An Integrative Exploration of Psychological Resilience in Informal Caregivers of Persons with Multiple Sclerosis

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ABSTRACT/RÉSUMÉ

[French version follows]

Informal caregiving is growing in demand and is far from a uniform experience. Some caregivers report burdensome effects, while others attest to a wide range of benefits associated with their role. In the context of informal caregivers of persons affected by chronic neurological conditions (CNCs), psychological resilience is increasingly being explored as a protective factor that may account for variability in the caregiver experience; however, multiple sclerosis (MS) caregivers are noticeably absent from this body of work. To synthesize current evidence concerning resilience conceptualizations, assessments, and health correlates within this population, this thesis included a systematic review of resilience in CNC informal caregivers in which MS caregivers were unrepresented. Following this review, a qualitative study was conducted in informal MS caregivers to ascertain MS caregivers' conceptualizations and unique lived experiences of resilience. Twenty-four semi-structured interviews of Canadian MS informal caregivers were conducted. Informed by the socioecological model of resilience in caring relationships, transcripts were analyzed using flexible thematic analysis. In support of the conceptual ambiguity of resilience, caregivers did not concur on a single resilience conceptualization. Emergent themes contributed to the creation of a cyclical model of resilience that incorporates adversity in the form of continuous loss and obstructed health-related self-care, individual and community resources, and multilevel adaptive pathways. We use our model to prompt future research directions and inform the development of effective resilience-enhancing interventions for MS caregivers.

Le rôle d'aidant informel, de plus en plus demandé, est loin d'être une expérience uniforme. Certains aidants signalent des effets pénibles, tandis que d'autres attestent d'un large éventail d'avantages associés à leur rôle. Dans le contexte des aidants informels de personnes atteintes de maladies neurologiques chroniques (MNC), la résilience psychologique est de plus en plus étudiée en tant que facteur de protection pouvant expliquer la variabilité de l'expérience des aidants ; cependant, les aidants de personnes atteintes de sclérose en plaques (SP) sont notablement absents de ce corpus de travaux. Afin de synthétiser les preuves actuelles concernant les conceptualisations, les évaluations et les corrélations de santé de la résilience au sein de cette population, cette thèse comprenait une revue systématique de la résilience chez les aidants informels des CNC, dans laquelle les aidants de la SP n'étaient pas représentés. À la suite de cette revue, une étude qualitative a été menée auprès des aidants informels de personnes atteintes de SP afin de déterminer les conceptualisations et les expériences vécues uniques de résilience de ces derniers. Vingt-quatre entrevues semi-structurées d'aidants familiaux canadiens atteints de SP ont été réalisées. Informées par le modèle socio-écologique de la résilience chez les aidants, les transcriptions ont été analysées à l'aide d'une analyse thématique flexible. À l'appui de l'ambiguïté conceptuelle de la résilience, les aidants ne se sont pas entendus sur une seule conceptualisation de la résilience. Les thèmes émergents ont contribué à la création d'un modèle cyclique de résilience qui intègre l'adversité sous la forme d'une perte continue et d'une entrave à l'autogestion de la santé, les ressources individuelles et communautaires et les voies d'adaptation à plusieurs niveaux. Nous utilisons notre modèle pour orienter les recherches futures et informer le développement d'interventions efficaces pour améliorer la résilience des aidants de la SP.

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CHAPTER 1
REVIEW OF THE CURRENT LITERATURE

1.1 INTRODUCTION

1.1.1 An Overview of MS

Multiple sclerosis (MS) is a progressive chronic neurological condition (CNC), and is the most common cause of chronic neurological disability among young adults in the western world.[1,2] MS is conservatively estimated to affect over 2.5 million individuals worldwide and is reported to have the highest prevalence in Canada, with approximately 100 000 Canadians or 1 in every 385 individuals affected by the disease.[3] MS is primarily characterized by inflammation, demyelination, and neurodegeneration.[4,5] The cause of MS is largely unknown; however, its uneven etiological distribution across populations has been attributed to environmental exposure and genetic susceptibility.[6] Due to its typical early age of onset during prime adolescent or young-adult life, its unpredictable progressive disease course, and its polysymptomatic and heterogenous nature, MS carries with it vast social, psychological, and physical costs.[1] In truth, with no cure and limited ability to prevent disease progression via disease-modifying therapies, the majority of persons living with MS experience the accumulation of moderate-to-severe disability long-term,[7,8] considerably impacting the individual and their surrounding family and friends as their functional independence steadily dissipates.[1]

MS can be distinguished by three primary clinical courses: relapsing remitting MS (RRMS), primary progressive MS (PPMS), and secondary progressive MS (SPMS).[9] The RRMS course is characterized by periods of clearly defined exacerbations of disease activity and symptoms (i.e., relapses) which are followed by partial or complete recovery.[10] Persons with

RRMS often present with mild-to-moderate disability levels.[11] About 90% of all people living with MS present with a RRMS course at onset.[10] As a minority, 10% of individuals with MS present with a primary progressive course at onset;[12] PPMS is characterized by continuous accumulation of neurological disability, typically without relapses.[9] It is estimated that approximately half of people with RRMS will develop SPMS within ~10-20 years of disease onset.[9,11] SPMS is preceded by a RRMS course and is characterized by the continuous accumulation of neurological disability most often without defined relapses.[9,11] Both progressive forms of MS (i.e., PPMS and SPMS) lead to severe outcomes (e.g., requiring assistance to walk short distances) as a result of ongoing neurodegeneration.[11]

The location and severity of damage within the CNS caused by MS disease activity results in a variety of functional impairments,[13] irrespective of clinical course, causing persons with MS to endure major disruptions to their daily lives. Cognitive impairment is prevalent among persons with MS,[14,15] in addition to changes in mental functions which often manifest psychologically as fatigue,[16] depression,[17,18] and anxiety.[19] Frequent physical impairments associated with MS include restrictions in cardiovascular function (demonstrated as aerobic deconditioning), movement or neuromusculoskeletal function (observed as impaired gait and muscle weakness), and sensory function (including imbalance, ataxia, and visual disturbances).[20–24]

1.1.2 MS and Other Chronic Neurological Conditions

MS belongs to a group of conditions known as long-term or chronic neurological conditions (CNCs), which represent a diverse group of conditions resulting from injury or

disease of the central nervous system that will affect the individual for the remainder of their lives.[25] These conditions may be sudden onset (e.g., stroke, spinal cord injury), intermittent (e.g., epilepsy), progressive (e.g., MS, dementia, Parkinson's disease (PD), motor neuron disease (MND) and other neurodegenerative disorders), or stable with or without age-related degeneration (e.g., polio, cerebral palsy).[25] Generally, neurological conditions possess a long and variable time course with a diversity of symptoms.[25,26] As discussed previously in persons with MS, many individuals with CNCs suffer from multiple complex impairments, which include cognitive, behavioural, and communication problems in conjunction with marked physical deficits.[25,26] Indeed, neurological conditions, particularly those that are progressive in nature (e.g., PD, MS, MND), account for a significantly high number of years lived with disability and represent the second leading cause of death worldwide.[27,28] Henceforth, long-term disability management from multidisciplinary healthcare, rehabilitation, and community services constitutes a key necessity for CNC populations,[26] particularly in the area of progressive heterogenous disorders, such as MS.

Specifically within the context of MS, the advancement of disability in individuals diagnosed with the disease is highly burdensome for both themselves and their surrounding family systems, as their independence, functionality, and ability to manage life roles are negatively affected.[29–31] For instance, studies have reported that the challenges associated with physical and cognitive disability management contribute to elevated unemployment rates in people with MS.[32] Similar findings have been reported in other progressive CNC populations, such as PD.[33] These findings reflect limitations in the ability to perform occupational and social roles within broad CNC populations.[32–34]

1.2 INFORMAL CAREGIVING

1.2.1 Defining the Informal Caregiver Role

The accumulation of neurological disability in MS and other CNCs often results in many persons with these conditions requiring care and support from others to carry out essential tasks of everyday living.[35,36] This role is usually fulfilled by an informal caregiver, also known in the literature as a family caregiver.[37] Expressly, the term informal caregiver refers to an individual who has the responsibility of providing unpaid care for a family member (e.g., spouse, child, parent) or close friend.[37] Informal caregivers frequently possess a biological or familial relationship to the care-recipient; however, this is not always the case, and many informal caregivers are chosen family or long-term spousal partners of the care-recipient.

It is important to understand that there is a distinct experiential difference between formal and informal caregivers. Firstly, formal caregivers receive payment for their caregiving services and are required to possess a level of accredited training in their professional service providing role.[36] Additionally, paid caregivers exist across a plethora of institutional and government care settings, including long-term care or nursing homes, hospitals, and travelling home-care agencies. Contrarily, informal caregivers provide care for their family member, friend, or partner exclusively within the home setting without pay or compensation.[36] As the caregiving role progresses across the life span, informal caregivers may be involved in transitions from community to formal health care settings (i.e., home to long-term care).[38] With that said, consideration of the role of informal or unpaid support providers of institutionalized loved ones in long-term care settings (i.e., nursing homes, assisted living facilities) or hospitals is outside the scope of this thesis.

1.2.2 The Evolving Societal Implications of Informal Caregiving

Informal caregiving and its societal implications are changing, as the role evolves to become more complex and longer-lasting.[39] Gradual advances in medical technologies have enabled people with serious neurological conditions and disabilities to live longer than ever before.[40] At the same time, the incidence of chronic illness is also increasing in Canada.[41] These demographic changes significantly challenge current and future healthcare systems and in response to this demand, the number of caregivers nationwide are steadily rising.[42] Specifically, the heightened prevalence and increased CNC longevity, renders neurological disorders the most important contributors to years lived with disability,[28] thereby substantially increasing the need for informal caregiving in the context of CNCs.[41] Of added importance, healthcare models are shifting to move patient care and management away from hospital settings and into outpatient and homecare settings.[43] Consequently, this transition amplifies the demand for informal caregivers who may not be adequately equipped to manage these additional responsibilities. Notably, despite increased reliance on informal homecare, informal caregivers are often marginalized by existing healthcare systems and procedures who have failed to make fundamental structural changes to effectively support and engage caregivers.[44] Informal caregiving is conceptualized as an emerging public health issue encompassing complex and fluctuating roles, particularly as rising life expectancies of care-recipients tax the ability of caregivers to provide sustained and complex care.[40] As such, the socioeconomic value of caregiving to society is immense and is projected to exponentially increase in the coming decades.[45]

1.2.3 Informal Caregiver Health and Vulnerabilities

Informal caring in MS, as well as other CNCs, extends beyond physical hands-on care to include cognitive and psychological tasks such as: anticipating future support needs, supervising and monitoring, preserving the care-recipient's sense of self and dignity, and helping the care-recipient accept and develop new and valued roles as their condition evolves.[46] Typical caregiving commitments consist of providing prolonged hours of care to fulfill the care-recipients' needs. As a product of the critical functions that caregivers regularly preform, government health agencies and researchers have demonstrated increasing concern for maintaining optimal caregiver health.[45] Moreover, this initiative is exacerbated by the fact that, at times, the informal caregiving role may become both physically and mentally daunting.

Given the lack of training and non-existent monetary reimbursement for their care, informal caregivers may confront significant and ongoing challenges within their role. Although there are many rewarding aspects of providing family care,[47] informal caregivers tend to experience role overload, financial strain due to lost income, and are problematically unequipped with sufficient knowledge of the illness and care needs of the care-recipient.[36,45] These struggles may be compounded by the fact that the role itself typically requires significant changes in the caregiver's daily lifestyle, including the need to be regularly available to provide support and vigilance in caring activities.[48] These daily support demands and their ensuant lifestyle impacts come at the expense of caregivers' own personal time and self-care requirements. Recurrently, caregivers must negotiate their role without sufficient expectations, guidance, and support to effectively execute their daily support responsibilities.[48]

Despite caregivers' regular contact with clinicians while coordinating medical appointments and miscellaneous services for the care-recipient, oftentimes the sole focus of clinicians is the patient with the chronic illness, and the physical and psychological needs of the caregiver are overlooked.[39] Indeed, healthcare providers are not compensated for their time spent educating informal caregivers about patients' medical conditions and treatments, and they are rarely even trained in such matters of conservation or clinical care.[39] Inasmuch as there is a lack of clinical support for informal caregivers, caregivers are seldom educated regarding caring expectations and responsibilities, and may experience a heightened sense of impotence, as caregiver availability and adequacy is problematically assumed by our societal health systems.[39]

From the onset of injury or diagnosis of illness in the case of MS, informal caregivers often struggle to accept the life-altering diagnosis, while being compelled to make adjustments in their romantic, marital, or familial relationships to accommodate their new caregiver role.[36,45] Oftentimes, the extent of these ongoing duties results in marked levels of distress and consequential poor psychological and physiological health outcomes.[49] For informal caregivers of persons with MS, and CNCs more generally, the strenuous caregiving role tends to culminate in increased depression, anxiety, social isolation, and poorer reported quality of life in comparison to non-caregiving matched control populations.[46,49–54] As such, this subjective phenomenon is typically referred to as *caregiver burden*[55] and, in turn, the predominant existing informal caregiving theoretical models are founded on the basis of stress and coping processes.

1.2.4 Theoretical Models of Informal Caregiving: Stress, Burden, and Coping

Amidst the narrative that caregiving responsibility exerts a negative impact on the caregiver, the earliest model to be applied to the informal caregiving health context is Lazarus and Folkman's transactional theory of stress and coping.[56] This theory states that the stress process begins with an appraisal period where certain emotions may be triggered by an encounter with stimuli.[57] When stimuli are appraised as threatening, harmful, or problematic (i.e., stressful), the ensuant distress initiates coping strategies to enable emotional management and attentional devotion to addressing the stressor.[57] True stress is experienced when exposure to a stimuli appraised as challenging collectively exceeds the individual's capacity to cope, and ultimately produces unfavourable outcomes within the individual or environment.[56] Traditional applications of this theory in the informal caregiving sphere tend to focus on indications of maladjustment in response to caregiving stressors when mediated by coping processes.[58,59]

Building upon Lazarus and Folkman's stress and coping theory, scholars began to address caregiver stress among informal caregivers via the assessment of caregiver burden, and its conjunct outcome of caregiver burnout. Specifically, caregiver burden is conceptualized by theorists as the subjective perception and assessment of stress that the care-providing situation may represent.[60] Despite its apparent simplicity, the concept of burden itself has been criticized on the basis of its inconsistent conceptualizations and vague assessments.[61] Depending upon the author, burden may refer to multiple dimensions of caregiving including physical, psychosocial, emotional, and financial consequences and this conceptual discordance has lead to diverse forms of assessment.[60]

Contemporary and preponderant work has adapted Lazarus and Folkman's stress theory to suggest that caregiver burden represents the subjective lived experience of the caregiver, informed by their unique perception of their support role.[62] Hence, burden is akin to the initial appraisal step whereby the caregiver evaluates the stress level of the situation, incorporating judgements of resource availability.[60] Subjective burden, as a reflection of this appraisal process, mediates the demands of caregiving and resultant outcomes, including the outcome of caregiver burnout.[60] Current views define caregiver burnout as a tridimensional syndrome in response to the stress present within the caregiving context.[60]

To advance the stress and coping theory, several researchers have developed and evaluated models to explore the mechanisms of caregiving stress more profoundly, namely with respect to how it impacts the wellbeing of the individual beyond the outcome of burnout alone. One widely adopted model is the stress process model,[63] and another is the appraisal model.[64] The former conceptual model posits that the stress process is made up of four domains: the stress context, the primary stressors, the mediators of stress (e.g., coping, social support), and the manifestations or aftereffects of stress (e.g., depression, anxiety, physical health).[63] The latter appraisal model is similar to the stress process model inasmuch as it considers the caregiver's background (e.g., help received, existing health) and incorporates stress outcomes in the form of burden, negative affect, or depression.[64] However, the distinguishing feature of the appraisal model is its emphasis on caregiving appraisal, in acknowledgement that stress is a subjective experience.[64] Therefore, it may be affirmed that caregiver burden is a subjective occurrence that exists outside activity demands alone, emerging as an effect of individualized appraisal processes.

Successively, these traditional stress process and appraisal models were combined into an integrative model of dementia caregiver stress and burden.[65] As a whole, this model is more comprehensive and includes primary stressors, mediating secondary stressors, the subjective appraisal process, and exacerbating and mitigating factors.[65] Broadly, these factors interact within the caregiving context or background, which refers to the individual's socioeconomic status, ethnicity and culture, gender, and age.[65] Most recently, these aforementioned frameworks were coined as the Informal Caregiving Integrative Model (ICIM) by Gérain and Zech.[60] With a focus on burnout as a response to chronic stress, the principal goal of the ICIM is to highlight the importance of all relevant determinants of informal caregiver burnout in relation to the individual, their setting, and sociocultural context.[60] Together, these dimensions are mediated by the caregiver's appraisal of their situation, role, and relationship to the care-recipient.[60]

When considering these various perspectives and theoretical orientations discussed herein, it is clear that the informal caregiving experience may activate the stress process; however, this process and ensuant outcomes are inherently complex and dependant on the caregiver's background, interaction between stressors, subjective appraisal events, and widespread mediating factors. These elements suggest that examining systems of informal caregiver stress, burden, and burnout is a promising first step to assess caregiver health vulnerabilities and, even more ingeniously, catalyze the understanding of protective factors that may have the capacity to attenuate stress and personal exhibitions of burden.

1.2.5 Informal Caregiving in MS

To echo global caregiving trends, informal unpaid caregivers are the primary providers of support for those affected by MS.[66–68] Recent international figures suggest that the number of people living with MS is increasing overall and, thus, one would assume that this is paralleled by an increase in the prevalence of MS informal caregivers worldwide.[69] With that said, it is difficult to estimate the number of people affected by MS requiring care today as a result of the great variances in MS care needs and fluctuations in need over time as a function of the disease course and type.[70] One recent large-scale study conducted in the United Kingdom analyzed almost 17 000 people living with MS and suggested that 46% received informal care from friends or family members.[71] This figure may even underestimate the current reality, as some studies have reported that 58% of persons with MS require informal care and report at least one caregiver, with daily care requirements increasing proportionately with increasing disability levels.[70,72]

MS informal caregivers undertake tasks that offer emotional, physical, informational, and financial support,[73] and these support demands are the product of the inevitable challenges that accompany living with the variable cognitive, motor, and psychological symptoms of MS which often manifest in an unpredictable, non-linear, trajectory.[74] Studies report that the impact of the disease for informal MS caregivers can occur soon after diagnosis, prior to the emergence of notable disability and the corresponding physical demands of the caregiving role.[75,76] Moreover, even in the absence of marked disability in MS presentations, MS caregivers are subject to considerable psychological strain associated with the emotional and psychosocial support they must confer.[55,75,76]

The burden of those caring for persons affected by MS is thought to be exacerbated by many factors: the predominately young age at disease onset; the unpredictable disease course; the absence of a cure among disease modifying therapies; the episodic and progressive nature of the disease; and disabling functional and cognitive impairments.[77] Emergent research suggests that the impact of cognitive impairments in MS presents significant coping difficulties for their informal caregivers.[78] To understand adjustment in MS caregiving, evidence of the utility of the stress and coping model of Lazarus and Folkman has been demonstrated.[77] Consistent with this model, predictors of adjustment in informal MS caregivers include care-recipient characteristics, caregiver gender, social support, appraisal, and coping strategies.[77,79] Findings suggest that MS caregivers are subjected to multiple stressors that are responsible for a breadth of lifestyle intrusions, and consequently, MS caregivers report elevated levels of depression and distress when compared to non-caregiver community norms.[77]

Nevertheless, the experience of caregiving for a loved one is broad and remarkably dynamic, and is believed to not be, in essence, wholly positive or wholly negative.[80] Although the positive and negative impacts of informal caregiving are undeniably related, the positive impacts may be unaffected by the negative elements of the caregiving experience and flourish independently via their respective pathways.[60,64] In truth, caregiving is reasoned to be an activity of mixed valence for the caregiver, and the activity itself may be positively affirming and caregiving satisfaction may increase with demand.[64]

A range of evidence indicates that MS caregivers report varying benefits associated with their care providing role, such as personal growth, strengthening of relationships, finding meaning and joy, enhanced compassion and empathy, increased appreciation for life, and an

advantageous change in goals.[47,79,81–83] Topical findings suggest that tasks in MS caregiving are far from solely detrimental to wellbeing, and also may elicit a positive contribution to the caregiver through the development of adaptive coping strategies, such as positive reframing and supportive engagement.[84] This variability in the caregiver experience, in conjunction with the coexistence of both benefits and hardships associated with the caring role, suggests that certain caregivers are better equipped to adapt to the demands of their role than others as they engage in positive caregiving trajectories separately from subjective experiences of burden. In turn, this fact emphasizes the importance of identifying protective factors that buffer against the potential adverse effects of caregiving, while simultaneously empowering caregivers and reinforcing the known positive benefits of their role.

