

Review Article

Understanding the Struggles for Informal Caregivers Caring for People with Amyotrophic Lateral Sclerosis

Ammarah Y. Soofi* and Vanina Dal Bello-Haas

School of Rehabilitation Sciences, McMaster University, Canada

Abstract

Amyotrophic lateral sclerosis (ALS) is a progressive, devastatingly fatal, neurodegenerative disease. Due to the nature of the disease, ALS takes away a person's movement independence typically early on after disease onset, thus making the person with ALS (PALS) rely on caregivers for day-to-day functioning. The purpose of this paper is to 1) address the challenges faced by caregivers of PALS; 2) unpack the needs of caregivers in order to identify the effect these challenges have on quality of life (QoL); and 3) examine coping strategies and potential interventions to help these individuals while assuming the role of a caregiver. The term informal caregiver is associated with a family caregiver or unpaid caregiver, and is used to differentiate these individuals from paid care providers and/or other health care providers. Research indicates that informal caregivers (I-caregivers) reported significant decreases in QoL, particularly in regards to physical symptoms. As the disease progresses, I-caregivers are required to perform an increasingly greater number of physical tasks, all of which can take a toll on energy levels, leading them to report decreased QoL especially related to physical health. Studies have also found that the levels of anxiety and depression in ALS I-caregivers are related closely to the degree of the PALS's incapacitation. Social supports, resiliency, finding purpose in caregiving, and valuing the patient-caregiver relationship, all have significant effects on the I-caregiver's ability to coping with caring for a PALS. Providing adequate care and implementing strategies for the I-caregiver in a timely manner may enhance the informal caregiving experience.

INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is an unrelenting, degenerative disease affecting the nervous system [1], with unknown etiology. Onset of ALS occurs between the ages of 40 to 70 years [2], a time of life which encompasses raising families, establishing and re-affirming careers, and engaging in leisure, volunteer and other pursuits. Approximately two out of every 100,000 people per year are diagnosed with ALS, and in Canada, and 2500 to 3000 individuals currently live with this fatal disease [3]. ALS primarily affects the motor nervous system instigating selective death in both upper and lower motor neurons in the primary motor cortex, brainstem, and spinal cord causing rapidly progressive muscular paralysis [4]. The end results includes problems with walking, controlling movement, balance, breathing, swallowing and speaking, and the person with ALS (PALS) struggling to carrying out dailly life tasks [1]. The development of mobility-related and other impairments ultimately results in PALS relying primarily on their caregivers, especially during the later stages of the disease.

*Corresponding author

Ammarah Y. Soofi, IAHS 402, School of Rehabilitation Sciences, McMaster University, 1400 Main Street West, Hamilton, Ontario, L8S 1C7 Canada, Email: soofiay@mcmaster.ca

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- Person with ALS (PALS)

Caregivers are individuals who provide assistance to a person who is incapacitated to some degree and needs help [5], and include formal and informal. Informal caregivers may be primary and secondary caregivers, with a primary caregiver spending most of every day assisting an individual with daily activities [6]. According to Donelan et al. [6], 64% of primary informal caregivers are female and just more than half (51%) are 45 to 64 years old, and their average yearly income is \$20,000 or less. A secondary caregiver is usually family member, friend or neighbour who sometimes helps with caregiving activities out of concern for the well-being of the patient [7]. Informal caregivers are unpaid, can be full-time or part-time, and may or may not live with the person in need of care [7]. On the other hand, formal caregivers are paid care providers associated with a service system, and are usually not related to the patient [5]. Informal and formal care differs at the relationship level i.e. patient to caregiver, but also in terms of qualifications, cost to the person needing caregiving, and environment. Therefore, for formal caregivers, caregiving is a paying job, whereas for informal

caregivers it is often believed that there is a responsibility to care for the person in need [5].

Caregivers come from all walks of life and all age groups. Family caregiving can be a rewarding experience for many people. However, caregiving comes at a cost, and often leads to caregiver burden [6]. According to Kim et al [8], caregiver burden can be defined as “a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual” [8]. Some caregivers are forced to miss work or give up employment to provide care, leading to short-term financial strain and potentially long-term financial instability. Other related issues with family caregiving include: modification of family organization, difficulty raising dependent children, and sustaining physical injury while providing care [8]. Additionally, child caregivers may encounter difficulties in academic and social contexts due to psychological distress, such as depression, feelings of isolation, and disturbed sleep [9-12.1]. Caregiving can cause serious harm to an individual's economic, emotional, psychological, and physical well-being [13-15].

