson D, Rose JM, Lovett SB (1993) Social support and caregiving burden in family caregivers of frail elders. J Gerontol 48: 245–254.

51. Vrabec NJ (1997) Literature review of social support and caregiver burden, 1980 to 1995. Journal of Nursing Scholarship 29: 383–388.

52. Kazemi et al. Caregiver burden and coping strategies in caregivers of older patients with stroke. BMC Psychol (2021) 9:51