1.3 PSYCHOLOGICAL RESILIENCE

1.3.1 Conceptualizations and Measurements of Resilience

One protective factor that is garnering increased research attention is psychological resilience.[85] In general, resilience possesses many overlapping meanings and uses, which have become exacerbated by its growing popularity.[86] From the physical sense, resilience may refer to the body's ability to withstand or recover from trauma or injury and is frequently present in aging literature, defined as the ability to resist functional decline.[87] However, most interest in the human capacity for resilience focuses on psychologically resilient functioning as an inquiry of the social sciences. Within this realm, psychological resilience is traditionally viewed as an important *way* of coping and, in turn, may be empirically differentiated from coping itself.[88] This is because one may have both problematic and positive means of coping, and conceptually

resilience processes are wholly defined within the domain of the latter, whereby positive developmental outcomes are achieved over time in relative equilibirum.[88] Henceforth, resilience may be distinguished from coping through its endurant presence of successful developmental outcomes, and may include problem-focused or emotion-focused strategies, though it exists at a broader conceptual level.

With its distinction from coping, the blossoming scholarly interest in psychological resilience within the caregiving realm is a product of a transition from a deficit model of caregiving to a model that fixates on healthy development in spite of risk exposure and vulnerabilties.[89] In truth, emerging resilience theory converges on strengths rather than weaknesses.[89] However, due to its interdisciplinary origin, psychological resilience is a complex and nuanced phenomenon and many scholars of health and behavioural sciences struggle to consistently define and measure the elusive concept.[90] Some studies suggest that resilience represents personal qualities or attributes that enable individuals to thrive despite adversity,[91] or even that resilience is a personality trait characterized by stability, resourcefulness, flexibility, and the ability to 'bounce back' in order to overcome adversity.[92,93] Nonetheless, the examination of resilience via assessments of personality characteristics remains a point of contention within the literature.[93] As resilience research has evolved, the focus of studies has moved away from exclusively identifying key factors or correlates of resilience in tandem with its supposition as a fixed singularity or personality chracterisitc.[93] Alternatively, scholars have migrated to now seek to identify and understand the mechanisms by which resilience factors operate, conceptualizing resilience as a dynamic *process*.[93]

In this reframed context, resilience is operationalized, in short, as a "dynamic process encompassing positive adaptation within the context of significant adversity."[93(p156)] Resilience describes processes and patterns of protective adaptations that contribute to positive wellbeing outcomes despite exposure to stressors or adverse events that pose a notable risk to physiological or psychological health.[93,94] The examination of resilience has historically emphasized the avoidance of deleterious outcomes.[95] This remains true as, without argument, resilience refers to 'bouncing back' from challenging experiences or moving forward in the face of hardship.[93,96] To inform the debate encircling the nuanced construct of resilience, Windle (2011) conducted an extensive review of over 270 resilience-related primary research articles, synthesized via concept analysis and stakeholder validation, ultimately generating the following definition: "Resilience is 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. Across the life course, the experience of resilience will vary."[93(p163)] Within this definition, it is important to consider the timeframe in which resilience transcends as a constellation. Indeed, unlike coping processes that refer to short-term temporal periods, resilience may refer to the expression of stability or unchangeability over time because of the regulation of coping processes over time. As such, this definition quoted above will be consistently applied throughout this thesis.

The advancement of resilience science, in addition to the evaluation of interventions and policies designed to promote resilience, demands the development of reliable and valid measures to ensure data quality.[97] However, as a reflection of the complexity of defining the

construct of resilience and the lack of a unanimous operationalized resilience definition, a 'gold standard' resilience measure has yet to be established. Some common scales used to quantitively measure resilience include the Resilience Scale (RS),[98] the Connor-Davidson Resilience Scale (CD-RISC),[91] and the Resilience Scale for Adults (RSA).[99] Across studies, divergent approaches towards quantitatively measuring resilience have obscured estimates of resilience prevalence, and given rise to inconsistencies relating to the magnitude of association between resilience and protective processes and risk factors, as well as potential downstream wellbeing outcomes.[85,97] Broadly, this inconsistency within resilience assessments effectively undermines the interplay between important interacting elements and optimal resilience processes.[97]

Prominent resilience scholars conducted a methodological review of resilience measures and determined that the majority were missing some form of key psychometric information.[97] This is due, in part, to the absence of an widely accepted standard available for criterion validity, therefore validity must be established indirectly via construct validity.[97] This represents a continued limitation in resilience measurement, which may extend further into the resilience field. Lastly, regarding interpretability and relevance, clarification of clinically meaningful changes in resilience scores and sub-scores are rarely specified. When considering all quality criteria, most resilience scales currently available possess moderate levels of quality. Some scales, such as the CD-RISC and RSA, possess high quality ratings and have been commendably developed for use within adult populations,[97] although they have yet to be rigorously validated among caregiving-specific populations.

1.3.2 An Ecological Framework of Resilience

To capture caregiving challenges and the mechanisms by which resilience functions within the caregiving context, several studies[100–102] have applied the Ecological Model of Resilience (refer to Figure 1) developed by Windle and Bennett (2011).[103] This framework emphasizes that the outcome of resilience is not expressed via superior functioning or remarkable flourishing; rather, it reflects the maintenance of normal or 'better than anticipated' development or functioning (e.g., physical or mental wellbeing), despite exposure to the obstacle in question.[103] In essence, resilience refers to an equilibrium state of operation, whereby one's health does not flounder in the wake of inimical events. In summary, the literature concurs that there are three core elements of resilience which align within an ecological model: 1) an encounter with adversity or cause of distress; 2) the ability to resist or adapt to said adversity via a range of assets and resources; and 3) the achievement or preservation of positive outcomes in the face of such adversity.[100]

The resilience framework advances the notion that resilience operates across multiple levels, which perpetually interact with one another.[103] These levels mirror the human ecology framework,[104] which has increasingly permeated into resilience literature.[105,106] Building upon this theory, this framework aims to comprehend people within their interplaying physical, social, and environmental contexts, instead of positioning them within an isolated social vacuum.[103] This framework identifies a number of assets, both fostered within the individual or their surroundings, that may enhance caregiver risk or, alternatively, act to foster resilience.[103]

Quite simply, resilience may be derived from various individual, community, and societal resources.[101,103] Individual resilience resources typically include psychological resources (e.g.,

mastery, personal control, self-esteem),[101] biological resources (e.g., gender, age), health behaviours (e.g., personal traits and lifestyle interests), and material resources (e.g., income, financial means).[103] Community level resilience resources, available in geographically close or neighbouring regions,[101] encompass social support (i.e., from friends or family), social cohesion or participation (e.g., support groups, religious groups), and housing.[101,103] Resilience resources at the societal level consist of social policies, laws, the economy, national associations, government agencies, and general health and social services (e.g., respite services, homecare, long term care).[101,103] Many factors, including culture, religion, gender, and sexuality may be intertwined within these complex structures.[101] Henceforth, resilience bears a multidimensional nature, and may be cultivated simultaneously within the individual, their immediate surroundings, and their social environment.[100,103]

1.4 RESILIENCE IN THE CAREGIVING CONTEXT: CURRENT EVIDENCE

1.4.1 Resilience and Caregiving in Dementia and Other Chronic Illnesses

When considering resilience in the context of caregiving, the majority of the research has focused on caregivers of older adults and people living with dementia.[103] These studies provide evidence identifying a variety of influential resilience factors. For example, in a qualitative study, factors at all three levels of the Ecological Model of Resilience – individual (psychological and material resources), community (family relations, social support, participation, and cohesion), and societal (health and societal care, other services) – facilitated resilience among older spousal caregivers of persons with dementia.[100]

In contrast, a systematic review outlined primarily individual factors (context of caring, dementia symptomology of care-recipient, caregiving duration, coping style, personality characteristics, ethnicity, and culture) as major components of resilience among dementia caregivers.[107] Still, authors acknowledged that resilience may be enhanced via multiple pathways and was not dependent on select predetermined factors.[107] Additionally, a longitudinal study reported that caring for a woman, having provided care for a longer duration of time, and having utilized greater formal and informal community and societal resources (i.e., in-home help services, overnight hospital services, and extra help from friends and family), predicted higher resilience levels at baseline.[108]

More recently, a cross-sectional survey study concluded that emotional and informational social support exerted the greatest influence on resilient coping among dementia caregivers.[109] Caregivers who perceived greater access to tangible support were also more likely to be highly resilient.[109] Likewise, greater availability of affectionate support and positive social interaction predicted high resilience.[109] Merely one individual factor, gender, was identified as a significant predictor, with women being more likely to report high resilience.[109] Moreover, a newly published systematic review – centered on resilience in caregivers of persons with chronic, advanced, and end of life illness – determined that resilience was associated with improved caregiver quality of life and decreased emotional distress and, in turn, alleviated caregiver burden.[110] In congruence with previous work,[109] social support and positive communication were found to support resilient coping strategies in the same systematic review.[110]

1.4.2 Resilience in the Context of MS and MS Caregiving

Despite the fact that resilience is becoming increasingly examined in caregiving research in a variety of populations, the literature specific to resilience in MS is scant and resilience literature related to MS caregivers is relatively non-existent. One qualitative study exploring healthy aging in persons with MS did identify resilience as a subtheme,[111] but the study itself failed to provide a detailed description of resilience, nor an examination of its underlying mechanisms. Another cross-sectional survey study linked resilience to self-compassion and enhanced quality of life in persons with MS.[112] Psychosocial findings related to resilience in MS suggest that the association between social support and superior wellbeing may, in fact, be mediated by resilience.[113] In line more with the field of exercise physiology, recent research has even reported significant associations between psychological resilience and functional outcomes (i.e., strength and gait endurance) in persons with MS who have moderate disability levels.[114]

To our knowledge, only one qualitative focus group study has incorporated MS caregivers in their examination of resilience. Specifically, in this study MS caregivers (in addition to community stakeholders) were asked to respond based upon their experiences with people who have MS and how they perceive those individuals themselves exhibit resilience,[115] rather than how the construct of resilience pertains to their personal self. In this study by Silverman and colleagues (2017), persons with MS were also polled in focus groups to provide direct testimonies which detailed their understanding of resilience and related barriers and facilitators.[115] Although phenomenological analysis was not conducted separately by each of the three participant groups, and thus resilience insights specific to MS caregivers were not

obtained, participants found it challenging to generate concise definitions of resilience, but managed to provide profoundly expressive descriptions.[115] Facilitators of resilience emerged predominantly at the individual level, including psychological adaptation, social connection, finding life meaning, planning and physical wellness.[115] Contrarily, resilience depletion, negative thoughts and feelings, social limitations, social stigma and physical fatigue emerged as barriers to resilience.[115]

1.5 RATIONALE AND STUDY OBJECTIVES

As resilience garners increasing attention in the caregiving literature, it is clear that resilience is an important avenue to cultivate wellness within this vulnerable cohort. However, in order to explore resilience processes in specific populations and contexts, it is important that the current relevant literature is synthesized to formulate a conceptual and methodological foundation for novel research endeavours. Overall, resilience literature supports the notion that a broad range of factors influence caregiver resilience, yet incongruence among scholars with respect to the conceptualization and measurement of resilience within the literature is evident, which presents a challenge for future resilience research and practice.[116] Improving our understanding of resilience as a construct, while strengthening the reliability of its measures and clarifying associated factors, will better reveal how resilience capacities may be leveraged and verified clinically to better support CNC caregivers in their role. As such, a narrative synthesis of the current literature involving psychological resilience in CNC caregiving is warranted and represents an essential step in laying the groundwork for future explorations of

resilience in understudied MS caregiver groups, as well as to guide clinical decision-making and policy developments tailored to the MS-specific caring population.

As the literature in resilience and caregiving approaches saturation in caregivers of older adult populations and some CNC populations such as dementia, AD, and even PD, resilience research in MS caregivers remains starkly absent from this breadth of work. The lack of representation of MS in the resilience and caregiving literature is particularly problematic because MS caregivers represent a unique caregiving population with a complex role that typically transverses many life stages. The study conducted by Silverman and colleagues (2017) and others[117] left us with an indisputable conclusion: MS elicits an incomparable caregiving experience due to the early onset of disease, lengthy life-expectancy, heterogeneity of symptoms, innate unpredictability, and accumulating physical and emotional losses without cure. Indeed, the MS caregiving role in inextricably linked with the disease experience which pervades many significant life stages including parenthood and career-building. In truth, MS informal caregivers must provide unwavering daily support for their loved ones, whilst often not even knowing what the next day, month, or year will bring as a product of the disease. Unquestionably, such adversity merits some magnitude of resilience, as novel sources of adversity are imminent with the unavoidable advancement of disease activity and, in turn, disability accumulation within their partner or family member.

Hence, the purpose of this thesis was twofold: (i) to summarize and critically examine the current literature investigating psychological resilience in CNC informal caregivers using a systematic review approach; and (ii) to explore the conceptualizations and experiences of resilience more narrowly in MS informal caregivers through one-on-one interviews. To achieve

the former, we opted for a systematic review approach; systematic reviews are broadly defined as a form of research synthesis intended to identify and retrieve evidence relevant to a particular issue and to appraise and synthesize the results of the search to inform practice, policy, and future research.[118] Historically, systematic reviews have been used to summarize evidence of effectiveness, which has been prevailingly generated by randomized controlled trials (RCTs) and meta-analyses. However, health practitioners assert that they are concerned with more than cause and effect questions to inform evidence-based practice and, in response, systematic reviews have expanded to synthesize more diverse research inquiries, including qualitative and mixed-methods.[119]

Contrarily, a scoping review is described as a process of broadly mapping the existing literature or evidence base of a particular domain, often used to identify gaps and parameters of a body of literature.[120] Instead of the broader scoping review methodology, we pursued a systematic review approach comprised of a focused research question and narrow parameters for two principle reasons: (i) to provide sound, structured evidence to inform practical applications, while similarly stimulating resilience-promoting policy development; and (ii) to investigate inconsistencies and conflicting results within the resilience literature to provide critical ground work for resolving such conflicts.[118]

Consistent with the ecological resilience framework for caregivers, this thesis also aimed to qualitatively examine key resilience facilitators at the individual, community, and societal levels. The identification of advantageous resource areas for resilience development, while simultaneously pinpointing areas with problematic deficiencies for resilient systems, are both crucial for lasting advancement in resilient processes and represents the first step in designing

solutions which address key resilience barriers. Obtaining narrative insights into the distinct experiences of MS caregivers is imperative for the sequential development of tailored strategies, programs, and interventions to satisfy support needs and promote resilience in this population. Though resilience is a novel and nuanced construct, this thesis advances the assertion that it is an essential facet of caregiver wellbeing and warrants profound multi-method and integrative research investigation.

CHAPTER 2: PAPER 1

Towards conceptual convergence: A systematic review of psychological resilience in informal caregivers of persons living with chronic neurological conditions

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Preface: This article included collaboration between myself and all authors. The search strategy was finalized and conducted in consultation with a health sciences librarian, Nigèle Langlois. Article screening and data extraction was accomplished by myself, Ms. Cardwell, and Ms. Jiang. The writing and presentation of the introduction, methods, results, discussion, and conclusion was completed mainly by myself, with significant contribution and revisions from Dr. Fakolade, Ms. Cardwell, and my supervisor, Dr. Pilutti.

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2.1 ABSTRACT

Background: The demand for informal caregiving in persons with chronic neurological conditions (CNCs) is increasing. Psychological resilience, which describes the process of maintaining positive adaptations in the face of adversity, may empower and protect caregivers in their role. Thus, synthesis of resilience evidence within this specific population is needed.

Objective: In this review, we aimed to: 1) examine origins, theoretical frameworks, and conceptualizations of resilience; 2) summarize current resilience measurement tools; and 3) synthesize predetermined correlates, predictors, and outcomes of resilience within informal caregivers of persons affected by CNCs.

Methods: We sourced peer-reviewed English articles published up to July 2020 across five databases using relevant search terms involving CNCs, informal caregivers, and resilience.

Results: A total of 50 studies were retained. Nearly half (44%) of retained studies used trait-based resilience definitions, while a portion (36%) used process-based definitions. Twelve different resilience scales were used, revealing mostly moderate-high resilience levels. Authors affirmed that resilience is related to multiple indicators of healthy functioning (e.g., quality of life, social support, positive coping) as it buffers against negative outcomes of burden and distress. Discordance relating to the interaction between resilience and demographic, sociocultural, and environmental factors was apparent.

Conclusions: Incongruity remains with respect to how resilience is defined and assessed, despite consistent definitional concepts of healthy adaptation and equilibrium. The array of implications of resilience for wellbeing affirms the potential for resilience to be leveraged within caregiver health promotion initiatives via policy and practice.

Patient or Public Contribution: Findings may inform future recommendations for researchers and practitioners to develop high-quality resilience-building interventions and programs to better mobilize and support this vulnerable group.

2.2 INTRODUCTION

Chronic neurological conditions (CNCs) represent the leading cause of disability and the second leading cause of death worldwide.[27] Globally, it is estimated that approximately one billion people, roughly one in six of the world's total population, are currently living with a CNC.[27] These conditions possess an enduring time course, and are associated with various complex symptoms, including cognitive impairments, behavioural and psychological problems, and marked physical deficits.[25,26] Neurological symptoms and their accompanying disability present challenges for the individual, as independence, functioning, and the ability to manage life roles (e.g., employment) are limited. For instance, studies of progressive CNCs (e.g., MS and PD) have reported that the challenges associated with physical and cognitive disability management contribute to elevated unemployment rates.[32] These findings reflect limitations in the ability to perform occupational and social roles within afflicted populations.[32–34]

Disability associated with CNCs results in many persons with these conditions requiring care and support from others to carry out tasks of everyday living, particularly within the home.[35,36,53,121] This role is typically fulfilled by an informal caregiver – an individual who has the responsibility of providing unpaid care for family members or close friends.[37] Caregivers often experience role overload, financial strain due to lost income, and are unequipped to provide ongoing and complex support for their care-recipients.[36,122] The extent of this ongoing commitment can culminate in adverse mental and physical health outcomes.[49,122] For informal caregivers of persons with CNCs, the caregiving role may contribute to increased stress, depression, anxiety, social isolation, and poorer reported quality of life in comparison to the

general non-caregiving population.[49,50,62,123] This phenomenon is referred to as *caregiver burden*.[55]

Indeed, depleted caregiver wellbeing or burden impacts the caregiver's ability to provide sufficient support, and is further linked with increased rates of institutionalization of people living with CNCs.[124] Nevertheless, the experience of caring for a loved one with a CNC is broad, dynamic, and rarely uniform.[80] Despite facing difficulties, some caregivers experience fewer caregiving consequences, and report rewarding and fulfilling aspects of providing care (e.g., personal growth, strengthening of relationships, enhanced compassion),[47,81] and positive health outcomes (e.g., reduced depressive symptoms).[125,126] Such variability in experience suggests that not all caregivers are harrowed by burden, and that certain caregivers are better equipped to succeed in their role than others. Thus, further exploration of proactive and protective strategies which may buffer against the negative effects of burden is needed, and this review seeks to address this gap in knowledge.