Roach et al [16], reported that informal caregivers of PALS have a significant decrease in quality of life (QoL), particularly in regards to physical symptoms, due to performing a significant amount of physical tasks such as transferring the PALS from the bed to wheelchair, or retrieving items that the PALS needs and can no longer access. All of these tasks are energy consuming and can especially affect a caregiver's physical health [17]. Other studies have reported that the levels of anxiety and depression in ALS caregivers are closely related to the degree of the patient's incapacitation [18-20]. Caregiving for someone with ALS puts most informal caregivers, especially family caregivers, at risk for physical and emotional distress [21]. The constant adaptation of the primary caregiver to the demands of the ALS disease process may cause intense burden and depression. Therefore, understanding the issues related to caregiving is important in order to help caregivers develop strategies and methods for coping with the risks of caregiving in a timely manner. The purpose of this paper is to perform a literature review addressing the challenges faced by caregivers of PALS, unpacking the needs of caregivers in order to identify the effect these challenges have on QoL; and to explore coping strategies and potential interventions to help individuals assuming the role of caregiver.

CAREGIVER BURDEN IN INDIVIDUALS CARING FOR PALS

Informal caregiving is associated with burden and distress, but research findings on the specific factors that influence caregiver burden vary. For example, burden and distress have been linked to the daily amount of time spent caring, as well as functional impairment levels with disease progression [2]. Deimling and Bass [22], found that caregiver burden was directly associated with a dependent person's level of physical limitations. In the case of PALS, performing basic activities of daily living such as walking, feeding, toileting, bathing, and dressing becomes progressively more difficult. Eventually PALS are incapable of carrying out such activities independently. ALS caregivers often experience burden due to personal and social restrictions such as not having time to meet friends or to exercise. Caregivers also

experience physical and emotional problems such as body pain, depression, and exhaustion [23,24].

Despite potentially having additional assistance from other family members in the home-based environment, caregivers spend nearly 15 hours a day attending to the needs of the PALS, which is remarkably high for a person to manage [25]. The amount of time spent and the emotional strain endured during caregiving requires high physical effort, particularly during the advanced stages of the disease. As described earlier, PALS need assistance to move and this can be problematic for caregivers with physical impairments themselves. This is especially true for older caregivers who may be experiencing some age-related problems such as back pain or arthritis, as well as chronic conditions. The increase in dependency of the PALS on a primary caregiver highlights the need to identify factors that cause burden and that may also influence QoL of the caregiver [2].

Some have reported that depression and distress levels of caregivers for PALS are high [25]. Gauthier et al.[20], and Pagnini et al.[27], report that caregiver burden and depression are positively associated with PALS physical disability, and increase over time. Conversely, there are studies that have found that QoL is maintained or even increases with caregiving [28], and that caregivers of PALS experience decreases in depression [29]. Furthermore, Lo Coco [2], found that lower levels of QoL in ALS caregivers is not always associated with PALS who are more physically or psychologically impaired. These unequivocal findings indicate that the relationship between a caregiver's psychological and physical status and the PALS disability levels are debatable [30]. Although physical disability is associated with the ALS disease, more evidence indicates that behavioral impairments such as apathy and disinhibition also occur in a significant proportion of PALS [24]. A recent systematic review [24], reported that PALS with increased physical disability and behavioral impairments demonstrate higher caregiver burden primarily in depression. There is a sufficient amount of evidence in high agreement between the well-being of the PALS and of the caregiver, therefore suggesting that a decrease in caregiver well-being can also negatively impact that of the PALS [24].

Much of the available research on ALS caregiving uses a quantitative approach, however there is a need for more thorough qualitative approaches in order to gain a better understanding of patients' and caregivers' experiences [31-33]. In Aoun et al.[31], qualitative study, family caring was described as a task that is very demanding and overwhelming, and characterized by sequences of loss and despair. The role change from family member (spouse/child) to caregiver, struggle with accepting the diagnosis, absence of empathy from medical professionals, serious emotional consequences for the caregivers, and the difficulty in attaining appropriate palliative care are all factors linked to caregiver burden in ALS [12,31,34]. Additionally, family caregivers emphasized their concerns for safety of the PALS, felt they had many social restrictions, were frequently exhausted, struggled with rage, frustration, and loss of affection, and were unsure about the future [23,30]. Despite these concerns, the caregivers did try to adjust to the situation by: attempting to remain strong, maintaining a sense of normality, seeking specialist services, implementing a problem-solving approach,

taking an 'everything a day at a time' approach, trying to remain optimistic, attempting to reduce signs of grief, ending appear resilient [26,35,36].