To account for this variability, research in the caregiving field is becoming increasingly focused on a protective construct– resilience – which, when described briefly, denotes caregivers' ability to adapt to the physical and psychological requirements of their role.[85,101] This transition echoes a paradigm shift in research from a burden-centred caregiving model to a strengths-based model that fixates on healthy development in spite of health risks.[89,96] Still, there remains ample debate among the literature regarding how psychological resilience is defined. Traditionally, *trait definitions* are used to conceptualize resilience, whereby researchers illustrate resilience as a fixed personal attribute or inherent ability.[92,93,127] This distinction suggests that resilience is stable and unmalleable across the lifespan.[127] More

recently, scholars have investigated the adaptive mechanisms underlying resilience, conceptualizing resilience as an active dynamic *process*.[93] Defining resilience as an adaptive process accepts that resilience may fluctuate in the face of different challenges and stages of the life course and, in turn, is modifiable.[103,127]

Despite the historical contention, most scholars converge on three core components of resilience: 1) an encounter with adversity; 2) the ability to resist or adapt to said adversity; and 3) the achievement of positive outcomes.[100] To further apprise the debate encircling resilience, Windle (2011) conducted an extensive review of over 270 resilience-related studies, generating the following definition: "Resilience is 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. Across the life course, the experience of resilience will vary."[93(p163)]

Evaluation of interventions and policies intended to foster resilience are dependent upon reliable and validated measures. As a reflection of the ambiguity of the resilience construct, a number of resilience measures are available, with minimal progress towards a standardized measure for broad applications.[91,97,128] A methodological review of fifteen resilience scales determined that the Connor-Davidson Resilience Scale (CD-RISC),[91] the Resilience Scale for Adults (RSA),[99] and the Brief Resilience Scale (BRS)[129] obtained the highest ratings among authors, despite quality and psychometric defficiencies.[97] Most scales reflect the availability of assets that contribute to resilience (e.g., CD-RISC, the Resilience Scale)[98] or evaluate resilience as an outcome of the capacity to 'bounce back' (e.g., BRS).[97,128] Certain quantitative instruments measure resilience as both an outcome and process of coping (e.g.,

RSA).[128] Presently, few measures are available to account for the complexity of resilience from a multilevel and temporal perspective.[97] With limited access to quality scales developed for use in the general adult population, researchers lack robust evidence to inform their choice of resilience measure for differing target populations and contexts.[97]

To understand caregiving challenges and the mechanisms by which resilience operates within the caregiving context, multiple studies[100–102] have used the Ecological Model of Resilience.[103] This model suggests that resilience operates fluidly across multiple inter-related levels including individual, community, and society.[103] This model identifies resources and assets, existent within each of these levels, that may enhance caregiver risk or, alternatively, act to foster resilience.[103] More recently, O'Dwyer and colleagues proposed a model of resilience in caregivers that conceptualizes resilience as a cyclical process, while accounting for the variable context in which the individualized experience of adversity occurs, with varying progressions and magnitudes.[116]

Dissonance persists in the resilience and caregiving literature. A qualitative study among dementia caregivers found that caregivers did not agree on whether resilience was a trait or process, nor could they concur on the factors associated with resilience and its causal pathways.[116] Similarly, a systematic review outlined mainly individual factors as major components of resilience among dementia caregivers; however, the authors acknowledged that there is no single avenue to increase resilience.[107] A recent systematic review determined that resilience was associated with improved caregiver quality of life and alleviated caregiver burden in end of life and palliative care contexts, although authors observed a lack of interest in other psychological aspects that may contribute to resilience.[110]

Although the literature supports the notion that a broad range of factors may influence caregiver resilience, the lack of congruence with respect to the conceptualization and measurement of resilience within the literature presents a challenge for future research and practice.[116] Enhancing our understanding of resilience, its measures, and associated factors will delineate how resilience capacities may be leveraged and monitored clinically, via intervention, programs, and service development, to better support CNC caregivers in their role. The objective of this systematic review was to synthesize and assess the current scientific literature on the concept of resilience in CNC informal caregivers. We aimed to: 1) critically examine origins, theoretical conceptualizations and definitions of resilience; 2) synthesize current resilience measurement tools; and 3) summarize correlates, predictors, and outcomes of resilience.

2.3 MATERIALS AND METHODS

Our protocol was registered in the PROSPERO database (CRD42020206662). This systematic review was executed in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement and reporting guidelines (see PRISMA 2020 Checklist – Appendix 2).[130]

2.3.1 Search Strategy and Selections

A peer-reviewed search strategy[131] was developed in consultation with a health sciences librarian. Five databases (MEDLINE(R) (Ovid), Embase Classic+Embase (Ovid), PsycINFO, CINAHL (EBSCO), and Web of Science Core Collection) were searched to locate relevant articles

published from inception to July 27, 2020. The databases were selected to source peer-reviewed articles across a variety of disciplines including nursing, medicine, behavioural sciences, and multidisciplinary fields. As a result of the degree of novelty of our search concepts, no limits to language or publication date were applied. Searches were limited to "human", where possible. Reference lists were reviewed for additional publications. Relevant search terms were categorized into three distinct themes: CNCs, informal caregivers, and psychological resilience (see Appendix 1).

2.3.2 Eligibility Criteria

Following a modified PICO framework,[132] we included quantitative, qualitative or mixed-methods studies that focused on psychological resilience among community-dwelling adult informal caregivers (≥18 years old) of adults with CNCs (see Table 1). Depending on their origin and etiology, CNCs are typically divided into four groups: 1) sudden onset conditions (e.g., acquired brain injury (ABI), spinal cord injury (SCI), traumatic brain injury (TBI)); 2) intermittent conditions (e.g., epilepsy); 3) progressive conditions (e.g., dementia, MS, PD, motor neuron disease (MND) and other neurodegenerative disorders); and 4) stable with/without age-related degeneration (e.g., polio or cerebral palsy).[25] Articles that were not available in English were excluded. We excluded meta-analyses, dissertations, systematic reviews, case reports, opinion pieces, commentaries, and grey literature.

2.3.3 Screening process

Retrieved articles were managed using Covidence online systematic review software (Veritas Health Innovation Ltd, Melbourne, Australia). One author (NL) ran the initial search, and another (LP) merged the results into Covidence, where electronic data could be exported, tracked, deduplicated, and managed. A two-stage screening process was used to determine eligibility for inclusion. Articles were first screened for relevance by title and abstract by three reviewers (OM, KC, KJ), with the intention of retaining only articles which involved resilience (i.e., resilience was directly referred to in the title or abstract). Any articles with ambiguous representations of resilience were conservatively retained to the next level of review. In the second stage, full texts were reviewed based on eligibility criteria. Agreement of two reviewers (OM and KC) was required for article inclusion at this stage, resulting in 100% inter-reviewer agreement. Discrepancies between reviewers were resolved by a third party (LP).

2.3.4 Data Extraction

Data were extracted using an Excel template developed by the research team. The following parameters were extracted: a) study information (i.e., author, year, country, purpose, design, recruitment setting, and sample size); b) participant characteristics (i.e., age, gender); c) caregiving context variables (relationship to care-recipient, CNC); and d) resilience components (operationalized definition of resilience, source of definition, measure of resilience, resilience score, resilience-related results). Two independent reviewers completed the data extraction (OM and KC). Once both reviewers completed their respective extractions, results were compared, and any discrepancies were discussed in detail and clarified in a consensus meeting.

If consensus among reviewers was not reached, the final decision was made by the supervising author (LP). Authors were contacted for missing data in included studies.

2.4 RESULTS

Following the removal of duplicates (*n* = 3835), 7339 studies remained to be screened (see Figure 2). The title and abstracts of these studies were screened, and 207 articles advanced to full-text screening. Following our review, 49 publications met the inclusion criteria. An additional publication was located by reviewing the reference lists of included articles. Thus, a total of 50 publications were retained. Articles reporting data from the same participant population at different time points are reported together.

2.4.1 Study Characteristics and Caregiver Sample Demographics

2.4.1.1 Study characteristics

Most (*n* = 46, 92%) studies were published within the last ten years of conducting our search (i.e., during or after the year 2010). The majority of studies originated from Europe (*n* = 20, 40%)[100,109,133–150] and North America (*n* = 20, 40%);[80,101,151–168] followed by Asia (*n* = 4, 8%),[169–172] South America (*n* = 4, 8%),[173–176] and Australia (*n* = 2, 4%).[177,178] Across studies, the sample size ranged between 18[156] and 691.[166,167] Most of the quantitative studies were cross-sectional (*n* = 34, 68%) or longitudinal in design (*n* = 1, 2%). Only four (8%) studies were intervention-based.[155,160,170,171] Seven (14%) studies used a qualitative design involving semi-structured interviews,[100,136,137,158,159] open-ended questionnaires,[80] or content analysis.[101] Four (8%) studies adopted a mixed-methods design.[139,156,157,172]

2.4.1.2 Caregiver demographics

A total of 5992 caregivers were sampled across studies. As depicted in Table 2, the mean age of caregivers ranged between 40[162] and 76[163] years. Most caregivers were women (55-97%).[153,173] The majority of the caregivers were cohabitating spouses or partners (*n* = 2898, 48%), followed by offspring or children (*n* = 1674, 28%), parents (*n* = 353, 6%), siblings (*n* = 167, 3%), grandchildren (*n* = 58, 1%), or undisclosed 'other' (*n* = 838, 14%) such as friends or other relatives.

2.4.1.3 Chronic neurological conditions

The most commonly reported CNCs were progressive conditions (*n* = 43, 86%). A substantial portion (*n* = 37, 74%) of the progressive conditions studied were dementia, Alzheimer's disease (AD), or other dementias (e.g., mixed, vascular). The remaining progressive conditions were PD (*n* = 2, 4%), PD related dementia (*n* = 2, 4%), and MND (*n* = 1, 2%). Few studies (*n* = 7, 14%) included sudden onset conditions including SCI,[143,145,152,177] ABI,[134,145] and TBI.[162,177,178] No studies included intermittent (e.g., epilepsy) or stable (e.g., polio, cerebral palsy) conditions.

2.4.2 Conceptualization, Measurement and Levels of Resilience

2.4.2.1 Resilience conceptualizations

Certain (*n* = 7, 14%) studies minimally or unclearly defined resilience,[160,171] briefly presenting it as a general protective psychological factor,[135,145] or simply in relation to stress[141,142] or positive coping.[133] The remaining articles (*n* = 43, 86%) offered some type of a

theoretical resilience definition (refer to Table 4). When broadly discussed, the vast majority of included articles incorporated the idea of healthy adaptation into their conceptualizations of resilience. Further, most referred to preserving some level of wellbeing, equilibrium, or positive functioning in the face of adversity. Many (*n* = 13, 26%) studies referred to the significance of internal and external resources, protective factors, and relational and situational contexts in facilitating resilience development.[100,136–140,144,150,152,159,163,168,178]

Beyond these commonalities, researchers differed in terms of whether they defined resilience as a multidimensional process or personality trait. On one side of this discordance, some studies' (*n* = 8, 16%) language illustrated resilience as a personal quality, skill, or attribute enabling caregivers to adapt in the experience of hardship.[109,140,149,152,155,161,163,178] Comparably, resilience was described in articles (*n* = 7, 14%) as an individual's ability or capacity to adjust successfully and maintain normal functioning despite adverse trauma,[148,150,158,165,166,174,175] alluding to the belief that resilience is a fixed competence. In fact, one study's central purpose was to test the hypothesis that caregiver resilience is a personality trait, after which they concluded that resilience is, indeed, an individual characteristic.[175] Thus, a total of 22 (44%) studies explicitly advanced trait definitions of resilience.[80,101,135,141,142,144–146,148,150,151,155,157,161,165–169,174–176] In contrast, a substantial portion (*n* = 18, 36%) of researchers opted for construing resilience as a dynamic process.[100,109,134,136–140,147,153,154,156,159,162,164,170,172,177] Some (*n* = 7, 14%) authors used a more mixed model of resilience, presenting the concept of resilience as a hybrid of both a personality characteristic and an evolving process.[143,149,152,158,163,173,178]

2.4.2.2 Origins of resilience definitions

Authors conceptualized resilience in a diversity of forms, citing numerous sources in support of their interpretation. The majority of authors interpreted resilience from a combination of sources, electing to not advance a singular coined definition. Few studies specified the use of a specific resilience theory or framework. Of the frameworks explicitly included, The Ecological Resilience Framework[103] applied to caregivers was most common and incorporated in four studies (8%).[100,101,136,137] Two sets of original resilience theorists were frequently accredited as the primary source of authors' understanding and characterization of resilience. These theorists include: 1) Wagnild and Young[98] who offer a trait-based resilience definition; and 2) Windle and colleagues who conceptualize resilience as an unfixed process.[93,103] The former was utilized in some (*n* = 4, 8%) studies;[155,161,174,176] and the latter was found in multiple (*n* = 8, 16%) studies.[100,136–139,154,159,162]

2.4.2.3 Measurement and levels of resilience

In quantitative and mixed-methods studies, twelve different instruments were used to measure resilience. A summary of the characteristics of these twelve scales is presented in Table 5. Three (6%) studies used caregiver-specific measurements.[134,171,172] The most commonly used resilience scale was the Resilience Scale (RS) by Wagnild and Young.[98] Twelve (24%) studies[143,155–157,161,163,164,173–177] used the full version of the scale, whereas four (8%) studies used the short form.[151,166–168] A second common scale was the CD-RISC.[91,179] Seven (14%) studies used the full version of the CD-RISC,[135,149,150,160,165,170,178] while one (2%) study used a shortened form.[145] Another commonly used scale was the six-item BRS,[129] reported in seven

(14%) studies,[133,141,142,148,152,154,169] Original validation of the included scales reported acceptable to strong internal consistency (α =.67-.95). Several (18%) of retained studies assessed resilience scale reliability within their caregiver samples,[144,147,148,152,154,164,170,171,173] demonstrating acceptable to strong internal consistency (α =.73-.96). Three (6%) studies developed and validated instruments to measure caregiver resilience,[134,151,172] and reported strong reliability (α =.87-.96).

Most quantitative and intervention studies assessed and reported the level of resilience among sampled caregivers. However, the majority of studies (*n* = 22, 44%) did not interpret these resilience measures in reference to scale-based criteria nor in comparison to other populations; instead, most attended to other resilience-related results, incorporating resilience as a modulator, outcome, or into higher-level models. Within those that did measure and interpret resilience as a continuous variable, sampled caregivers demonstrated moderate-to-high resilience levels in seven (14%) articles;[143,156,161,168,169,173,175] while two (4%) articles also inferred low resilience levels in a minority of participants.[143,156] Numerous studies (*n* = 10, 20%) sought to categorically classify participants into different resilience groups, either as resilient or non-resilient,[100,136,137] or in some version of low, medium, or high resilient groups.[109,139–142,162,177]

2.4.3 Correlates, Predictors, and Outcomes of Psychological Resilience

2.4.3.1 Sociodemographics and contextual resources

Twelve (24%) studies examined sociodemographic or contextual factors including gender, injury or disease severity, and clinical symptoms associated with

resilience.[109,138,142,143,145,152,162,169,173–176] Our synthesis revealed heterogeneity in studies reporting the relationship between sociodemographic and clinical characteristics and resilience. Six (12%) articles demonstrated that demographic, CNC severity, clinical, and health status variables were not significantly related to caregivers' resilience levels.[143,162,173,175–177] Contrarily, findings from 11 (22%) studies indicated that demographic and clinical variables were significantly related to resilience, including income,[147,171] employment status,[169] gender,[109,157,169,171] ethnicity,[167,171] age,[157] and dementia severity.[174]

Income was positively associated with resilience in one study[133], while being of middle or upper class was positively associated with resilience in another study. [157] In one study, being unemployed or a fulltime homemaker was positively correlated with resilience.[169] The relationship between gender and resilience was inconsistent; two studies associated being a woman with higher resilence scores,[109,171] while two studies found the opposite, reporting positive associations with being a man and resilience scores.[157,169] Different ethnic groups were shown to have higher resilience levels, inlcuding African Americans in comparison to Caucasions in a North American sample,[167] and Hindus in comparison to Buddhists in a South Asian sample.[171] Finally, one study reported that advanced age was postively associated with resilience scores,[157] and another study reported that resilience increased with clinical dementia severity.[174]

Three (6%) studies investigated resilience resources or assets – markers that are typically positioned conceptually upstream to resilience development. For instance, studies broadly examined resilience resources at multiple ecological levels.[100,101,137] In three (6%) explorative articles, resilience resources emerged at the individual, community, and societal

levels.[100,101,137] In five (10%) cases, resilience was related to specific behaviours, such as treatment uptake,[146,160] private prayer,[165] and likelihood of care-recipient abuse or neglect.[135,150]

2.4.3.2 Social support and relational outcomes

Social support availability was a predominant construct assessed as an antecedent to resilience.[109,136,150,152,154,168] Among three (6%) studies, social support was repeatedly predictive of resilience,[109,154,168] with emotional and informational support the most likely to predict resilience. More specifically, four (8%) studies examined the association between resilience and relationship outcomes, including relationship satisfaction[141,152,163] and family dynamics.[147] Three (6%) studies determined that resilience was positively linked to romantic relationship benefits,[152] relationship satisfaction,[141] and family dynamics (e.g., empathy, family problems).[147] However, another study did not find resilience to be significantly correlated with marital satisfaction.[163]

2.4.3.3 Caregiver burden

A pattern across study objectives emerged, such that resilience was conceptually explored as a protective factor in opposition to caregiver burden. Indeed, numerous (*n* = 13, 26%) studies sought to examine the relationship between psychological resilience and burden.[141–144,149,157,164,165,167,169,174,177,178] A key finding congruous across 12 (24%) reviewed studies was that caregiver burden was inversely associated with resilience.[139,141–144,149,164,165,167,169,177,178] Occasionally, caregiver burden was investigated in tandem with other

variables reflective of wellbeing such as life satisfaction,[143] positive or negative affect,[177] social support,[149,167] general distress,[157,164] quality of life,[174] and coping.[165] Within seven (14%) studies that evaluated the association between resilience and burden, resilience was significantly and positively linked to multiple wellbeing outcomes, namely relationship satisfaction,[143] positive affect,[177,178] social or spiritual support,[135,167] quality of life,[174] and coping.[178] In fact, in one recent study, social support mediated the relationship between resilience and burden.[149]

2.4.3.4 General health outcomes

Independently of burden, resilience was explored in direct association with a number of positive and negative health outcomes; these variables consisted of psychological distress,[139,145,148,152,156,160,161,168] health-related quality of life,[148,160,162] mental health,[133,153–155,170] and coping strategies.[161,166] Three studies (6%) that examined coping and its connection with resilience determined that coping strategies positively correlated with resilience,[161,166,178] specifically problem-focused coping,[161,178] and emotion-focused coping.[161] A second notable result among six (12%) studies was the inverse relationship between resilience and psychological distress,[139,145,148,152,156,168] reinforcing the concept that resilience assumes an adaptive psychological function and attenuates stress. Similarly, findings within 15 (30%) studies that did not involve burden showed that resilience exerted a positive impact on mental health outcomes, with a persistent inverse association with depressive symptoms,[133,139,153,157,173–176] and a direct association with quality of life,[148,162,174,175] along with other general mental health indicators.[80,155,170]

2.5 DISCUSSION

We undertook this review to document the scope of published research on psychological resilience among informal family caregivers of adults with CNCs. The volume of reviewed studies published within the last ten years is evidence that psychological resilience is being increasingly investigated in the field of informal caregiving, particularly within the context of dementia. However, this increased interest in resilience is accompanied by minimal conceptual consensus from a mosaic of scholarly origins, and findings suggest a lingering debate between process and trait-based definitions.

Some popular measurement tools were detected in included studies (i.e., The RS, CD-RISC, BRS), yet a plethora of scales were employed to assess self-perceived resilience, with minimal use of caregiver-specific instruments despite characteristic similarities. Furthermore, in reports of resilience levels, some interpreted resilience as a continuous variable, while others categorically divided samples into stratified high-low resilient groups, making it difficult to judge how resilience capacities compared to other populations. A broad array of resilience predictors, correlates, and outcomes were observed, whereby resilience was inversely associated with burden, distress, and depressive symptoms and directly associated with various caregiver wellbeing indicators including quality of life, coping, social support, and mental health. These results affirm the potential for resilience to be leveraged within caregiver health promotion initiatives via policy and public practice.

As a product of its growing popularity, retained articles contained a range of understandings of resilience. Although the majority of resilience descriptions converged on components of adaptation and healthy functioning, the range of conflicting conceptualizations

demonstrates that any form of consensus regarding resilience in informal caregiver research has yet to be achieved. On one end of dissent, there was prevailing fixation on individual resilience, with conceptualization and measurement of resilience as a fixed characteristic or personality trait. These definitions appeared in sharp contrast to contemporary understandings of resilience as a dynamic process which interacts with the surrounding environment. Disagreement surrounding how caregiver resilience is defined and operationalized, in addition to the lack of a widely accepted resilience theory or conceptual framework, renders investigation of the construct inconsistent.[180]

One retained study explored conceptual resilience discrepancies between academic definitions of resilience and caregivers' personal conceptualizations, and found that caregivers extended the concept more broadly and emphasized the role of self-compassion.[139] The implications of self-compassion as a protective factor for psychological wellness have been previously documented in informal caregivers,[181] and may represent a useful avenue for future resilience research. With this study as an important example of a more caregiver-centered approach,[139] researchers should strive to actively involve vulnerable informal caregiver populations within the research process, commencing with resilience conceptualization and moving towards harmonization with clinical and academic definitions.

Similarly, the lack of a persistent definition of resilience within caregiver health research perpetuates the tendency of scholars to position resilience within statistical models as either a modulator of wellbeing or a binary outcome itself, that is either present or absent.[96] In actuality, modern resilience researchers argue that resilience is likely to exist on a continuum that fluctuates across different domains and the lifecourse.[93] Nevertheless, conceptual

inconsistencies hinder the validity and generalizability of resilience findings and represent a barrier to providing direction for the development of clinical applications designed to enhance resilience within targeted caregiver populations. To mitigate these inconsistencies moving forward and quell lingering nuance, a comprehensive resilience framework, encompassing all hierarchical aspects of resilience, is needed. CNC caregiving research should attempt to follow this unified caregiver-centred resilience framework to navigate this robust interdisciplinary construct across developmental trajectories. Ultimately, this will enable profound understanding of the vast interplaying processes of resilience.

The current divergence in resilience conceptualization and assessments may be representative of the relative novelty of this concept in comparison to other long-standing psychological constructs which have had been validated across populations and widespread contexts. Equivalently, the differing use of quantitative resilience scales supports the notion that there is no gold standard of resilience assessment.[97] The absence of homogeneity in resilience measurement undermines the ability of researchers, clinicians, and community members to reliably monitor and evaluate the efficacy of resilience-building programs.[182] This lack of standardization further prevents resilience levels from being compared *across* different caregiver subpopulations.[96] Similarly, with few developed and validated condition-specific scales within the new resilience field, it is difficult to reliably verify and contrast resilience levels *within* distinct caregiving populations. It is recommended that future resilience and caregiving research draw on contemporary views of resilience from broad literature to formulate context-specific measures, while attending to the evolving theory and research. This will surely elevate

the quality of resilience-based research moving forward, while preventing further dispersion within the field.

The underrepresentation of caregivers of more rare chronic neurological conditions in included studies was apparent and presents a challenge for advancing disease-specific resilience applications. Few studies examined sudden onset conditions, there was an absence of stable and intermittent types of conditions, and progressive conditions consisted of mostly dementia. As we approach a saturation of research in resilience in dementia caregiving, resilience in caregiving populations of other CNCs (e.g., MS, MND, epilepsy, cerebral palsy) remains understudied. This is problematic because it has been empirically proven that caregiver demographics and health outcomes vary as a function of the specific CNC encountered.[183] It is important that such overlooked populations amass further interest in the field of resilience investigation, allowing their respective resilience processes to be equitably understood, measured, and harnessed.

In an effort to account for discrepancies in the caregiving experience across different CNCs, there remains dispute within the literature concerning the degree of influence demographic and clinical factors exert on manifestations of resilience. The reviewed studies herein captured the relationship between resilience and age, gender, income, employment status, ethnicity, and clinical injury or disease severity; some studies reported that these factors were significantly associated with resilience,[109,147,157,167,169,171,174] while others did not.[143,162,173,175–177] This debate is further compounded by the fact that most sampled caregivers were spousal and middle-aged women from homogenous cultural regions. This dispute clouds current understanding of the intersection between resilience and individual and contextual

factors related to the caregiver population, such as biological underpinnings, environment, and culture – all of which have been integrated into resilience perspectives.[96,105,184] In line with socio-ecological models of resilience,[103,105,185] it is imperative to clarify which sociodemographic and environmental factors facilitate resilience development in CNC caregivers via a culturally-specific approach which embraces hetergeneity.[107] One way to determine how contextual factors influence the resilience trajectory is by conducting longitudinal studies.[96] As most (80%) of the included articles originated from western English-speaking countries, multicultural representation within resilience and caregiver research remains deficient. Future research should strive to explore CNC caregiver resilience across cultures and contexts to accurately profile differing environmental and demographic factors and their influence on resilience within diverse community settings.

Finally, we observed resilience exploration in connection to caregiver burden in one quarter of the included studies. This prevalence suggests that resilience research in CNC informal caregivers is inconsistent with resilience research in other disciplines, as broader disciplines now favour a strengths- and competence-based approach.[89,96] We acknowledge that a portion (30.5%) of the studies in our review excluded burden from their design and depicted the positive link between resilience and wellbeing. However, it appears that many researchers continue to examine the negative consequences of caregiving, and how resilience protects caregivers from impending risk innate to their role. This, in turn, fails to abandon the outmoded deficit-based model of caregiver resilience and mental health.[96] Despite the expected inverse relationship between resilience and burden, we caution against the assumption that caregiver burden and resilience can coexist, such that one determines the other. Instead, it is advised to

position each concept as mutually exclusive, as the exact causal mechanisms responsible for their association remain unknown.[105,185] Arguably, through conflation of dimensions of flourishing and languishing, our understanding of resilience becomes obscured by the pathologies and dysfunction denoted by caregiver burden.[185] It is suggested that scholars adopt a more proactive or preventative approach that prioritizes building strengths,[96] while simultaneously no longer assuming that CNC caregiving is uniformly burdensome.

2.5.1 Limitations

This study possessed some limitations. Firstly, resilience is a wide-ranging and nuanced concept that parallels with other psychological topics (e.g., hardiness, adaptation, coping) across many psychosocial disciplines. To address this concern, we adopted a broad approach in our initial search strategy to acquire as much relevant literature as possible; still, it is possible that we missed relevant literature as a consequence of our resilience-specific focus. Secondly, due to the nature of many variables often examined in close association with resilience, it is possible that there was potential methodological bias among retained studies in describing these relationships, including issues of simultaneity and reverse causality.

There is scarcity of research in family caregivers of more uncommon conditions which limited the extent to which the protective role of resilience in more unique care providing situations could be explored. The overrepresentation of dementia-related caregiver populations, and the overall heterogeneity of included studies, rendered it challenging to offer any condition-specific conclusions at this time. Lastly, this study was limited by its inclusion of only English-language publications, which limited our search to primarily studies conducted in

North America and Europe. This limitation made it challenging to obtain diverse geographical representation and assess how resilience varies widely across countries and cultures.

2.6 CONCLUSION

This review synthesized the existing knowledge on resilience in informal caregiving for persons living with a CNC. Findings revealed an insufficient level of agreement among researchers with respect to how resilience is theorized, conceptualized, and assessed. 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 superior health and psychological flourishing, and contributes to optimal stress management among CNC informal 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. Furthermore, while a strengths-based approach does not currently unanimously prevail across the reviewed literature, there is room for evolution to dissociate weakness, risk, and deficit-focused models of caregiving from resilience and to cultivate approaches rooted in caregiver empowerment. With limited representation of intervention studies, there is a need to develop targeted interventions for informal CNC caregivers aimed to promote resilience and increase awareness of the positive aspects of caregiving.

CHAPTER 3: PAPER 2

A continuum of languishing to flourishing: A qualitative study of psychological resilience in multiple sclerosis informal caregivers

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Preface: This article included collaboration between myself, Dr. Fakolade, Ms. Cardwell, and my supervisor Dr. Pilutti. All authors were implicated in theme development. The writing of the introduction, methods, results, discussion, and conclusion was completed primarily by myself, with significant contribution and revisions from Dr. Fakolade and Dr. Pilutti.

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3.1 ABSTRACT

Resilience research in informal caregiving in chronic neurological conditions is growing in popularity, but multiple sclerosis (MS) caregivers are noticeably absent from this body of work. Due to the disease's early age of onset, prolonged life expectancy, and heterogeneity, MS caregivers represent a unique population. We explored MS caregivers' experiences of resilience by applying the ecological resilience framework to investigate resilience resources. Twenty-four semi-structured interviews of Canadian informal MS I caregivers were conducted via videoconference. Transcripts were analyzed using reflexive thematic analysis. Emergent themes constructed a cyclical model whereby resilience exists within a continuum, beginning with encounters with hardship and extending to thriving adjustment. Within this model, key themes included reports of additive challenges, impactful individual and community resources, and multi-level adaptive pathways. Within this cycle, the achievement of healthy adjustment exerted a positive feedback function and informed future responses to lifelong challenges. Although this sample appeared to be resilient, inadequate resources and a lack of programming at the community and societal levels were evident. These findings could provide researchers and decision-makers with relevant information for designing and implementing resilience-building interventions for MS caregivers that attend to contextual factors and current systemic support deficiencies.

3.2 INTRODUCTION

Multiple sclerosis (MS) is one of the most common causes of neurological disability among young adults in the western world, and is estimated to affect 2.8 million individuals worldwide.[186] Due to its early onset in young-adult life, unpredictable disease course, and polysymptomatic and heterogenous nature, MS carries with it great physical, psychological, and social costs for the person with the disease and their friends and families.[27] As the disease progresses, the majority of persons living with MS experience the accumulation of permanent long-term disability,[7] which results in the loss of functional independence and the increased need for personal assistance.[35,36]

3.2.1 Informal Caregiving in the MS Context

The support needed by persons with MS is largely provided by informal unpaid caregivers, usually friends or family members.[67] These informal caregivers undertake a variety of services which offer essential forms of support (e.g., physical, emotional, informational)[73] to enable persons with MS to participate in daily life activities and remain functioning within their home amidst gradual disease progression.[187] As a result, informal caregivers tend to experience role overload, physical taxation, and financial strain due to lost income.[36] Caregivers may also lack knowledge regarding the complex needs of the care-recipient.[45] Consequently, the magnitude and extent of caregiving duties may result in poor mental, emotional, and physical health outcomes.[49] Some MS caregivers report increased levels of stress, depression, anxiety, social isolation, and poorer quality of life in comparison to non-caregiver age-matched controls.[50,51,117]

Nevertheless, the experience of caregiving for a loved one with MS is seldom uniform.[80] Evidence suggests that MS caregivers report a wide range of benefits associated with their role, such as personal growth, strengthened relationships, deepened empathy, and an increased sense of appreciation for life.[81,83] The coexistence of both benefits and hardships within the MS caregiver role implies that some individuals may be better equipped than others to adapt to the demands of caregiving. This evidence also highlights the need for strategies to reduce burden and leverage positive adaptations in MS caregivers.[188] However, before effective strategies can be developed, we must understand precisely which factors account for differences in experiences of adaptation to the caregiving role. One factor that may be responsible for variability in the caregiver experience is psychological resilience.

3.2.2 Resilience

The concept of resilience is lacking a unified theoretical foundation,[128] with two prominent conflicting schools of thought: some perceive resilience as a fixed individual trait, while others define resilience as a dynamic process.[103] Still, most scholars agree on three core components of resilience: 1) an encounter with adversity; 2) adaptation; and 3) the achievement of healthy functioning.[100] Specifically, within the context of caregiving, resilience is conceptualized as the maintenance of wellbeing despite experiencing high care demands.[189]

Moreover, the process of resilience is believed to depend on diverse resources from multiple levels, which interact with one another.[103] Informed by ecological theory,[104] Windle and Bennett[103] developed a theoretical resilience framework applied to caregivers to better delineate the mechanisms by which resilience operates across inter-related ecological levels.

Recently, multiple studies have utilized this framework to comprehend informal caregiver resilience as influenced by interplaying physical, social, and environmental contexts.[100–102] This model recognizes that caregivers draw on individual (i.e., psychological, biological, health behaviours, monetary materials), community (i.e., social support, social cohesion, participation, neighbourhoods, housing), and societal (i.e., policies, government agencies, health systems, social services) resources, which may enhance risk for caregiver burden, or alternatively, foster resilience.[101,103] This framework emphasizes the multidimensional nature of resilience as it may be cultivated within the individual and their broader social context.[100,103]

3.2.3 The Current Study

In MS, the early age of symptom onset (20-40 years)[186] and comparable life expectancy to someone without the disease,[190] means that the MS caregiver role can encompass a lifetime, spanning several key life stages, such as parenthood and career-building.[117] Recent grounded theory work has sought to remodel life course perspectives in persons living with MS,[191] drawing from recent studies of healthy aging in MS.[192] Findings from this qualitative study depicted the MS life course as a complex and staged process of transformation with the primary objective of living a life with MS as good as possible.[191] To echo this perspective among caregivers coexisting alongside persons with MS over the lifespan, the experience of MS caregiving may be inclusive of copious life periods and, in turn, very different from the more commonly studied caregiving populations of older adults and care-recipients with other chronic neurological conditions (CNCs) which typically emerge later in life (e.g., dementia). Understanding the experiences of MS caregivers is an imperative step towards the

development of tailored strategies, programs, and interventions that may begin to address the unique support needs of this population. Specifically, via the application of the ecological resilience framework for caregivers,[103] the aims of this study were to: a) explore MS caregivers' conceptualizations of resilience; b) examine how MS caregivers develop and experience resilience; and c) determine which assets and resources influence resilience in MS caregivers.

3.3 MATERIALS AND METHODS

3.3.1 Overview

The present study used a qualitative design consisting of semi-structured interviews. Such interviews are conducive to eliciting rich narratives of caregivers' own unique experiences, enabling exploration of perspectives, beliefs, and the role of relationships within the context of resilience cultivation.[193,194] This study was framed by ontological relativism and epistemological constructivism. We acknowledge that multiple context-dependent realities exist, and that knowledge is socially constructed based upon unique personal experiences and values. Guided by these philosophical assumptions, we elected to focus on individuals' perceptions through semi-structured interviews exploring subjective experiences of resilience. We sought rich depictions of each participant's experience and worked to generate an understanding of resilience that also provided room for variations.

3.3.2 Participants

Participants were recruited from a longitudinal online survey study of resilience in informal MS caregivers conducted by our research team. The inclusion criteria for the survey

study were: (i) 18 years or older; (ii) currently providing physical, emotional, or informational assistance for a person with MS for more than one hour daily; (iii) a resident of Canada; (iv) and fluent in English. Individuals who reported difficulty with memory, calculation, or reasoning that significantly interfered with their daily functioning were excluded. Convenience sampling was used to contact prospective participants (*n* = 441) via email who had indicated interest in participating in the interview in the baseline survey. Out of those contacted, most (*n* = 417) did not respond further due to the nature and level of commitment of the qualitative interview component. Ultimately, a total sample of 24 participants was obtained. All participants provided informed consent prior to the interview (see Research Ethics Approval – Appendix 3). To assure participants' confidentiality and anonymity, we removed all identifying information from interview transcripts. We refer to participants according to pseudonyms in the presentation of study results.

3.3.3 Quantitative Measurements

Demographics, caregiving characteristics, and resilience levels were captured quantitatively in the initial online survey. Demographic information included age, gender, race, relationship to care-recipient, marital status, education, employment status, annual household income, and whether they lived with their care recipient. We asked caregiver participants to report the level of MS-related disability of their care-recipient using the Patient-Determined Disease Steps (PDDS) scale.[195] The PDDS is a questionnaire that uses an eight-level ordinal scale (0 = normal to 8 = bedridden) to measure disability. Additionally, years of caregiving, and the average minutes per day spent in caregiving activities were collected.

Resilience was measured using the 25-item Connor-Davidson Resilience scale (CD-RISC).[91] This instrument is based on a five-point scale (0 = not true at all to 4 = true nearly all the time) over the span of the previous month. Total scores range between 0 and 100, with higher scores reflecting greater resilience levels. This scale has good consistency, reliability, and validity.[91,97]

3.3.4 The Interview Process

Following a synthesis of current caregiver and resilience literature referenced below, a semi-structured interview guide was developed by contributing authors. The guide was based on questions utilized in a qualitative focus group study designed to examine resilience and related factors in MS caregivers and other MS stakeholders,[196] in addition to recent qualitative applications[101,136,137] of the ecological resilience framework for caregivers.[103]

Interviews were conducted between July and October of 2020. The interviews were conducted by the first author (OM), by Zoom (Zoom Video Communications Inc, San Jose, California) videoconference (*n* = 22) or telephone (*n* = 2), according to participant preference. While face-to-face in-person interviews are commonly preferred for building rapport and attending to nonverbal cues,[197] this was not possible given that this research was conducted during the global COVID-19 pandemic when physical distancing and other restrictions largely prevented in-person interactions. Fortunately, research comparing the use of remote interview methods with face-to-face interviews has demonstrated no differences in the resulting data.[198–200] Indeed, remote communication can have added benefits such as increased participant comfort and anonymity, decreased social pressures, and increased access to hard-to-reach

groups facing accessibility limitations.[198] Furthermore, the interviewer can still remain attentive to non-verbal cues as participant faces are visible on Zoom, and cues such as pauses and changes in intonation are present when speaking on the phone. Via these two interview platforms, the interviewer was able to provide an encouraging, affirming, and non-judgmental space, which promoted detailed and rich recollections of past experiences,[139] despite the sensitivity of content. Interviews were audio-recorded, transcribed, and anonymized. Interviews lasted between 45 and 90 minutes.

3.3.5 The Interview Guide

Interviews began with an introductory period to develop rapport and to provide the researcher with context. The participant was then asked how they would define the concept of resilience. If the participant demonstrated uncertainty in their resilience conceptualization, they were prompted to find a synonymous phrase or word to capture the thoughts they were attempting to articulate. The subsequent portion of the interview focused on evoking discussion related to key caregiving challenges experienced by the participant throughout their journey, while also conferring their initial reaction to these hardships. Next, the participant was asked to detail how they have adapted their caregiving strategies and activities throughout the duration of their supportive role. This was followed by a question asking the participant to share what has enabled them to be resilient throughout their personal aforementioned challenges. Specifically, the participant was asked to identify the societal, community, and individual factors that have helped them to develop resilience. Finally, the participant was asked to illustrate the factors that have hindered their resilience development and

maintenance of wellbeing through the experience of salient caregiving challenges. The complete interview guide, including introductory and concluding statements, can be found in Appendix 4.

3.3.6 Data Analysis

Interview transcripts were entered into NVivo 12 (QSR International Pty Ltd, Melbourne, Australia) for independent coding by the first author (OM). A reflexive thematic analysis was conducted.[201,202] We situated themes within the context of caring relationships and MS as a socially constructed illness, informed by how individuals come to live and comprehend illness and how illnesses are formulated by sociocultural factors.[203,204] Additionally, our approach used the ecological resilience framework[103] as a tool to contextualize and deepen the interpretation of themes.

Data familiarization by the first author was accomplished by actively reading and re-reading the material. Following data familiarization, the first author (OM) generated an initial codebook consisting of both deductive and inductive patterns of meaning organized across the three ecological levels. The existing ecological resilience framework was used to code themes in relation to caregivers' encounters with adversity, individual, community, and societal resilience resources, and adjustment consequences. This form of organization enabled the identification of patterns among resilience processes within the dataset with respect to their ecological location, constituent similarities, and manner of interaction with other emergent resilience processes which permeated across ecological levels.

As new codes emerged more inductively, the codebook was expanded and refined. While transcripts were singularly coded by the first author (OM), the second (AF) and last (LP) authors acted as 'critical friends' to challenge initial codes, contribute to the development of new codes, and stimulate reflection. A robust set of codes representing relevant elements of resilience was finalized during the second round of coding. Once coding was completed, OM began the process of identifying cardinal themes by examining high-level patterns within and beyond the ecological framework, ensuring that there was clarity in scope and boundary of each theme, and that themes demonstrated an overall fit with research objectives. Following final discussions between all authors, overarching themes were inferred, and the entire dataset was reviewed by OM to ensure that the candidate themes were representative. Afterwards, final themes were explicitly defined.

3.3.7 Study Quality

Aligning with our relativist approach, we did not view quality criteria for this research as universal or concrete because values for quality are ever-changing and highly context dependent.[205,206] Rather, we drew from a dynamic list of relevant traits from different scholars which have markedly contributed to the qualitative methodological landscape.[201,206,207] Ultimately, we chose the following criteria: the worthiness of the topic (e.g., public health significance of caregiving across disciplines); resonance (e.g., thick descriptions and rich interpretations of the data that could be transferable to different situations); plausibility (e.g., situating our findings in relation to existing frameworks of resilience); meaningful coherence (e.g., compatibility between the study purpose, methods, results, and interpretation); and

reflexivity (e.g., multiple critical friend discussions to stimulate reflection upon, and exploration of alternative explanations and interpretations of the data).

3.4 RESULTS

3.4.1 Characteristics of Study Participants

Table 6 provides a summary of care partner demographics, characteristics, and mean resilience scores. Participants (*n* = 24) were mostly middle aged, with a mean age of 57 years (*SD* = 14). In terms of gender, the sample was fairly evenly distributed, with 46% (*n* = 11) identifying as men, and 54% (*n* = 13) identifying as women. The sample was comprised of persons of primarily European (*n* = 11, 46%) or North American (*n* = 11, 46%) descent; only one (4%) participant was of Asian descent. Most caregivers were spouses (*n* = 20, 83%), two (8%) were parents, one (4%) was a sibling, and another (4%) was an adult child of the care-recipient. The majority (*n* = 21, 87.5%) of participants were married, two (8%) were separated or divorced, and one (4%) was a widow. Nearly all (*n* = 23, 96%) caregivers were cohabitating with the care-recipient. With respect to the disability level of the care-recipient with MS, participants reported a median (IQR) PDDS score of 5 (4) ranging from 1 to 7. Hence, MS care-recipients at minimum required intermittent unilateral or bilateral walking support. The mean duration of caregiving was 13.7 years (*SD* = 9.6), ranging considerably from 1 to 30 years. The average number of minutes per day dedicated to providing assistance was 183.8 (*SD* = 176.5) minutes per day, with a substantial range between 10 and 600 daily total minutes. The mean CD-RISC score was 67.0 (*SD* = 11.1).