Although caregiver burden has been widely studied in a variety of patient populations there are still only a few studies that have investigated the impact of caregiver strain in ALS. Goldstein et al.[19], found that greater patient functional impairment was correlated to higher caregiver depression scores, and Hecht et al.[23], and Chio et al.[10], found positive associations between functional impairment and perceived burden. Hecht et al.[23], also determined that personal and social restrictions, together with physical and emotional problems, were the main components of burden. These researchers suggest that support for caregivers should begin as soon as possible, as burden of care increases with increasing functional impairments. Caregivers should not only take care of the PALS, but it is imperative that they also care if themselves, in order have the capacity to provide sufficient support [29]. According to Chio et al.[10], the PALS and the caregiver relationship should offer mutual support to help relieve burdene.g., the caregiver supports the PALS by caring for them, and the PALS supports the caregiver by valuing and encouraging efforts.

CAREGIVER BURDEN EFFECT ON QOL

Due to the devastating and inevitable progression of ALS, it is clear why this disease would affect the PAL's family, as well as impact the QoL of the PALS and caregivers [37]. The concept of QoL is multidimensional and can be defined as the personal evaluation and perceived satisfaction with physical functioning, psychosocial well-being, socioeconomic status, emotional well-being, family functioning, symptom distress, and spiritual well-being [38,39]. The literature has emphasized that psychosocial stress and depressive symptoms in PALS have effects on the mental health of their caregivers [10,40,24,34], and likewise caregiver's burden has an effect on the PALS psychosocial and emotional well-being [24]. As this evidence has surfaced through several studies, it is important that therapeutic teams are aware of the strengths and weaknesses of caregivers, in order to help them improve their coping skills [10]. For example, if the caregiver is the spouse of the PALS, over 60 years of age, and is also a social individual, the caregiver may find it frustrating and very difficult to constantly keep up with the physical and emotional demands of the PALS (weakness). Therefore, the spouse should have a coping strategy that involves their strengths (social events) and that would allow for relief from perceived burden. A good resource for this caregiver could be a support group consisting of other caregivers of PALS.

Although family caregivers of PALS are deeply affected by the illness, the impact the disease has on spouses and children is particularly overwhelming with the pressure of trying to maintain positivity. According to Rabkin et al.[26], when the caregiver appears exhausted and unhappy, the PALS' perception of being a burden increases, as does levels of distress. However, the findings by Woolley and Ringel [41], are contradictory to Rabkin et al.[26]. determined that both physical and mental health well-being scores in spouse caregivers were close to that of the general population. In their study, over 800 primary caregivers of PALS patients. A 36-item self-report Quality of Life Scale along

with additional questions, were used for this study. Participants reported high scores in life satisfaction, and this did not change as the disease progressed. Another study conducted by Bromberg and Forsheew [42], focused on ALS spouse caregivers. Fifteen patients with nearly normal pulmonary function and fourteen spouses were interviewed and the Schedule of the Evaluation of Individual Quality of Life scale was used to measure the QoL of the individuals. This study found that ALS had a more significant impact on the mental health and QoL of caregivers, compared to PALS. The results of this study were in contrast to the Woolley and Ringel [41], study findings, indicating a need for further research.

In 2000, Rabkin et al.[26], explored another aspect of distress in spousal caregiving. Their study examined spousal caregiver adjustment to the PALS' disease progression and functional impairments, and reported two significant findings: 1) caregivers who could not afford extra help were more likely to be distressed because they felt guilty if they had to leave their spouse alone to attend to something else. As a result, these carers tend to neglect their own health and needs; 2) Caregivers who found positive meaning in caregiving experience had less burden, regardless of time since diagnosis or assuming the caregiver role, or disease progression [26].