3.4.2 Summary of Main Themes

To comprehend MS caregiver resilience, we drew from participants' illustrations and contemporary theories of resilience as a cyclical endurant process. Ultimately, the experiences shared by participants were captured beneath a single overarching theme which extends beyond linear and segregated resilience trajectories: "resilience is a continuum of languishing to flourishing." Collectively, the narratives of MS caregivers were subsumed within four smaller themes as a reflection of the complexity of resilience and its constituent conceptual pillars: "resilience resonates divergently," "additive caregiving challenges," "resilience resources originate from human connection," and "adaptation begins with a learned mindset". Firstly, the subtheme of divergent resilience emerged from caregivers' abstract understandings of resilience in their own words. The subtheme regarding dominant additive challenges embodies statements pertaining to the overabundance of compounded and continuous challenges innate to the MS caregiving experience. Participants moved forward within a resilience continuum despite constant challenges by leveraging individual and community resources generated from the power of human connection as social and interactive beings. Lastly, participants discussed ingenious adaptive processes that would not have been possible without their progressing wisdom and cultivated mentalities.

3.4.3 Overarching Theme 1: Resilience is a continuum of languishing to flourishing

In the examined context, resilience cannot be portrayed conceptually as a fixed linear outcome or trajectory. This notion is supported by the transitory nature of the challenges

inherent to MS caregiving, and reflects the unique characteristics of the disease (e.g., chronicity, progression, heterogeneity, unpredictability, polysymptomatic etiology). Within the MS caregiver role, the presence of continuous struggles and accumulating losses places resilience along a fluid spectrum, determining caregivers' future experiences of adversity and their health outcomes. Henceforth, Figure 3 depicts caregiver resilience within a cyclical paradigm.

In accordance with the three facets of resilience (i.e., an encounter with adversity, adaptation, and preserved wellbeing), this cycle operates synergistically with multiple influencing factors, including resilience resources and adaptation components. In essence, the availability of individual, community, and societal resources informs the caregiver's process of adaptation. Collectively, these system factors contribute to caregivers' degree of adjustment and healthy functioning, situated along a continuum of languishing to flourishing. Consequential adjustments exert a feedback function whereby they contribute to caregivers' experiences of future encounters with hardship, encompassing subsequent appraisal and adaptive processes.

3.4.4 Subtheme 1: Resilience resonates divergently with MS caregivers

In their resilience definitions, most participants incorporated an encounter with adversity and referred to the concept of adaptation. A few participants described resilience as attaining equilibrium in mental state or the development of superior mental and physical wellbeing following confrontation with a problem. Participants' definitions of resilience aligned

with both *trait*-based and *process*-based resilience conceptualizations. With respect to trait-based definitions, Arthur described resilience as a partnered concept:

> *I think part of resilience is the property of the person, and in this case the person you're looking after.*

Participants frequently described resilience with certain attributes such as perseverance, patience, and inner strength; some even associated resilience with the quality of being resolute, determined, and firmly rooted in intent:

> *I think [resilience] is a strength, maybe of character that you are – you have some sense of determination.* (Vivienne)

With that said, a number of participants alluded to resilience as a more fluid construct, conceptualizing resilience as a flexible process, involving long-term grit and continuity. This notion tended to incorporate the role of emotions and their provisional nature:

> *Resilience […] is about bouncing back, I think, right? Allowing yourself to have those very real emotions, giving yourself that space to feel those very real reactions to things, and then saying, "OK, I can't change that, let's move on, let's find a plan." I think a lot of people think that resilience is about not being affected by things, but I don't find that accurate. You know, I have to feel everything first and process it and then I can move forward with plans.* (Tara)

> *I think people vacillate between having to get through a difficult physical problem and the emotional need to bear down and work through it. And prepare for it again in the next hour or the next day or next spring.* (Daryl)

3.4.5 Subtheme 2: Dominant caregiving challenges are additive

3.4.5.1 Accumulating loss due to disease progression

Across all participants, emotions of grief were experienced as a result of the loss associated with the navigation of MS as an incurable disease possessed by a loved one.

Emotions of grief originated from loss due to missed opportunities, advancing physical limitations, and the impact the disease exerts on their relationship with the person affected by MS. As such, MS caregivers were grieving multiple connected losses from the past, present, and future. For instance, when asked about his emotional response to the deteriorating health of his wife with MS, Eli shared:

> *The biggest challenge of the whole experience is you're not grieving for a day or a week or a month, it's for the whole thing. Because there's always that change and […] you're also grieving the loss to come.*

Caregivers described MS as a series of losses and, in turn, an experience of continuous grievance for exacerbated losses:

> *[MS] is a loss of one thing after another after another after another. You know, the loss of being able to walk, you know the loss of being able to have a partner that can assist with household chores, that can assist with childcare, that can support you.* (Laura)

For spousal caregivers, grief stemming from the unforeseen changes in their relationship and future together as a couple was discussed frequently. Unplanned futures were difficult for caregivers to accept:

> *I still every once in a while, have a bad day and I'll just be down in the dumps because it's not fair. Just things like that, we can't go on a hike in the woods or we can't buy that house within a matter of minutes, it's taken us months and months to do everything. I still get upset by stuff like that.* (Grace)

The primary challenge with the loss experienced by caregivers as a consequence of MS was that caregivers could never find solace in knowing that their loss was complete or definite. Just as caregivers began to adjust to losses spawned from their care-recipients' latest disease progression or disability accumulation, and accept the associated ramifications for their life and partnership, another form of complicated loss was just around the corner. The unpredictability and incompleteness of loss made it exceptionally difficult for MS caregivers to durably

surmount caregiving challenges as, unlike in non-progressive disease contexts, another form of significant loss is likely imminent. This theme further supports reframing resilience within a cyclical model, whereby resilient processes are characteristically indefinite within MS caregiver experiences.

3.4.5.2 Helplessness and obstacles to empowerment

Grief in caregivers coexisted with a sense of helplessness and a lamentation over a loss of control in the face on an unpredictable disease. These emotions were often intertwined with pity and frustration:

> *I am frustrated that there isn't a cure, frustrated that there's no real treatment for the type of MS [my wife] has […] It is frustrating that there isn't anything better right now.* (William)

Feelings of powerlessness were typically heightened by difficulties linked to MS healthcare and research navigation, including a lack of definitive answers from healthcare providers, limited MS treatment options, and challenges related to accessing and coordinating support resources for the care-recipient. The limited accessibility of information and resources available to PwMS and their families was a marked obstacle for caregiver empowerment. For instance, participants recounted their experiences with these shortcomings of the health system:

> *When [my husband] was first diagnosed, the neurologist gave us a pamphlet and wished us luck*. (Jolene)

> *[The neurologist] didn't give us any information on paramedical services that might be useful, like, physiotherapy, occupational therapy, things like that […] There are so many things that can add quality to life […] And it's hard for me to find this information and these resources.* (Tara)

Due to its early age of onset and mild to advanced disability levels, MS can impact families at all stages of life and in very different ways. The lack of appropriate support by disease stage increased caregivers' sense of helplessness, contributing to the inability to obtain validating support from community services. Caregivers identified this unmet need and remarked that seeing more advanced stages of the disease can even be frightening:

> *The big issue for me with MS is there's just absolutely no support. You know the only group in town for my husband is on a Friday morning and, you know, when he first got MS I brought him there and the people were so different in where they were at with the disease that he was just horrified with the progression in most of the people that were there.* (Linda)

> *I haven't found any local resources that I really think were appropriate for us, because we are relatively young and, like, it's crazy, because there's so many people out with MS or people that know people with MS, and there's just not local groups that get together.* (Tara)

Notably, barriers to accessing high-quality community supports are far from ubiquitous. In truth, support access for persons with MS and their families is a function of numerous factors, including residing in urban versus rural settings, regional or local activism, access to transportation, other life commitments, and financial resources. This reality was frequently acknowledged by participants and coloured their recounts of past interactions with community services.

3.4.5.3 Role intersection and threatened self-care

The most significant challenge experienced by caregivers was the threat their role posed for their ability to prioritize their own self-care requirements. Caregivers' personal needs were overshadowed by the complex social, emotional, and physical needs of care-recipients. Participants reflected on these complexities:

> *I completely lost track of my own personal life and bubble in that time [of MS diagnosis], because the focus was totally on [my husband]. I felt like I needed to try to keep everything in check, so that I could be there for him and not really acknowledge the impact that things had on me.* (Sophia)

Likewise, caregivers acknowledged the impact negotiating a support role can have on caregiver wellness, and that some caregivers are subjected to problematic vulnerabilities:

> *We [caregivers] are so immersed in providing care for someone else so we have to recognize that we're equally as needing and as valuable as worthy of care and we can't get it from that partner, right? We can't get that care from them. They're not able to give it to us so we have to find somewhere*. (Laura)

Furthermore, roles and responsibilities intersected to compromise caregivers' capacity to practise self-care. Participants encountered hardships when trying to balance their caregiving role with other life roles such as their duties as a professional, community member, and parent, sibling, or child. For instance, Tara conceded that she felt overwhelmed by her intersecting caregiving roles in both home and professional settings:

> *All of this caregiving is kind of, like, piling up on each other, right? Having a baby, and then a partner that will need caregiving, and then I was working in a long-term care home all kind of at the same time. I was like, this is too much.*

3.4.6 Subtheme 3: Resilience resources originate from human connection

As participants sought to thrive within their roles, resilience resources at the individual and interpersonal level were most frequently discussed. Participants cited the importance of individual factors of mindfulness within their daily lives and empathy when approaching their support role. These factors typically possessed a protective function for caregiver-care-recipient relationship wellbeing, strengthening the quality of their relationships and preventing relational strain. Thus, even individual-based factors themselves permeated into relational and community ecological levels.

3.4.6.1 Mutuality, general social support, and community engagement

As a characteristic of the interpersonal relationship between the caregiver and care-receiver dyad, mutuality is a construct that denotes relationship quality.[208] Mutuality was a key interpersonal level resource shared between the caregiver and care-recipient that promoted resilience. Compassionate shared communication and honesty were crucial for relational wellbeing:

> *Make sure that there's the open communication with the person that you're caring for, that you can understand what the symptoms are and how they're impacting them, so that you can work together to come up with a plan to help.* (Serena)

> *As best I can, I try to see things from [my wife's] perspective and try to approach it with empathy. I don't always succeed at that, but at least I try to imagine what it's like for her and see if there are ways that I could intercede or offer support or something that will help out.* (Leroy)

General social support was a core channel of community resilience. Participants shared beliefs that many of their hardships could not have been surmounted without the support of friends, family, neighbours, and coworkers. Caregivers benefited from various forms of support, but emotional support was particularly valuable. It was important that caregivers had someone to confide in, regardless of whether that person was able to fully appreciate their struggles:

> *Mentally I need social connections, I need people to talk to […] it's really difficult for people to understand, but they listen, and they do the best they can and that's good enough right now.* (Linda)

> *Having somebody else to bounce off, a balance board, just to talk through ideas or talk through different – I had a really good friend that her daughter was blind because of cancer. And she was a really good friend when [my husband] was first diagnosed too. So, she was a really good sounding board.* (Grace)

While social connection is universally valuable, participants expressed that the relationships they shared with people who genuinely had some grasp of what they were going

through were of the greatest importance. It was through these intentional high-quality and understanding relationships that caregivers were able to overcome some of their most weathered caregiving challenges. Despite the utility of community support, participants expressed at times that they found it difficult to ask for help. Still, caregivers unanimously agreed that reaching out to others in times of need was essential to not only care for the care-recipient, but also to care for themselves:

> *I resisted [asking for help] for a really long time and I think that's part of why I got into a crisis […] I've had a good support system, but I think probably it was to my detriment that I didn't reach out to some community groups earlier because that really did help […] That's been another resource for me, right?* (Laura)

Community initiative and involvement, such as volunteering and religious group participation, was described by caregivers as a means of personal enrichment, sustaining wellbeing and providing a meaningful opportunity for temporary reprieve:

> *I'm a volunteer, I've been an active volunteer for 20 years […] Volunteering does feed your soul […] That involvement in my community spiritually is very – well spiritually it feeds your soul.* (Linda)

> *Staying involved helps me from getting depressed and controlling depression […] The social interaction, the groups that – you know, I organized the chess club and ran some chess tournaments and so on. That was an activity in the community and so on and that gave me a bit of a profile in the community and, you know, some social status which I think that sort of thing was very helpful. It was also a bit stressful, but it was a good kind of stress.* (Richard)

3.4.6.2 Engagement with professional societal networks

At broader social levels, caregivers seldom shared that they used societal resources beyond healthcare systems. Some participants highlighted the role of the local health integration network (LHIN) services, sharing that the network had connected them with helpful healthcare professionals:

> *[The occupational therapist] had a lot of really good ideas, even right from the beginning when, when [my husband] was still kind of walking, but really struggling a lot. But he's so proud he didn't want to use the crutches all the time. It's like well let's take some heavy furniture and put it in different places that he can hang onto the furniture and he doesn't feel like he's on crutches. So she's been really good, she's been really helpful. And even when I needed another person to say "You know look, Laura can't lift you into bed anymore. You need a lift."* (Laura)

> *Look into as many services as you can find. Like, getting LHINs, like, help outside, physiotherapy, I think personal support workers coming in the house are number one.* (Lorraine)

Through connections facilitated by these services, caregivers were able to obtain additional help as they managed care-recipients' changing disability levels. Trained external providers represented a neutral party that relieved potential sources of strain in the caregiver-care-recipient relationship as independence declined in the individual with MS.

3.4.7 Subtheme 4: Adaptation begins with a learned mindset

Through processes of emotional management and compartmentalization, participants were able to draw on individual resources to develop a mindset conducive to adaptive processes. These adaptive processes facilitated favourable adjustment outcomes within the resilience cycle and influenced how caregivers responded to future encounters with adversity within their role. By compartmentalizing their reactions to unfavourable illness-related events and openly accepting the restraints they placed on the care-recipient and their life together as partners or family members, caregivers managed to continue to adaptively move forward:

> *There's so much you learn you can't control. So, don't worry about it. There's nothing I can do until it happens, so, we'll just focus on what we can deal with.* (Tracey)

> *Accept the limitations of the person that you're caring for […] Accept that it will happen but don't take it out on the partner […] You know the famous quote of 'accept the things you can't change and change the things you can't'. And so if there is an action you can*

do then that's fine, if there's nothing you can do then you just have to accept the fact that that's the way it is and move on and find other things to do. (William)

Caregivers' accepting mentalities and sequential adaptation processes were influenced by individual and community resources. As their caregiving experience progressed and was matched by a deepening mindset of acceptance, participants commonly adopted a proactive approach, observing key indicators in the care-recipient and sensitively recognizing the care-recipient's limitations:

Learning what [my husband] was capable of was - and what is his limits, and when during the day. I find those are pretty consistent with his MS. He's more tired in the mornings so he won't do anything before 10 and then at seven he's done. So I'm just figuring out how he is. We've learned to manage a lot of stuff. (Jolene)

Well so some ways I'll adapt for my wife, you know obviously when she's experiencing episode of flare ups, they will usually limit her physical stamina to do things or her, sometimes her physical strength. So, say chores around the house that are let's say more laborious like vacuuming for example […] we've adapted by sort of trading off the things that are harder for her to do. (Leroy)

Situational anticipation – that is the ability to read the care-recipient and prevent problematic situations before they arise – was a skill that caregivers developed over time. This skill contributed favourably to magnifying the resilience cycle and promoted positive adjustment consequences. This acquired approach was followed by high-efficacy problem-solving, including actions that preserved autonomy in the care-recipient, incorporated creative solutions, and tackled MS via lifestyle factors:

I'm always encouraging [my husband], let's try to get a dish here you know like when he couldn't reach the sink to spit anymore. OK, so you know you can still brush your teeth, we're not going to give up on this, but here just hold the dish. You know, differed things like that. (Laura)

About ten days before our wedding, [my husband] had a flare, and so it was just, okay, so these are the facts, this is what's happening, and we just tried to come up with

> *contingency plans of, like, if his legs get too weak, we can re* rent a wheelchair if we have to, or we can get a walker for him, and we had icepacks. (Sophia)
>
> *We looked back towards my partner's lifestyle and experiences, diet, emotional, physical, mental status. Anything that could've been a contributing factor […] and we wanted to find some sort of pattern in terms of is it stress, is it a diet, is it environmental factors that kind of brings out these kinds of relapses so that we know that we can work with our everyday situation to prevent any of this stuff from happening […] We changed diets ASAP, we really looked at the broader picture of just our lifestyle.* (Norah)

It was through these complex processes that participants were able to exhibit personal growth and preserve wellbeing, preparing them to adeptly rise above future caregiving challenges. In the absence of key resources and adaptive steps, participants were placed at risk of burnout and other deleterious outcomes, and the resilience cycle was temporally disrupted.

3.5 DISCUSSION

3.5.1 Main Findings

To our knowledge, this is the first study to explore how MS caregivers individually conceptualize and experience resilience. Our analysis constructed a cyclical model of resilience whereby ever-present challenges are overcome within a complex and continuous paradigm. We did not intend to determine *if* MS caregivers achieve resilience, but rather *how* they participate in the ubiquitous process. This focus aligns with Masten's assertion that resilience is made of ordinary rather than extraordinary processes; and is a natural process of human adaptation.[209] Our findings suggest that MS caregivers possess comparable resilience levels to other caregiving populations,[150,160,165] but exhibit differing lived experiences of resilience.

Accordingly, caregivers expressed difficulties defining resilience and no consistent definition was adopted. To echo current debate in the resilience literature, some caregivers

perceived resilience as an individual trait, while others described it as a process. This discordance confirms that resilience is enigmatic both as an academic construct and when considered by community-dwelling caregivers. Interestingly, multiple caregivers associated resilience with emotional regulation. This finding is supported in literature where emotional regulation has been linked to building resilience.[210] Beyond its presence in participants' conceptualizations, references to emotional regulation also emerged within pathway factors of the resilience model, as the initial step in the tiered adaptive process. In the dataset, emotional regulation facilitated perspectives that incorporated acceptance and minimized disadvantageous reactive behaviours. This valuable tool learned by caregivers is an example of an advantageous change in competence associated with the caregiving role and further supports emerging strengths-based models of informal caregiving, where a positive caregiving narrative predominates. Accordingly, this form of emotional response regulation could represent a gainful area to target as a means of harnessing resilience processes in MS caregivers.

As the catalyst component of the resilience cycle, participants identified diverse challenges within their caregiver role that coexist with many benefits of caregiving. These challenges included accumulating loss, a marked sense of helplessness exacerbated by deficiencies in community and health systems, and threatened health-related self-care compounded by intersecting life roles. Within the ecological resilience framework, caregivers surmounted challenges through individual resources such as cognitive empathy and daily mindfulness. Primarily, community resources originating from social connection were

integrated into resilience pathways, consisting of caregiver-care-recipient mutuality, broad social support systems, and meaningful community participation.

The process of adaptation as a feature of resilience in MS caregivers proved to be highly nuanced; however, several patterns emerged. When discussing resilient experiences, participants shared that their adaptive decision-making processes were informed by an overarching mindset. Caregivers' socially constructed mentalities were permeated by radical acceptance, emotional compartmentalization, and redefined appreciation. Overall, these mindsets prevented shared suffering from becoming debilitating for the caregiver, and enabled caregivers to steadily adapt in their helping role.[211] Similarly, through open acceptance of care-recipients' limitations, caregivers were motivated by unconditional love to persevere and alleviate suffering in the person affected by MS, a devotion frequently deepening their partnership.

The clarity afforded by accepting perspectives guided successive adaptation through empowerment; participants adopted a proactive approach and leveraged factors they still could control. Indeed, a proactive approach, preceded by situational anticipation, was a common theme among testimonies of adaptation. Caregivers learned to detect key indicators in care-recipients to better interpret and respond to their mental and physical state. This approach enabled caregivers to intervene before problematic consequences arose for the person with MS and prevented the need to turn to less effective reactive strategies. When caregivers felt empowered, their confidence and caring capabilities increased, which improved their quality of care and stimulated patterns for future action. Intriguingly, this process has been comparably identified in existing empowerment literature in informal caregivers of older adults.[212]

Efficacious problem-solving action typically followed this anticipatory approach, whereby caregivers were able to minimize avoidable care-recipient suffering and preserve autonomy. In fact, interpersonal communication and caregiving practices that are autonomy supportive for the care-recipient have been identified to improve chronic illness outcomes,[213] and may confer benefits for both the caregiver and care-recipient. Thus, these actions permitted heightened adjustment and wellbeing benefits, which exerted a feedback function to prepare caregivers for future hardships along the resilience spectrum.