Another potential threat to QoL of caregivers is increased social isolation [25]. However, the level of distress from social isolation also depends upon the type and frequency of past social involvement prior to becoming a caregiver. Nevertheless, maintaining a social support system for the caregiver may be difficult to accomplish, as family and friends often stop visiting or become awkward in the presence of the PALS once the disease severity increases [43]. Ciechoski and Heimen-Patterson [44], found that caregiver's social contacts outside the home also decreased when there is increased care demands put on the caregiver's personal time. This finding was also true for when the disease progressed towards ventilator dependence and the PALS and caregiver were limited to remaining in the home for convenience.

Relationship strain is another issue informal caregivers experience when roles change in the family. The decreased functional abilities of the PALS can lead to an unacknowledged shift in the relationship between children or spouses and the PALS, such as from a husband-wife, mother-daughter, and father-son relationship to a caregiver-patient relationship. McDonald's [37], ALS Patient Profile Project found that couples who reported having high levels of QoL despite living with and caring for a PALS, indicated that "living" was the center of their lives, not ALS. The term "living" was defined by the couples as being able to maintain their relationship through the course of the disease and by viewing the disease as a shared experience. Good communication was also a key factor in preventing accumulation of resentment, guilt or negative emotions over time [37]. The caregiver-patient relationship, whether the caregiver is a child or spouse, can be maintained. Attaining additional help if feasible for tasks involving physical care e.g., lifting, transferring, bathing and continuing previously shared activities [37], such as going to the park, watching a movie, and playing board games can facilitate a positive relationship.

Financial matters are another significant factor in caregiver burden as children or spouses often undertake money management responsibilities with which they may be unfamiliar. Additionally, since health insurance rarely covers home care requirements, some spouses and adult children caregivers are obligated to take on employment in order to meet the growing financial obligations. According to McDonald [37], prior to onset of ALS, only 3% of families mentioned any concerns about money, but after onset the percentage increased to 18%.

RESILIENCY AS A COPING STRATEGY

A caregiver who is able to find positive meaning in caregiving is more likely to adapt and problem solve and view caregiving as a positive and rewarding opportunity. Hayslip and Smith [45], define resilience as a positive adaptation to circumstances of past or present adversity. Some caregivers appear to exhibit resiliency when their quality of life is compromised by unexpected and difficult circumstances. Miller and Lawton [46], indicate that in the time of adverse life events, caregivers should learn to use their resources well in order to maintain positivity, develop satisfaction in caregiving, and value the experience. Setting priorities, reaching out to others e.g., family, friends, neighbours, religious groups, other caregivers, maintaining a healthy lifestyle through diet and exercise, and taking respite time are some tips that caregivers can and should take advantage of during their time as caregiver. A study by Rabkin et al. [26], assessed resilience and distress in patients with ALS and caregiver spouses. The researchers suggested that finding meaning in caregiving is an indication of resilience. However, this concept of resilience is mostly unknown within the caregiver population as they are unintentionally unaware of strategies and approaches they can take to maintain a mental health and well-being. This is likely due to the lack of research attention paid to resilience in caregivers because this concept is difficult to invoke within a psychological perspective [47]. Miller [47], explains resiliency using the following example – using a medical model, resiliency would be associated with recovering from a difficult surgery or surviving a physical disease like influenza. The assumption in the psychological domain is that a traumatic incident activates a natural resilient response, making it possible for the person to survive the event. Therefore, if the individual did not experience a traumatic event, s/he would not be seen as resilient, as resiliency is subjective to the observer's view.

On the other hand, caregiving is an ongoing personal experience. In the case of caregiving within the ALS population, there is greater possibility for a particularly exhaustive experience with distinct challenges, due to the devastating progression of the disease [39]. Given the adversity of caregiving in this context, caregivers require resiliency skills, not just adaptive survival intuition. Therefore, using resiliency as a skill set can influence the caregiver to: recognize and accept the negative event e.g., diagnosis of ALS; understand the disease in order to avoid denial; adopt new role expectations; and purposely make the intention to live life in the moment to maintain positivity in the PALS-caregiver relationship [47]. According to Seligman & Csikszentmihalyi [48], the primary assumption of resiliency is that it is a lifelong process of gathering and integrating unique strengths and qualities into a virtual collection of understandings and actions that become

a part of one's identity. Another assumption is that resiliency is the interaction of certain strengths and qualities that balance individuals through difficult situations, even after long periods of time.