3.5.2 Key Interpretations and Clinical and Systemic Implications

A central theme among challenges that mobilized resilience processes included the narrative of continuous loss and helplessness innate to witnessing a loved one endure a progressive disease. Research in other CNCs (e.g., acquired brain injury, dementia) has identified loss in caregivers as ambiguous.[214,215] In the context of chronic illness, ambiguous loss refers to a situation where a loved one is physically present, but psychologically absent, and this phenomenon, where loss is unclear or incomplete, affects both the care-recipient and caregiver.[216] Psychological absence in persons with MS, as a central component of ambiguous loss, may occur due to cognitive and behavioural deficits in long-term memory, attention, information processing, and executive functioning.[217] Furthermore, MS is an incurable illness with an unpredictable trajectory and is rife with ambiguity;[216] caregivers revealed that this genre of loss is often immobilizing and rendered them more prone to distress and relational conflicts.[216] With that said, empathy was a pivotal resilience resource used by caregivers to manage the loss associated with the mental instability exhibited by MS care-recipients. This

tool enabled caregivers to not take care-recipients' fluctuating psychobehavioural states personally and prevented relational strain. These findings highlight the need for clinicians to seek to empower MS caregivers as they experience ambiguous loss and chronic exposure to adversity, helping to preserve relational cohesion and strengthen resilience pathways via utilization of empathy.

To come to terms with ambiguous loss and alleviate feelings of helplessness, family and community processes have been shown to support resilient recovery.[218] Meeting with other families experiencing similar loss aids in the process of labeling feelings and encourages acceptance.[216] However, in their quest for support, caregivers reported that appropriate MS support tailored to the disability level, age, and life stage of care-recipients were unavailable due to the spectrum of MS stages and clinical presentations. Often, this shortcoming extended to MS caregiver specific support systems, rendering it onerous for caregivers to access a critical resilience asset: to find comfort in others and connect with those who comprehended what they were truly going through in that moment. Again, this reality supports the assertion that MS caregivers are unique from other CNC caregiving populations that tend to encompass conditions germane to older adults, leaving MS caregivers to navigate their loved one's illness at much different points in their life course without the same volume and efficacy of community support services. The impeded ability of MS caregivers to connect with persons who relate to their struggles represents a crucial area of need for future resource and program development at community and societal levels to ensure that MS caregivers have access to suitable interpersonal supports which encourage resilient systems.

Threatened health-related self-care, whether due to role overload, lack of time for personal needs, or poor service coordination, was a key finding. The most robust obstacles adversely affecting health-promoting self-care were additive, such that their support role and unmet needs made it exceptionally challenging for caregivers to cope with life challenges such as parenthood, the death of a loved one, moving or relocating, and personal health issues. This finding is concerning because low engagement in self-care practices in informal caregivers of persons with other chronic illnesses has been linked to increased anxiety, depression, poor quality of life, and other morbidities and appears to be the prerequisite for burden and crisis.[219,220]

Services to combat overshadowed caregiver needs were not always readily available, a reality reverberated by the minimal availability of societal resilience resources. Beyond the scant availability of these services themselves, unmet caregiver needs were compounded by a general lack of resource awareness due to insufficient distribution of information surrounding available services. This finding indicates that systems at the structural and policy levels are offering inadequate awareness and access to important high-level resources including complementary health services and affordable respite care. Indeed, the deficiency of support services accessibility and coordination for other informal caregivers has been previously documented in the literature,[220] particularly with respect to respite care and information awareness. Societal policies and programs should be targeted and developed to further enhance MS caregiver resilience and reduce risk. This assertion is supported by previous research in other caregiving populations which demonstrated that respite care is a significant resilience facilitator.[100,189]

Several participants referred to individual and community factors that have enabled them to intentionally prioritize their personal needs despite the ever presence of obstacles of self-care. Despite the permanence of these challenges, caregivers manage them adaptively via the integration of available resources and continuous adjustment. Ultimately, this finding points to the importance of social context, namely community and social resources, for resilience cultivation – consistent with previous MS literature.[196] Still, the majority of existing caregiver interventions focused on individual clinical and sociodemographic variables rather than surrounding context. Correspondingly, our findings suggest that broad service and systems level factors, rather than individual factors, are the most deficient areas of the resilience cycle and warrant targeted research, clinical, and policy-level focus.

With improved consideration of contextual factors and how they impact caregiver resource availability and efficacy, asset development for more vulnerable MS caregiver populations that are difficult to reach (e.g., those in rural areas or those who experience socioeconomic disadvantages) may be realized. Such populations ought to be targeted via innovative intervention mechanisms which favour telemedicine approaches to minimize accessibility barriers and promote continuity of caregiver support services.[221,222]

3.5.3 Strengths and Limitations

This study contributes much that is novel. By focusing on the distinct and understudied MS caregiver population, we offer an unprecedented perspective through which we examined resilience. Via in-depth individual interviews of a robust qualitative sample size,[223] we identified *how* MS caregivers experience resilience and pinpointed key challenges, resilience resources,

and adaptive mechanisms. Additionally, we sampled MS caregivers of care-recipients with a range of disability levels to ensure sufficient representation of the caregiving experience within a multi-course disease with mild to severe disability presentations.

Although this study obtained valuable insight into MS caregivers' experiences of resilience, it was not accomplished without limitations. Firstly, as qualitative researchers mindful of potential sources of bias, it is possible that high-resilient caregivers were more inclined to participate in this genre of research. Thus, experiences of resilience impedance may not have been as readily discussed. Another area of possible bias may have been a product of the first prompt in our interview guide, where participants were asked to define resilience in their own words. Although this question was designed to stimulate discussion and expose the participant to resilience as a construct, it may have influenced subsequent responses via some level of expectancy bias.

Furthermore, because participants were managing diverse life stages and possessed various needs, it was less possible to establish key areas of deficiencies for resilience development due to the latitude of discussed resilience factors. As such, longitudinal experience-based research may provide additional understanding of the relationship between transient forms of adversity at progressing life stages and cyclical resilience. It is to be noted that this article did not attend to the implications of assistive technologies (e.g., monitors, tablets) and mobility devices (i.e., wheelchairs, walkers, lifts) in managing the MS caregiver role. Assistive technology has been previously demonstrated to ease burden of care in dementia caregiving populations,[224] and represents a worthy avenue of future research in the unique MS caregiving domain, particularly from a dyadic (i.e., partnered) approach.

Additionally, this research was conducted in a sample of Canadian informal MS caregivers with minimal diversity. As a product of little geographic distribution and poor ethnic and cultural diversity within this sample, the influence of regional and sociodemographic factors on perceptions and experiences of resilience could not be determined. Still, this dataset was indicative of the importance of some factors such as age, gender, care-recipient disease severity, socioeconomic status and employment status for resilience development, and this may represent an interesting avenue for future research. Further, the majority of our sample consisted of spousal caregivers and other informal or family caregiving relationships were underrepresented. Thus, the patterns observed in this data may be more reflective of the spousal MS caregiver experience, and other MS caregiving relationships warrant more in-depth future examination.

Lastly, we must acknowledge the unprecedented international context of the 2020 global COVID-19 pandemic during which these data were collected. The pandemic itself has brought about significant changes in several aspects of society, including the abrupt and dramatic disruption of the daily routines of families worldwide.[225] Experiences of uncertainty, anxiety, and apprehension were common amidst COVID-19 stressors,[226] and these resultant forms of distress may have been especially salient for families affected by chronic neurological illness, such as MS. Although the themes discussed herein are presented generally and capture MS caregivers' lived experiences prior to the arrival of the pandemic, it is difficult to disentangle such topical circumstances from participants' current testimonies.

3.6 CONCLUSION

In MS caregivers, we demonstrate by applying the ecological framework[103] that the process of resilience is cyclical and encompasses complex antecedents, facilitators, and mechanisms of adaptation. Participants did not concur on a single resilience conceptualization, although their testimonies support that resilience is a normative process. Our analyses yielded a cyclical model of resilience headed by significant challenges of ambiguous and perpetual loss, powerlessness, and threatened health-related self-care. As modulators of resilience, resources emerged mostly at the individual and community levels. Adaptive pathway factors commenced with a mindful and accepting mindset, followed by empowered approaches and problem-solving action. Ultimately, through these intricate pathways, adjustment and wellbeing were achieved which cyclically informed future responses to challenges. These experiences of resilience within this population emerged in spite of inadequate resources at the societal level and points toward a need for better support stratifications and development of interventions that address contextual factors.

CHAPTER 4
INTEGRATIVE DISCUSSION AND CONCLUSION

4.1 OVERVIEW

To address the growing public health significance of informal caregiving, this thesis commenced with a systematic review that synthesized current resilience literature in informal caregivers of persons affected by CNCs, followed by an explorative qualitative interview study that examined the personal resilience narratives of informal MS caregivers. The main findings of the review contributed towards conceptual union of resilience and caregiver science and set the stage for future more refined resilience research where a paucity in knowledge persists. Our review examined traditional and contemporary resilience applications, and provided a summary of definitional trends, associated sociodemographic factors, and health correlates, predictors, and outcomes within the context of caring CNC relationships. This expansive synthesis served as a foundational background to inform the qualitative interpretation of MS-specific caregivers' resilience illustrations and prompted the development of a cyclical resilience model that captures MS caregivers' unparalleled experience of adversity, adaptation, and resultant resilience processes from a strengths-focused lens of empowerment.

4.2 REILIENCE IN CAREGIVING REVIEW

The resilience review conducted as a component of this thesis examined 50 quantitative, qualitative, and mixed-methods articles that involved psychological resilience in CNC informal caregivers. Interdisciplinary databases were searched to account for the novelty and ambiguity of resilience as a concept that has begun to transverse diverse academic domains. We should note that because resilience is widely recognized as a complex

phenomenon that is challenging to define and is often conflated with a number of other psychological concepts (e.g., hardiness, coping, self-efficacy),[93] it was impossible to review the entire breadth of related literature. Consequently, we were obligated to adopt a more narrowed resilience-centred search strategy. The limitations of this approach are discussed further in subsequent sections.

Most of the retained quantitative studies were cross-sectional in design, with a marked underrepresentation of longitudinal and intervention-based research. Studies involving caregivers of persons with dementia, AD, or mixed dementias clearly predominated in the literature. Few studies incorporated other progressive conditions; namely, caregivers of persons living with MS were not present whatsoever among the included studies. In a substantial portion of retained studies, fixation on individual trait factors hindered the reader's ability to appreciate the dynamic and temporal nature of resilience and obscured our understanding of its fundamental interactions with shifting contextual factors (e.g., social support, community service accessibility, employment status, clinical disease symptoms and severity).

Twelve different instruments were used to assess resilience and a lack of condition-specific instruments was observed, with only three studies validating resilience instruments among informal caregiver populations. Commonalities among the reviewed literature suggests that CNC caregivers have moderate to high resilience levels, although it was difficult to interpret these findings across included samples due to the lack of standard assessment tools among caregiving populations. Beyond methodological trends, findings revealed that resilience was associated with a broad range of health indicators; particularly, it attenuated psychological

distress and burden. To echo historical patterns within the literature, resilience was conceptually examined as a protective factor opposing caregiver burden. This trend contradicted topical resilience and caregiving models that converge on strengths and competencies in place of deficits and powerlessness.[89,96] We feel that, despite prevailing historical views, it is problematic to continue to assume that all caregivers are burdened by their role or subject to a stressful existence with negative health impacts. Contrarily, it has been reported that there are ample positive aspects of caregiving with potential benefits for health.[227–229] Recent sophisticated population-based studies have found reduced general mortality and improved longevity in caregiving populations when compared with non-caregiving controls.[230,231] Reconciling such emergent evidence that suggests that informal or family caregiving may confer mortality benefits[230,231] with the historical discourse that caregiving is a burdensome role detrimental for health[45,63,142,232] is crucial to afford intelligible guidance for future work in this field. We hope this dissertation, in conjunction with current perceptual shifts, encourages future resilience researchers to approach resilience in caregiving from a lens of empowerment that operates independently from deleterious caregiving experiences.

4.3 CYCLICAL RESILIENCE NARRATIVES IN MS CAREGIVERS

To supplement our intention to innervate progression in resilience science within vulnerable populations, we incorporated a cohort of caregivers that has yet to be characterized in resilience and caregiving research. Indeed, despite increased interest in psychological resilience and its implications for vulnerable caring populations, as demonstrated in recent

literature included within the systematic review herein, most research that conducted within this field has problematically overlooked informal caregivers of persons affected by MS. This represents a key barrier for the advancement of resilience-building interventions that target MS caregivers, while more broadly restricting advantageous societal developments for this cohort. Moreover, this contributes to further systemic inequities in resource access and allocation for those navigating MS and ensuing neurological disability in a family member or friend.

Prior to this thesis research, little was known about the experiences of MS caregivers themselves as they negotiated caring for a loved one with an incomparable neurodegenerative disease, nor how resilience systems existed within this unique supportive relationship. To address the limited understanding of the MS caregiver experience, and its implications for the transpiration of resilience, we qualitatively determined how caregivers describe resilience in their own words. Moving beyond how caregivers simply define this nuanced construct, we ascertained their encounters with adversity within the caregiving realm as prerequisites for resilience. Attending to modern socioecological resilience models and advancing a strengths-focused perspective of caregiving, we aimed to identify primary individual, community, and societal resources that contribute to resilience preservation as a ubiquitous positive caregiving experience. In doing so, hindrances or areas lacking resources pertinent for resilience cultivation were highlighted. While our intention was to not assess the degree of healthy functioning within each MS caregiver, as this is a subjective and variable metric difficult to quantify, we determined *how* caregivers adapt to their reoccurring struggles and flourish within their role and environment via interactions with available assets to attain a certain level of physical and psychological adjustment.

Following reflexive thematic analysis, several themes emerged from our dataset within a single overarching theme: resilience exists as a continuum of languishing to flourishing. The illustration of resilience as a fluid continuum (see Figure 3) emerged as a result of the changing nature of the challenges experienced by MS caregivers, as afforded by the unpredictability and progressive nature of the disease. Within this context, resilience could no longer be portrayed as a fixed outcome that is unceasingly sustained, and binarily present or absent. For exploration of MS caregivers' resilience experiences, operationalizing resilience in this linear stepwise way would disregard the fact that their challenges are never finitely overcome, as new physical and emotional challenges linked to disease progression and disability advancement are always forthcoming. However, in the temporal context of the present, adaptive processes conducive to advantageous caregiver and care-recipient adjustments may condition caregivers to respond to impending challenges in a more adept manner, thereby yielding positive effects for the caregiver and perpetuating the resilience cycle across lasting timeframes.

Additional subthemes solidified that the MS caregiving role is, in many ways, unmatched. A major theme posited that dominant MS caregiving challenges are additive, such that one challenge builds sequentially from another. An additional theme dictated that these compounded challenges were overcome by individual and community resources, fuelled by instinctive social connection. Lastly, a key pattern within the dataset suggested that adaptive processes in MS caregivers commence with an expansive learned mindset, which is typically developed over time through empowerment and acceptance and ought to be perceived as a useful tool acquired through the caregiving experience. Together, the attention to temporal

and developmental factors within these themes demonstrates that resilience is an enduring process that operates over a multitude of lived trajectories.

Multiple recommendations for future populations-based and clinical research, and organizational and policy initiatives tailored to the MS caregiving population were derived from this explorative study. The challenge of ambiguous loss that was immobilizing for MS caregivers was an area of concern among our thematic findings. However, in order to navigate this oppressive loss, empowered approaches within adaptive resilience pathways mobilized caregivers to provide care that was autonomy supporting for the care-recipient and minimized high levels of shared suffering and grief. To support MS caregivers better as they negotiate complicated losses and to facilitate journeys of resilience, our findings argue that systems and originations should adopt approaches rooted in empowerment via integrative family and community processes. Instead of restricting the focus of content on the burdensome risk associated with the caring role, future applications should emphasize and build upon all that caregivers overcome, while similarly elevating the propitious skills and relations they have developed throughout their journey.

Still, the process of overcoming MS caregiver challenges such as continuous loss, a sense of helplessness, and overshadowed needs was met with noteworthy barriers. Limited resilience resources were available for MS caregivers at the societal level, and the few that were accessible were typically ineffective, riddled with deterrent problems, or met with a problematic shortage of awareness. This underscores the need for societal level resources to be targeted by key stakeholders and policymakers and drastically improved with respect to service

awareness, accessibility, organization, coordination, and quality of content through collaboration and coordination with key partnerships.

4.4 INTERDISCIPLINARY CONTRIBUTION OF RESEARCH

As the demand for informal caregivers is expected to rise by more than 85% in the coming decades,[233] caregiver empowerment, enabled via a strengths-based resilience perspective and positive approach, represents a growing public health necessity. As previously discussed, adopting a strength-based approach involves mobilizing the existing competencies of caregivers and leveraging advantageous connections and resources in communities and organizations, rather than focusing on problems and deficits.[234] Accordingly, in order for societal structures and public healthcare systems to adeptly support informal CNC caregivers in their indispensable role, resilience within this population must be fully explored in alignment with such perceptual shifts towards an emphasis on narratives of flourishing. Both completed studies within this dissertation support the utility of empowerment-based approaches for health promotion within the informal caregiving field. The completed systematic review identified current discrepancies in resilience literature, contributed to a clearer understanding of resilience as a concept, and offered an integrative perspective of its complex implications, all while calling for further emphasis on an asset- or strengths-based approach to caregiving founded on a harmonized resilience standpoint. Whereas the qualitative study identified caregiver empowerment as a key building block for crucial adaptive pathways.

In the qualitative study, participant testimonies revealed that current approaches at the societal level are not enough, and health systems are failing to actively and effectively support

informal caregivers of persons affected by mild to advanced MS. Major themes pointed to the need for integration of contextual factors, such as care-recipient disability level and caregivers' intersecting care-providing occupations, into resilience-related actions, clinical decision-making, and community-based support programs. This assertion is further supported by the scant detection of resilience-building interventions within the systematic review. In truth, both studies support the notion that resilience-cultivating initiatives ought to be more heavily prioritized by community health systems, as combined results suggest that resilience operations have been historically neglected at higher structural levels. Unified main findings also call for intervention development that is tailored individually to caregivers, as the cycle of resilience varies greatly between contexts.

The variability in reported resilience themes is promising as this indicates that resilience processes are capable of being modified and facilitated through composite intervention approaches. For instance, interventions informed by this research may attend to an array of resilience-related factors including training in self-compassion, emotional regulation, mindfulness practices, and empathy to foster resilience processes. Qualitative findings also highlighted the importance of preserving healthy activities of daily living for caregiver wellbeing, such as general social support, purposeful community engagement, and opportunities for reprieve. We hope that interventions from broad disciplines begin to incorporate resilience theory within their design, and that resilient systems are targeted via integrative approaches from interdisciplinary origins.

4.5 LIMITATIONS AND FUTURE DIRECTIONS

4.5.1 Systematic Review: Scope and Applications

This first portion of this dissertation was not accomplished without limitations. With respect to the systematic review, due to the volume of studies collected in the initial search, it is plausible that pertinent research was missed during the screening process due to human error. The possibility of overlooking relevant research was compounded by the fact that psychological resilience itself is a multidisciplinary concept conflated with many other psychosocial constructs which may not have been detected by a resilience-specific search strategy. Additionally, apart from the incorporation of multiple reviewers, there was the potential for bias in article screening and selection.

Unfortunately, due to the variability in measures and outcomes within retained studies of this review, it was not feasible to combine data and perform analyses across studies in any meaningful way beyond descriptive analyses. Henceforth, the quantification of CNC caregiver resilience levels and the magnitude of the relationship between resilience and other implicated variables was not possible to quantify. The ability to make broad statements about resilience levels and associated factors across CNC caregiving populations was also hindered by the underrepresentation of caregiving populations of more uncommon neurological diseases, namely MND and MS. As the resilience and informal caregiving field harmonizes and caregivers of more uncommon conditions garner research attention, it will become possible to establish resilience levels and correlates across widespread studies and populations to afford clarity and convergence in this dissonant area of study.

Due to the fact that it is relatively still novel practice to integrate resilience within the informal caregiving and health field, few resilience-building interventions have been developed that target this vulnerable population. Hence, the systematic review was unable to offer a synthesis of the current state of resilience intervention research amidst the meager number (four) of included studies that were intervention-based. Expressly, resilience interventions for informal CNC caregivers still remains an under-developed area that could not be critically assessed by this body of work.