Resiliency factors may contribute to coping and improving QoL in caregivers of PALS. Caregivers who show resilient behavior possess positive views of the future i.e. are optimistic; maintain a satisfying and encouraging relationship with the PALS; have faith in spiritual beliefs and/or follow religious practices; and, are able to proficiently problem solve – all of which will likely lead to higher QoL during the caregiver experience [49]. Due to the rapid nature of the disease, PALS often experience difficulty walking, limb weakness, fasciculations, cramps and other symptoms and impairments [3], sooner than may be expected. Spouse or child caregivers will each change or loss as an emotionally stressful situation wherein it would be difficult to maintain QoL stability for both themselves as well as the PALS.

In the context of ALS caregiving, the course of the disease likely has negative effects on the balance between stable caregiver-patient relationships. Yet it is understandable that caregivers who exhibit resilience will recognize that the quality of their relationship with the PALS prior to disease onset is valuable enough such that they are motivated to maintain that balance, regardless of arising difficulties. However, if the relationship is already difficult to manage or becomes unstable, the perceived value of the imbalance may not be adequate enough to motivate the caregiver to exhibit resilient behaviour [50]. There is growing evidence that positivity can prolong motivation and confidence in optimistic individuals [51], and that optimism is an important component/factor of resilience. Peterson [36], indicates that optimism creates personal strength involving future-mindedness, determination, and the capability to adapt in changing situations, as resilience has cognitive, emotional, and motivational components. Peterson [36], further states that individuals with high optimism have better moods and are more determined and successful in goals they undertake. In relation to ALS caregiving, the caregiver's goal is to keep the PALS' QoL stable for as long as possible. An additional goal may be to avoid becoming personally distressed.

In comparison to caregivers from cancer and Parkinson's disease patients, the caregiving experience of caregivers for PALS represent a significantly lower QoL [34]. Burke et al. [34], speculates that the negative impact on QoL in caregivers is not necessarily due to the functional decline from ALS, but may be due to a caregivers "resilience, coping style, premorbid personality, and support networks" [34], (p903). Optimistic individuals are able to accept unfavourable news about a disease and are better prepared in facing the realities that come with such information [36]. As well, optimism should be a significant factor in the caregiver's QoL and psychological well-being, as it can alleviate the perceived burden of caregiving. A caregiver should value the role of caregiver since the disease is progressive and incurable, and the amount of time the PALS has to spend with loved-ones is limited. Therefore, if the caregiver views this role with optimism and as a privilege and opportunity to make the PALS' life meaningful and favourable, less burden may be experienced.

COPING STRATEGIES AND POTENTIAL INTERVENTIONS FOR CAREGIVERS

Tramonti et al., determined that caregiving in ALS causes interruption in the restoration of family balance, as this disease presents new and ever changing demands on the family [12.1]. Implementing problem solving skills is a coping method that can enable a caregiver in the role by solving a problem in the most effective way, and are specific to one's cognitive and behavioural abilities [52]. D'Zurilla et al.[53], note that individual differences in problem solving ability occur on a regular basis and one's ability to cope with and manage emotional reactions, and resolve real life stressful problems are related to a person's QoL in terms of psychological well-being and social competence. D'Zurilla and Nezu [54], created a model for problem solving skills which suggests that there are three types of problem solving skills: rational problem solving; solving by impulsiveness and carelessness; and avoidance. When applying this model in relation to ALS caregivers, those who use the rational problem solving skill would set certain goals and then consciously and systematically use effective techniques to meet these goals. Caregivers who use the second type of problem solving, involving carelessness and impulsivity, usually have incomplete and ineffective solutions. Last, those that avoid the problem by ignoring it and wait for the problem to solve itself, often have highly ineffective outcomes.

In addition to coping by problem solving, Chang et al.[55], examined if the caregiver-patient relationship was influenced by religious or spiritual beliefs in elderly, disabled individuals. The authors found that caregivers' use of religious/spiritual beliefs as a coping strategy impacted their judgement of the quality of the caregiver-patient relationship. Caregivers handled the illness by using an active coping style in which they accept the illness and try to manage it in a positive and purposeful way [55]. Chang et al.[55], also reported that religious or spiritual coping had no effect on psychological distress. However, the study did find that using religious/spiritual coping with a valued relationship between carer and patient, appeared to enhance the psychological functioning of the caregivers. Therefore, it is likely that those ALS caregivers, who are spiritual or are a part of a religious group, have an increased likelihood of support to call upon for help if needed. For example, when relationships are strained by giving and receiving care, other church, mosque, or synagogue followers can be called upon to assume the role of a caregiver and fulfil many of the support functions [56]. This type of coping strategy should not be overlooked as it may contribute to significantly enhancing the QoL and psychological well-being of caregivers, especially for those who cannot afford to pay for assistance.