4.5.2 Qualitative Interview Study and MS-Specific Recommendations

In the second qualitative study, the characteristics of the sampled caregiver participants afforded both strengths and limitations to our research. The interviewed sample consisted of participants providing care for persons living with MS presenting with a range of disability levels, from mild (i.e., no walking impairment) to advanced disability (i.e., wheelchair or scooter dependent). This meant that MS caregivers provided narratives of adversity across many life stages and progressions of the disease. While this range provided sample diversity, testimonies based on differing amounts of caregiving demand as a function of disability level meant that caregivers were in need of a breadth of services. Consequently, this made it difficult to identify and magnify primary areas of support resource and service insufficiencies. Furthermore, the interview population lacked cultural and ethnic diversity and were from one single country (Canada). This demographic homogeneity made it challenging to explore the relationship between resilience processes and sociodemographic and varying contextual factors. Similarly,

the interview sample was comprised of mostly (83%) spousal caregivers, which leaves the experience of other MS caregiving relationships still relatively underexplored.

Within participant testimonies, experiences of adversity and distress as part of previous lived experiences readily emerged, which ultimately propagated into themes of loss and continuous and additive challenges. The saliency of such problems may have been partially attributable to the fact that interviews occurred during the first year of the global COVID-19 pandemic. In sweeping fashion, the novel coronavirus disease rapidly spread across western countries in early 2020, causing major lifestyle disruptions due to lockdown and physical distancing measures, and widespread anxiety.[235] Recently, scientific literature has demonstrated that the pandemic has caused mental health issues of anxiety, stress, and depression, namely within vulnerable and at-risk populations, such as those with pre-existing chronic illnesses and their care-providers.[236] Therefore, it is possible that the current distress-prone COVID-19 context may have coloured participants' responses and exacerbated tones of destitution in interview discussions.

Assessing a primary pillar of resilience – healthy functioning or wellbeing outcomes – in MS caregivers was beyond the scope of this work in spite of the fact that findings from the systematic review confirmed the vast implications of resilience for self-perceived wellness indicators. We principally focused on exploring *how* MS caregivers achieve resilient processes, and, as a result, our research design was not formulated to narratively explore explicitly which health outcomes are preserved or enhanced via resilience pathways, nor to what degree. Future directions in MS caregiver research should attempt to integrate qualitative resilience narratives of MS caregivers with quantitative self-reported health measurements (e.g.,

perceived stress, anxiety, depressive symptoms, and general comorbidities) via high-level mixed methodology and triangulation procedures. Multiple extensive reviews focusing on dementia caregivers have documented the link between resilience and psychological and biological factors,[237,238] and similar work ought to be accomplished in MS caregiver populations. Moreover, to advance resilience and health research in MS caregivers, it would be pioneering to examine how variances in resilience trajectories are associated with objective physiological health measures and indicators assessed within controlled clinical settings. Indeed, this initiative would echo emergent resilience research which has linked psychological resilience to vast physiological measures, such as systemic inflammation,[239,240] aging biomarkers,[241] cardiovascular disease risk factors,[242] physiological fitness levels,[243] and immune markers.[244]

4.5.3 Broad Limitations Across Studies and Combined Future Directions

Collectively, these aforementioned limitations point to broader shortcomings of this body of work. The attainment of conceptual convergence within resilience and caregiving science serves as an imperative step towards informing the development of efficacious resilience-building interventions tailored to caregiver populations. As previously discussed, there remains a shortage of literature incorporating resilience-building interventions in CNC caregiving populations, and naturally this extends to the MS field. To our knowledge, only one resilience-building intervention has been published in dyadic (i.e., partnered caregivers and care-recipients) MS-specific populations at the pilot stage.[245] Moving forward, the development and implementation of resilience-based interventions bespoke to distinct caregiving

populations merits receipt of significant research attention supported by high-level decision-makers.

Findings from the interview study support the demand for resilience interventions from community-dwelling MS caregivers themselves. Given the divergent barriers some MS caregivers face due to geographic location and conflicting life roles, it is advised that the delivery methods of such resilience interventions consist of innovative remote-delivery and telehealth strategies to encourage participation of MS caregivers who face accessibility difficulties. In truth, incorporating assistive technology within the development of web-based interventions may be a fruitful avenue to advance resilience-building initiatives. Recent reviews of online interventions designed to increase resilience in informal caregivers revealed that most are implemented in the form of web-based tools, mobile-apps, and social network services aimed to improve quality of life, enhance perceptions of social support, and minimize distress.[246,247] Unfortunately, much of the reviewed work is still at a formative development stage and integration of these technologies with assistive mobility devices has yet to be explored. Substantial work is needed to advance such interventions to evaluate their usability and impact. Indeed, determining the feasibility, efficacy, and effectiveness of such interventions shall require long-term commitment to high-quality clinical trials. Further, we recommend that such trials incorporate MS caregivers of care-recipients possessing differing disease subtypes and stages of progression to account for the characteristic heterogeneity within this group.

This thesis argues that the MS caregiving experience, and perhaps the experience of resilience itself, are distinct from other cohorts due to a host of differentiating factors. Consequently, future methodological work should aim to validate current commonly used

resilience scales across particular subpopulations, most especially MS caregivers. At a more narrowed level, the development of a validated instrument assessing caregiver resilience that is condition-specific may more adequately account for the differences in the caregiving experience as a product of the specific CNC afflicting care-recipients and is worthy of future pursuits. However, we caution that such scales may not be appropriate for examining resilience processes and magnitudes across broader CNC caregiver populations. With the anticipated evolution of the resilience field into a more enlightened and unified state, we encourage the concurrent development of psychometrically sound assessment tools to reflect contemporary resilience understandings to strengthen future work rooted in modern resilience processes.

Furthermore, much (68%) of the reviewed literature was cross-sectional in design, with only one longitudinal study included. Equivalently, the interview study solely interviewed participants at a single time point. Thus, the scarcity of longitudinal-based research in the resilience and caregiving field greatly limits our understanding of how resilience processes change over time. Indeed, without the adoption of more longitudinal study designs within this discipline, it will be unobtainable to examine resilience over developmental trajectories nor ascertain how variances in sociodemographic and contextual factors influence resilience trajectories over the life span. Moving forward, we recommend that studies focusing on resilience in informal caregiving advance longitudinal designs to account for temporal fluctuations in the resilience course.

With our suggestion for future resilience studies to employ longitudinal designs in the caregiving field, we feel that this work could be complemented by the integration of life course theory. Life course theory is a framework used to explain health and disease across populations

over time, and powerfully conceptualizes health disparities to guide important policy and clinical improvements via a preventive appraoch.[248] A recent study built a rationale for incorporating a life course perspective into resilience models in aging and multimorbidity contexts, arguing that the likelihood of cumulative effects along interminable resilience pathways necessitates a life course approach.[249] Previous research has applied the life course perspective to informal caregivers of persons with AD to analyze entry into the care trajectory (at AD onset), yielding a typology of socially constructed phases.[250] We feel that such methods could be mirrored in the examination of resilience in MS and other CNC informal caregiver populations to enable proactive and effective early detection of non-resilient caregiving trajectories and more sufficient intervention policies.[250]

Indeed, of particular interest for future research directions is the investigation of how resilience in CNC caregivers evolves from the point of entry into the caregiving role (i.e., disease onset) over time, particularly as the condition advances in the case of progressive CNCs (e.g., MS, MND, PD) or as care-recipients adjust to injury or disease activity in sudden onset (e.g., TBI, SCI, stroke) or intermittent (e.g., epilepsy) conditions. Understanding these trajectories will be crucial for profiling caregivers who may be more at risk of struggling to achieve resilience pathways, while also ensuring that they do not languish as a result of critical unmet needs.

In both the review study and qualitative study, the inextricable connection between resilience and contextual factors was evident, but not well understood. In the review study specifically, the link between resilience and sociodemographic factors and contextual resources was subject to considerable heterogeneity. It is plausible that such heterogeneity is attributed to the variance among caregiving experiences across different CNCs and may be evidence in

support of more narrowed condition-specific caregiving studies. Moreover, the lack of ethnic and socioeconomic diversity among the interviewed sample hindered our ability to ascertain precisely which caregivers are most at risk of adverse outcomes through multilevel environmental mechanisms. Specifically, the inability to coherently determine the relationship between resilience and select individual (e.g., race, gender, income, geographic location) and care-recipient (e.g., disease or injury severity) characteristics renders it challenging to pinpoint and target at-risk caregiver populations via sociodemographic surveying and tailored program development. From a proactive life course lens, future research directions should strive to clarify the link between resilience and contextual factors. Subsequent developments of informal or family caregiving and resilience models should aim to apprehend the interconnectedness and interdependence of resilience and the multiple social realms in which a caregiver exists.[249] Indeed, we argue that the continuum of resilience is a socially constructed concept centrally rooted in context subject to change over time, and this fundamental relationship can no longer be overlooked cross-sectionally or met with inconsistencies within the resilience field.

4.6 CONCLUSIONS

Collectively, this research provides important advancements for the resilience and caregiving field and responds to an integral need for further comprehension of the unique MS family caregiving experience. To integrate key findings across both articles within this thesis, we reinforced that resilience is a conduit for healthy adjustment and general wellbeing among vulnerable CNC and MS-specific informal caregiving populations. We believe that the future of

informal caregiver, resilience, and health research lies within a strengths-based perspective, whereby resilience is explored and cultivated via high-quality proactive approaches founded in empowerment. In addition to the need for conceptual convergence within the resilience field, we must radically dissociate the current resilience and informal caregiving rhetoric from prevailing deficit- and burden-focused narratives. Together, the attainment of these two motions built upon a fundamental underlying perceptual shift will strengthen the development and efficacy of resilience-building interventions tailored to MS and other CNC caregivers. Finally, both studies emphasized the significant implications of contextual and sociodemographic factors for studies of resilience, despite the fact that broad socioenvironmental contexts, encompassing community and societal resources, are generally not the focus of existing resilience and caregiving research and interventions. Future directions must clarify these paramount relationships further via high-level longitudinal methods comprised of socioeconomically and culturally diverse caregiver samples to enable the profiling and targeting of MS caregivers where resilient processes may be compromised and are most in need of community and societal level resilience facilitating resources.

CHAPTER 5
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CHAPTER 6
FIGURES, TABLES AND APPENDICES

Figure 1. The resilience framework in the context of caring relationships (taken from Windle & Bennett[103])

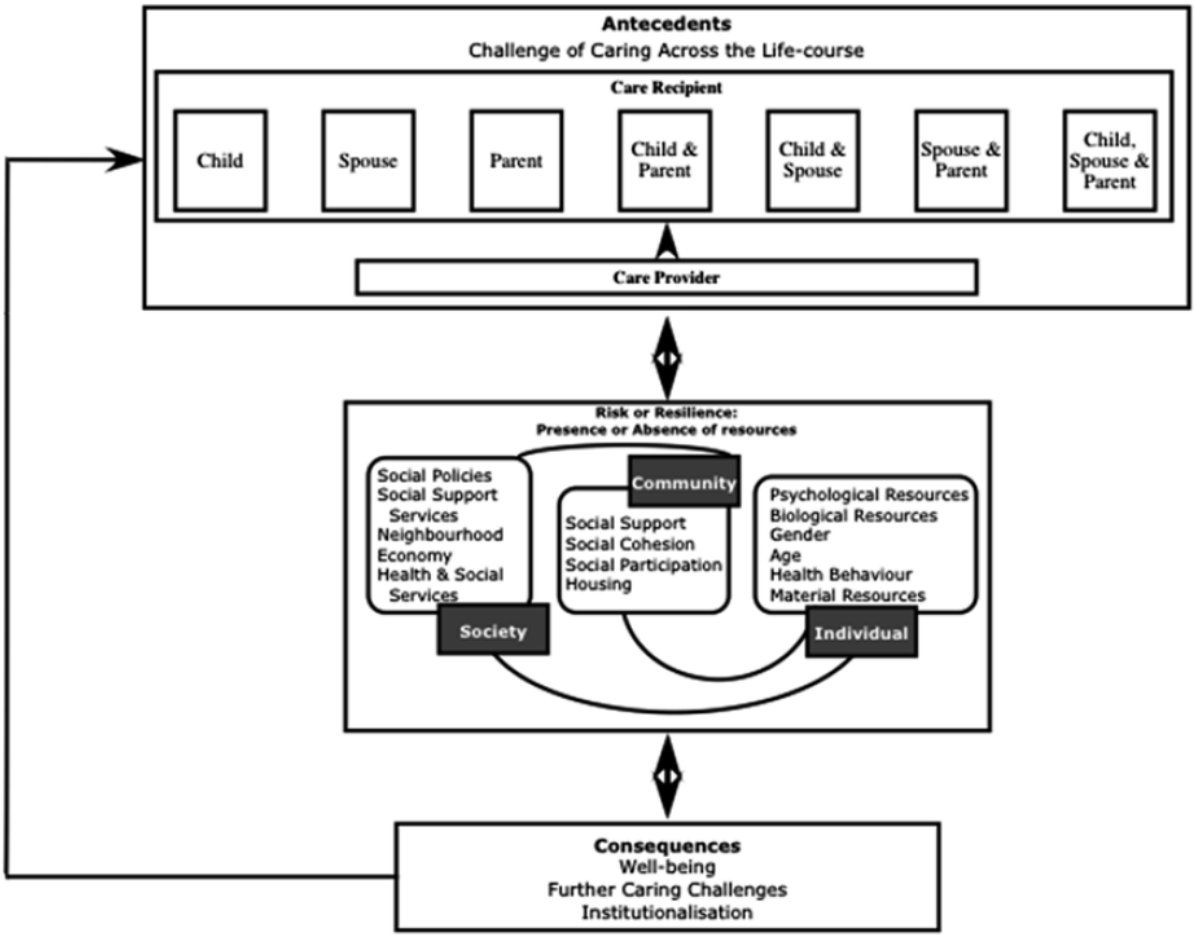

Figure 2. Flow diagram of the study selection process.

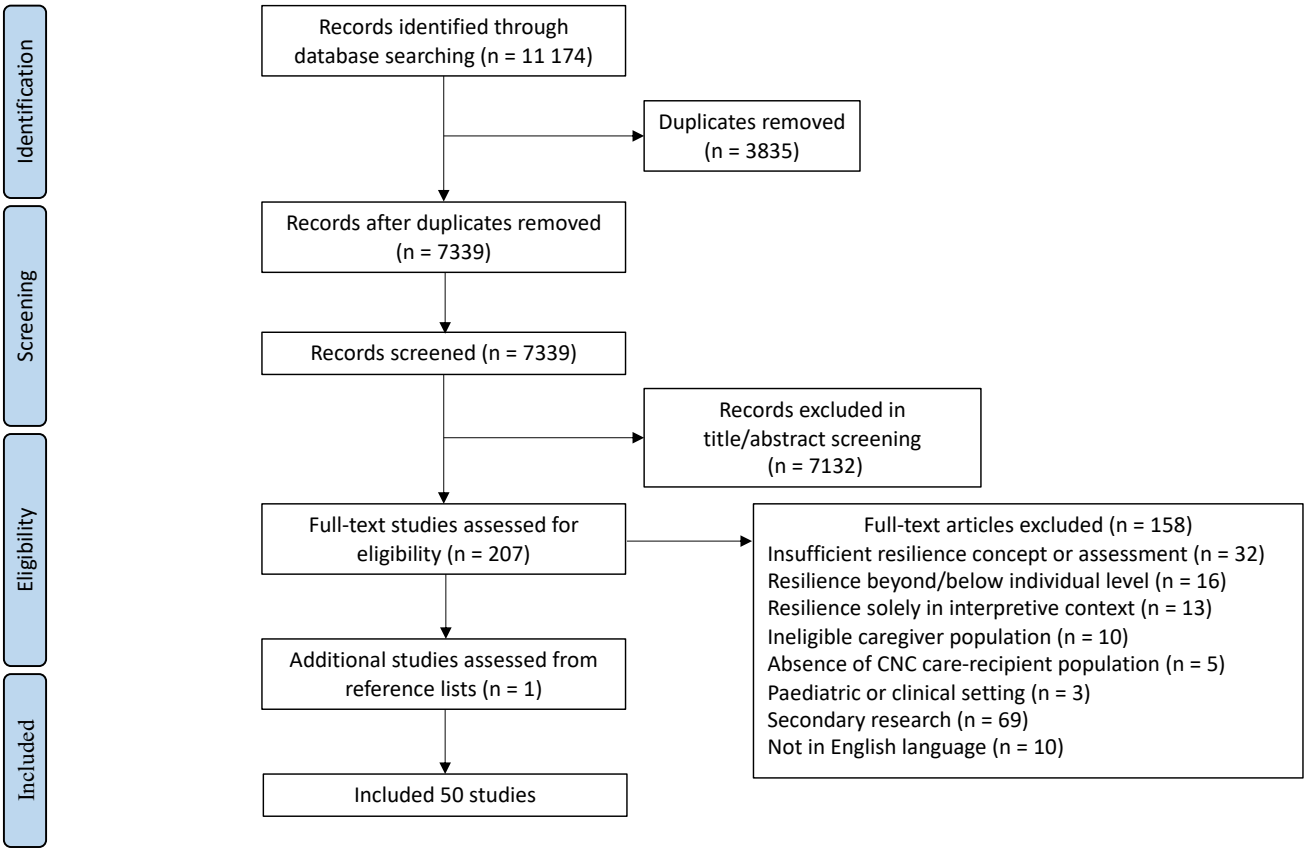

Figure 3. Conceptual framework of resilience resources and adaptive pathways within resilience cycle, adapted with permission from: Windle & Bennett[103]

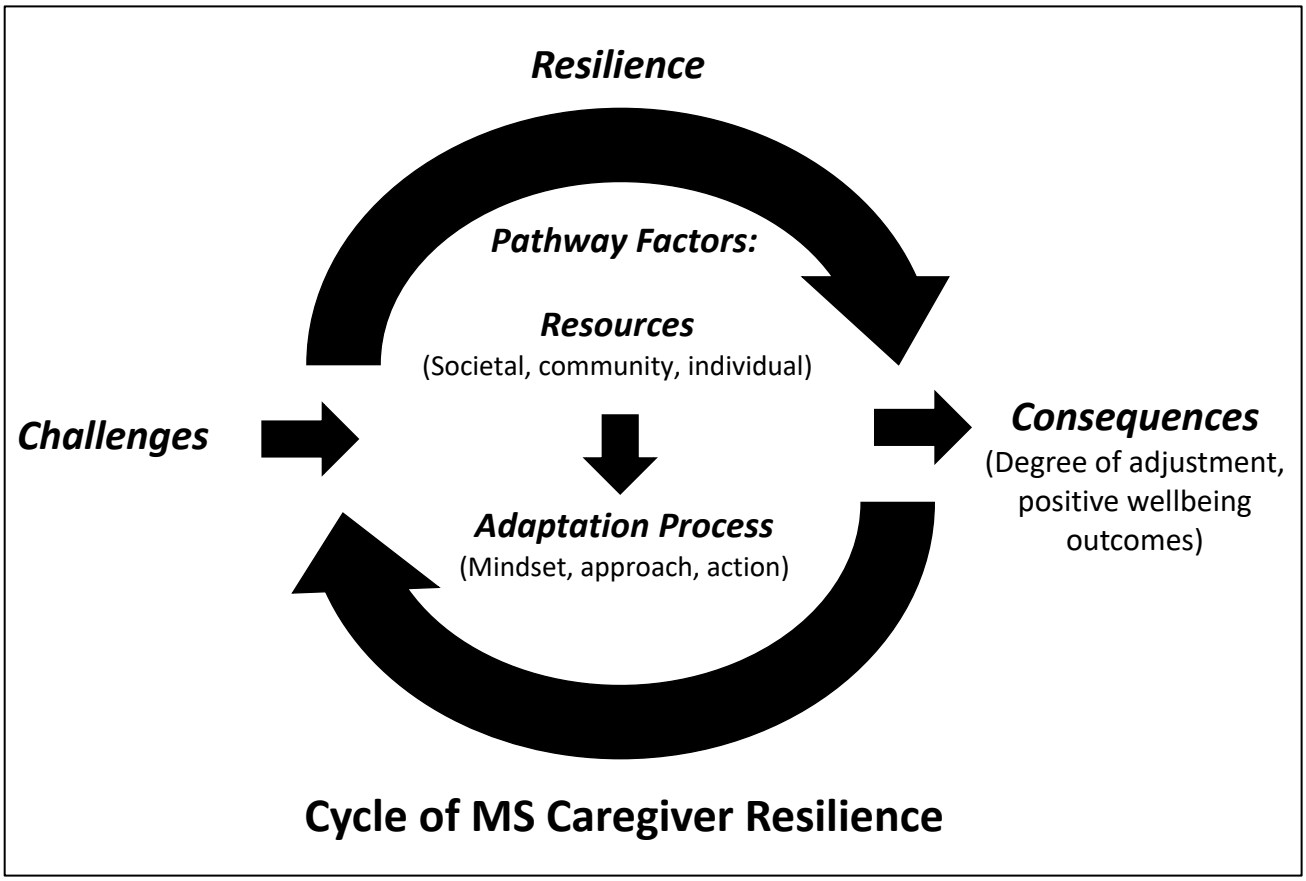

Table 1. Inclusion and exclusion criteria based on modified PICO.