The ALS Society of Canada suggests that open communication between members of the family is the best way to work through negative feelings linked to caregiving [3,57]. However, given that it may be difficult to do in some circumstances, speaking to a social worker or other members of an ALS support group may be helpful to resolve communication problems. It is strongly encouraged to have someone to talk to who can understand the issues and who will not be offended by the caregiver's feelings. Healthcare professionals, other ALS caregivers (informal or formal), support groups, friends or family members can be very helpful in this

area of coping [57]. As time constraints are a significant factor to caregiver burden, it is important that caregivers continue to have lives of their own and take care of themselves. Therefore, spending time with friends or family members who are not sick, or partaking in hobbies or activities in addition to caregiving, or spending time alone, would allow the caregiver to recover from the strain of caregiving and can help make them more effective, balanced carers [58].

Asking for help from others or arranging paid help if possible, for when the primary carer needs a break should not be something caregivers should hesitate to do, as ignoring one's own health and well-being is a cause of burden. Comparable to many other chronic diseases, ALS not only affects the person with the diagnosis, but those around them as well [57]. Therefore, caregivers also need support and resources to learn, accept, and cope with changes. Danucalov et al.[59], suggests that yoga, breathing exercises, relaxation techniques, and compassion meditation programs may be an effective intervention for reducing stress, depression, anxiety, and frustration in family caregivers. Additionally, low burden in caregiving could also be sustained by providing protective factors such as "targeted intervention aimed specifically at anxiety management, resilience-based strategies, and interventions known to improve QoL in caregivers and patients with neurodegenerative conditions." [34] (p903).

CONCLUSION

Although the research varies in its conclusions related to factors are linked to caregiver burden, there is agreement that most caregivers will experience some level of psychological and physical distress in response to the strain caused by having a family member receive a diagnosis of an incurable disease, such as ALS. The rapid nature of the disease places family caregivers into their roles, without giving them much time to adjust to the diagnosis or to assess how ALS will impact lives. In the end, how a person feels and adapts to the role of a caregiver in response to disease specific caregiving stress, is a critical component of that person's QoL. ALS caregivers who demonstrate resiliency report a higher QoL with better adaptation to the experience [26,29].

The presence of resiliency in caregivers can be detected early on after assuming the caregiving role. Resiliency variables reflect caregivers' subjective, emotional experiences and essential abilities. However, the carers' adaptive thinking and behavior i.e., self-reported QoL may vary according to the changing aspects of the caregiving experience and the stage of disease of the PALS. As a result, ALS caregiving is not a passive role, rather it is a dynamic process that is strongly influenced by the severity of the disease. Therefore, caregivers at risk of easily being burdened can be identified and referred for early cognitive behavioural interventions aimed to build resiliency and problem solving skills. For example, cognitive behavioural interventions may include: setting realistic goals e.g. participating in social activities, learning to manage stress and anxiety e.g. relaxation techniques such as deep breathing, distraction, identifying and challenging negative thoughts, and keeping track of behaviours, feelings, and thoughts [60]. Engaging in interventions may increase the likelihood that caregivers will better adapt to the stress of ALS caregiving and have a better QoL. Using such information, new interventions and programs can be created with the intention

of preventing caregiver depression and relieving caregiver burden. However, the conceptualization of resiliency among ALS caregivers is in its infancy.

Healthcare providers should become more aware of the factors leading to caregiver burden as these factors affect the PALS as well. In addition, more interventions and resources need to be applicable and attainable during the course of the disease, and should be available early on, in order to help caregivers cope with the ongoing physical and psychological strains encountered. Overall, social supports, resiliency, finding meaning in caregiving, and valuing the relationship between the PALS and caregiver all have significant effects on the caregiver's ability to coping with ALS [10,19,29,34,35]. Future research should also focus on the stress and burden of ALS caregivers from a qualitative standpoint in order to better understand the day-to-day living experiences of caregivers leading to burden, and effective strategies and interventions to manage the lived experience of caregiving.

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