PICoS	Inclusion Criteria	Exclusion Criteria
Population	Family caregivers of adult persons living with a CNC Community-dwelling adults (≥18 years old)	Formal/paid caregivers Caregivers of non-CNC or pediatric populations
Phenomenon of interest	Psychological resilience in individual family CNC caregivers	Resilience at the dyadic or community level Proxy or composite measures of resilience
Context	Any country Primary informal home care	Clinical or formal healthcare settings
Study Type	Quantitative, qualitative, mixed methods original research in the English language	Secondary research Unavailable in English language

Table 2. Study and caregiver sample characteristics in the 50 studies included in the review.

Author (year)	Country	Sample Size (n)	Age, Mean (SD)	Gender (% F)	Relationship to care-recipient (%)	CNC
Castellano-Tejedor & Lusilla-Palacios (2017)	Spain	75	48.55 (12.55)	84.0	Spouse/Partner: 44 Offspring: 39 Sibling: 8 Parent: 5 Other: 3	SCI
Senturk, Akyol, & Kucukguclu (2018)	Turkey	103	56.5 (9.91)	85.4	Spouse: 36.9 Mother: 42.7 Father: 16.5 Relative: 3.9	Dementia
Garity (1997)	USA	76	61.5 (14.1)	71.0	Spouse: 43 Offspring: 42 Sister: 8 Grandchild: 7	AD
Scholten et al. (2020)	The Netherlands	157	55.5 (12.4)	61.8	Partner: 78.3 Parent: 8.9 Child: 7 Other: 5.8	SCI, ABI
Brickell et al. (2020)	USA	346	40.6 (9.3)	96.2	Spouse/Partner: 91 Other: 9	TBI
Simpson & Jones (2013)	Australia	61 (TBI: 30 SCI: 31)	ABI: 54 (12) SCI: 50 (14)	90.2	Parent: 39.4 Spouse: 54.1 Other: 6.6	TBI, SCI
Cousins et al. (2013)	UK	27	**NIV** 57.56 (11.70) **Declined NIV** 65.88 (10.45)	74.0	Spouse/Partner: 40.1 Offspring: 7.4 Sibling: 11.1 Parent: 3.7	MND
Elnasseh et al. (2016)	Spain	105	57.71 (13.35)	74.3	NR	Dementia
Ertl et al. (2019)	Spain	95	51.1 (13.85)	78.0	Spouse/Partner: 60 Offspring: 26.3 Sibling: 9.5 Parent: 4.2	PD

Fitzpatrick & Vacha-Haase (2010)	USA	30	76.4 (6.0)	70.0	Spouse: 100	Dementia (AD or other)
Kimura et al. (2019)	Brazil	43	51.1 (15.2)	97.1	Spouse: 48.8 Offspring: 34.9 Sibling: 9.3 Other: 7	Young-onset AD
Ruisoto et al. (2020)	Spain	283	59.93 (14.56)	65.7	Offspring: 55.5 Spouse: 40.6 Other: 3.9	Dementia
Scott (2013)	USA	110	63 (11)	80.2	Spouse: 36 Offspring: 59.5 Other: 4	AD
Pessotti et al. (2018)	Brazil	50	54.7 (11.1)	88.0	Wives: 32 Daughters: 54	Dementia
Wilks & Vonk (2008)	USA	304	63 (13.5)	77.0	Spouse: 43 Offspring: 39 Friend: 4 Other: 14	AD
Rosa et al. (2020)	Brazil	106	57.9 (13.75)	79.2	Spouse: 37.7 Offspring: 52.8 Other: 9.4	AD
Chan, Yap & Khalaf (2019)	Malaysia	207	50.4 (14.5)	79.7	Spouse: 16.4 Offspring: 61.4 Other: 17.4 Unknown: 4.8	AD
Dias et al. (2016)	Brazil	58	62.5 (13.44)	79.3	Spouse: 44.8 Offspring: 51.7 Other: 3.4	Dementia (AD, vascular dementia, mixed dementia)
Serra et al. (2018)	Spain	326	59.9 (14.6)	65.7	Spouse: 55.5 Offspring: 40.6 Other: 3.9	Dementia
Sutter et al. (2016)	Spain	127	57.14 (13.01)	77.2	Spouse/Partner: 17.8 Offspring: 22.2 Sibling: 60	Dementia

Jones, Killett, & Mioshi, (2018, 2019)	UK	80	NR	73.8	Spouse: 65 Other: 35	Dementia
Jones, Killett & Eneida (2019a); Jones, Woodward & Mioshi (2019b)	UK	110	NR	66.0	Spouse: 62 Other: 38	Dementia
Wilks et al. (2011, 2018)	USA	691	61[†]	79.8	Spouse: 16.7 Offspring: 51.3 Sibling: 4.4 Grandchild: 6.6 Friend: 3.8 Other: 16.9	AD
Wilks (2008a); Wilks & Croom (2008b)	USA	229	45[†]	90.0	Spouse: 30 Offspring: 49 Friend: 8 Grandchild: 5 Other: 8	AD
Anderson, Daher, & Simpson (2019)	Australia	131	58.2 (14.3)	80.9	Spouse: 45 Parent: 44.3 Other: 10.7	TBI
Hayas, Arroyabe, & Calvete (2015)	Spain	237	55.6 (12.4)	77.6	Spouse: 47.3 Parent: 28.3 Child: 14.8 Sibling: 7.2 Other: 2.5	ABI
Vatter et al. (2018, 2020)	UK	136	69.44 (7.62)	85.3	Married: 94.9 Cohabitating: 5.1	PD related dementia
Ledbetter, Carr, & Lynn (2020)	USA	312	42.3 (11.9)	80.8	Spouse/Partner: 100	SCI
O'Rourke et al. (2010)	Canada	105	69.59 (8.66)	55.0	Spouse: 100	AD
Rivera-Navarro et al. (2018)	Spain	326	60.1 (14.5)	67.2	Spouse: 41.4 Offspring: 52.5 Son-/daughter-in-law: 2.5 Sibling: 0.9 Other: 2.5	Dementia

Tyler et al. (2020)	USA	253	59.92 (14.68)	73.1	Spouse: 68.8 Parent: 21.7 Friend: 1.2 Sibling: 4.3 Cousin: 0.4 Aunt/uncle: 1.2 Other: 2.4	PD
Ghaffari et al. (2019)	Iran	54	**Control** 43.4 (6.3) **Intervention** 42.6 (6.2)	**Control** 70.0 **Intervention** 88.0	**Control** Spouse: 20 Offspring: 80 **Intervention** Spouse: 12 Offspring: 88	AD
Lavretsky, Siddarth & Irwan (2010)	USA	40	**Control** 63.3 (13.4) **Intervention** 60 (9.4)	**Control** 55.0 **Intervention** 75.0	Spouse: 37.5 Offspring: 62.5	AD
MacCourt et al. (2017)	Canada	200	64.4[†]	79.0	Spouse: 61.9 Parent: 23 Other: 5.1	Dementia/ AD
[††] Pandya (2019)	India	96/96 (C/I)	**Control** 52.5 (10.67) **Intervention** 52.68 (11.03)	**Control** 86.5 **Intervention** 81.3	Spouse: 54.6 Offspring: 23.3 Son/Daughter in-law: 22.1	AD
Maneewat, Lertmaharit, & Tangwongchai (2016)	Thailand	150	NR	NR	NR	Dementia
Bull (2014)	USA	18	64 (14.1)	67.0	Spouse: 39 Offspring: 61	Dementia
Kidd, Zauszniewski, & Morris (2011)	USA	20	60.2[†]	85.0	Spouse: 100	Dementia
Bekhet & Avery (2018)	USA	80	57.0 (15.6)	90.0	NR	Dementia
Roberts & Struckmeyer (2017)	USA	33	NR	87.9	Spouse: 42.4 Parent: 48.5 Offspring: 6.1 Sibling: 3	Dementia

Han et al. (2019)	USA	39	62 (7.4)	76.9	Spouse/Partner: 7.7 Offspring: 82.1 Other: 10.2	AD and related dementias
Liu et al. (2020)	USA	27	69.04 (10.51)	77.8	Spouse: 46.2 Offspring: 50 Sibling: 3.85	Dementia
Donnellan, Bennett & Soulsby (2015, 2017, 2019)	UK	23	75 (7.46)	69.6	Spouse: 100	Dementia

† SD for total sample not reported.

†† Pre-test values reported

NR, Not reported; ABI, Acquired Brain Injury; AD, Alzheimer's Disease; MND, Motor Neuron Disease; NIV, Non-Invasive Ventilation; PD, Parkinson's Disease; SCI, Spinal Cord Injury; TBI, Traumatic Brain Injury

Table 3. Quantitative, mixed-methods, and qualitative articles' descriptions and summaries of resilience findings.

Author (year)	Purpose	Recruitment setting	Resilience scale or measure	Mean resilience score (SD)	Key results
Quantitative, cross-sectional or longitudinal studies (*n* = 35)					
Castellano-Tejedor & Lusilla-Palacios (2017)	To describe a sample of caregivers of persons SCI, their burden of care, resilience, and life satisfaction and to assess the relationships between these variables and other sociodemographic factors.	SCI acute unit from a tertiary university hospital following discharge	The Resilience Scale	141.93 (23.4)	Half of sample displayed moderate-high resilience; few had low resilience scores. Resilience was not related to caregivers' demographics or SCI severity. Burden was negatively correlated with resilience. Resilience was positively correlated with relationship satisfaction.
Senturk, Akyol, & Kucukguclu (2018)	To examine the relationship between caregiver burden and psychological resilience in caregivers of PWD.	Outpatient neurology department of a university hospital	The Resilience Scale for Adults	111.25 (23.9)	Negative correlation between caregiver burden index (CBI) and resilience scores.
Garity (1997)	To investigate the relationship between stress level, learning style, resilience factors, and ways of coping in AD family caregivers.	Support groups of an AD association	The Resilience Scale	144.4[†]	Participants were moderate-high on resilience scores and used problem-focused and emotion-focused coping. Resilience positively correlated with emotion-focused and problem-focused coping.
Scholten et al. (2020)	To identify intra- and interpersonal sociodemographic, injury-related, and psychological variables measured at admission of inpatient rehabilitation that predict psychological distress among dyads of individuals with SCI or ABI and their significant others six months after discharge.	Part of lager study conducted in regional rehabilitation centers	Connor-Davidson Resilience Scale Short-form	28.2 (6.1)	Higher baseline psychological distress, lower scores on adaptive psychological characteristics (combination of self-efficacy, proactive coping, purpose in life, and resilience), and higher scores on maladaptive psychological characteristics (combination of passive coping, neuroticism, appraisals of threat and loss) were related to higher psychological distress, as well as crosswise between individuals with SCI or ABI and their significant others.
Brickell et al. (2020)	To examine factors related to resilience in military caregivers across health-related caregiver QOL, caregiver sociodemographic variables, and SMV injury and health status.	TBI clinics at a national military medical center; marine corps base camp; community outreach activities	TBI-QOL Resilience Short form	55.6 (9)	There were no differences across caregiver resilience groups ('low-moderate', 'moderate', 'moderate-high') for most demographics, SMV injury, and health status variables. Low resilience was related to strain on employment due to caregiving duties, financial burden, caring for children, less personal time, caring for both verbal and physical irritability, anger and aggression, and

					lower SMV functionality. Lower resilience was associated with poorer health-related QOL scores across all groups.
Simpson & Jones (2013)	To investigate: the relationship between resilience and positive affect, negative affect, and burden in caregiving; the relationship between resilience and helpfulness of caregiving management strategies; and the similarities and differences in resilience among family TBI vs. ABI caregivers.	Review of medical records and staff caseloads	The Resilience Scale	140.2 (18.7)	Positive correlation between resilience and positive affect. Resilience demonstrated a negative correlation with negative affect and burden scores. No link between resilience and the relatives' severity of functional impairment. Participants with high resilience scores rated certain caregiving strategies as more helpful than those with low resilience scores.
Cousins et al. (2013)	To explore the influence of family caregivers on the uptake of NIV in persons with MND.	Specialist neurology and respiratory clinics	The Dispositional Resilience Scale	**NIV** 88.63 (13.2) **Decliners** 73.50 (15)	Caregivers supporting NIV treatment were more resilient. Caregiver resilience (commitment) was the strongest predictor of uptake of NIV treatment.
Elnasseh et al. (2016)	To examine whether healthier family dynamics are associated with a higher sense of coherence, resilience, and optimism in dementia caregivers in Latin America.	Regional neuroscience institute	The Resilience Scale for Adults	204.29 (21.8)	Family dynamics explained 32% of the variance in resilience. Income was associated with resilience. Greater family empathy and decreased family problems were associated with higher resilience.
Ertl et al. (2019)	To examine whether resilience moderates the relation between perceived stress and health-related QOL among PD caregivers in Mexico.	Outpatient neuropsychological services at national neuroscience institute	The Brief Resilience Scale	21.28 (4.4)	Resilience moderated the inverse relationship between perceived stress and mental health-related QOL. Resilience did not moderate the relation between stress and physical health-related QOL.
Fitzpatrick & Vacha-Haase (2010)	To examine the relationship between resilience and marital satisfaction in caregivers of spouses with dementia.	Gerontology research unit at regional hospital and local caregiver support groups	The Shortened Resilience Scale	5.5 (0.8)	Resilience was not correlated with marital satisfaction. Marital satisfaction was influenced most by caregiver burden (negative influence) and caregiver age (positive influence).
Kimura et al. (2019)	To investigate the relationship between clinical symptoms of people with Young-onset Alzheimer disease (YOAD) and carer resilience.	AD outpatient clinic at university institute of psychiatry	The Resilience Scale	141.4 (13.5)	Carers showed moderate-high levels of resilience. No relationship between carer resilience and both carer and care-recipient sociodemographic characteristics. No relationship between career resilience and clinical symptoms of persons with

					YOAD. Resilience was inversely associated with carers' depressive symptoms.
Ruisoto et al. (2020)	To examine factors that predict burden in a sample of family caregivers of PWD.	Referral lists of the associations of relatives of people with AD and other dementias, neurology outpatient clinics, and the national reference center of AD	The Connor-Davidson Resilience Scale	73.9 (13.7)	Caregiver burden correlated negatively with resilience. Resilience explained 18.7% of variance in social support and social support accounted for 46.11% of variance in burden. Social support partially mediated the relationship between resilience and burden in caregivers.
Scott (2013)	To examine the moderating effect of resilience between caregiver stressors and caregiver burden.	Community agencies that provide education and support to AD caregivers in region	The Resilience Scale	NR	Resilience was not identified as a moderator of the relationship between stressors and caregiver burden. An inverse relationship existed between resilience and caregiver burden.
Pessoti et al. (2018)	To evaluate family caregivers' perception of QOL, burden, resilience, and religiosity and relate them with cognitive aspects and occurrence of neuropsychiatric symptoms of elderly with dementia.	Clinical neurology outpatient clinic at regional hospital	The Resilience Scale	135.6 (22.5)	Resilience was associated with better perceived QOL, severity of dementia, higher intrinsic religiosity, and lower occurrence of depressive symptoms.
Wilks & Vonk (2008)	To explore whether the coping method of private prayer served as a protective factor or mediator between caregiver burden and perceived resiliency among AD caregivers.	Regional AD association caregiver support groups	The Connor-Davidson Resilience Scale	73.4 (13.4)	Burden positively affected the extent of prayer usage and negatively influenced resilience. Caregiver burden and private prayer influenced variation in resilience scores. Results support prayer as a mediator between burden and resilience.
Rosa et al. (2020)	To investigate resilience in caregivers of people with mild and moderate AD and the related sociodemographic and clinical characteristics.	Outpatient clinic of university institute of psychiatry and AD	The Resilience Scale	140.6 (17.2)	In persons with mild and moderate AD, caregiver resilience was inversely related to emotional problems. There was no difference between resilience in caregivers of people with mild vs. moderate AD. In the mild AD group, neuropsychiatric symptoms of the person with AD and caregiver's depressive symptoms were related to caregiver resilience. In the moderate

					AD group, caregiver QOL and co-residing with the care-recipient were related to resilience.
Chan, Yap & Khalaf (2019)	To explore caregiver strain and resilience of caregivers of patients with AD in Malaysia; to determine factors associated with caregiver strains in caregivers of patients with AD; and to determine the effect of resilience on the relationship between caregiver strains and caregiver or patient factors.	AD Foundation Malaysia	The Brief Resilience Scale	19.2 (3.3)	The sample demonstrated moderate-high resilience. Resilience was associated with gender and employment status. A negative correlation was found between resilience and caregiver strain.
Dias et al. (2016)	To investigate the relationship between resilience and sociodemographic and clinical factors of people with dementia; to test the hypothesis that caregivers' resilience is a personality trait, independent from the clinical symptoms of the person with dementia.	Physicians' referral from a dementia outpatient clinic	The Resilience Scale	137.6 (15.5)	Participants reported moderate-high levels of resilience. Resilience was not related to gender, clinical or emotional problems. Resilience was related to caregiver QOL, and inversely associated with depressive symptoms. There was no relationship between caregivers' resilience and sociodemographic and clinical characteristics of people with dementia. Authors concluded that resilience is an individual characteristic.
Serra et al. (2018)	To investigate a set of caregiver and patient factors, such as psychosocial protective variables, linked to abuse-related behavior of PWD.	Referrals from the associations of relatives of PWD, neurology outpatient clinics, and The National Reference Center of AD	The Connor-Davidson Resilience Scale	73.9 (13.7)	Resilience and social support were negatively associated with abuse scores (i.e., protective effect). Social support and resilience were associated with a lower probability of abuse.
Sutter et al. (2016)	To examine the relationships between personal strengths (optimism, sense of coherence, and resilience) and mental health of dementia caregivers from Latin America.	Regional neuroscience institute and university, local neurology outpatient clinics, flyers, word-of-mouth, local community connections	The Brief Resilience Scale	17.4 (5.6)	More manageability, general resilience, and social competence were uniquely associated with lower depression. Resilience and other variables were not predictive of caregiver burden or life satisfaction.

Jones, Killett & Mioshi (2018)	To describe the demographic and psychosocial characteristics of caregivers who attend Dementia Cafes, and to identify which factors influence the likelihood of family caregivers attending Dementia Cafes.	Dementia cafes and health and wellbeing events facilitated by local AD or wellbeing societies	The Brief Resilient Coping Scale	NR	Caregivers who attended Cafes reported higher resilience and subjective wellbeing; no difference in social support was detected.
Jones, Killett & Eneida (2019a); Jones, Woodward & Mioshi (2019b)	**2019a** To investigate factors that affect resilient coping in carers; to assess whether symptoms of distress vary between carers with differing levels of resilient coping; and to identify whether resilient coping acts as a mediator in the carer distress wellbeing relationship. **2019b** To compare socio-demographic characteristics and the availability of social support for carers with 'low' and 'high' resilient coping and to identify if social support predicted high resilient coping in informal carers of people with dementia.	Adverts in newsletters, carer information events held by local charities and an online carer's forum, dementia cafes	The Brief Resilient Coping Scale	NR[a]	**2019a** 'High' resilient carers reported less distress than 'low' resilient carers. Resilient coping partially mediated the relationships between wellbeing and caregiver distress (i.e., depression, anxiety, stress, and burden). Carers with high resilient coping skills reported less depression, anxiety, stress, and burden than those with 'low' resilient coping. **2019b** The availability of emotional/informational support was most likely to predict resilient coping and tangible support was the least likely. Only gender predicted high resilient coping. No single domain of social support had a greater influence on resilient coping.
Wilks et al. (2011, 2018)	**2011** This study assessed impact of AD patients' aggressive behavior (i.e., AD aggression) on caregiver coping strategies (task-, emotion-, and avoidance-focused) and caregiver resilience, and examined whether coping strategy moderated the AD aggression–caregiver resilience relationship. **2018** To understand whether spiritual support with AD caregivers acts as a moderating factor among the	Mailing lists from a non-profit AD services organization; African American communities (e.g., churches, community centers, adult day centers, a home health agency, caregiver homes)	The Shortened Resilience Scale	**2011** 5.9[†] **2018** 5.8[†]	**2011** Aggression negatively predicted caregiver resilience. All coping strategies correlated with resilience scores. Task-focused coping was positively related to resilience. Emotion and avoidance-focused coping strategies separately interacted with aggression and increased its negative relationship with resilience. Task-focused coping showed no moderating effect. **2018** For each ethnic group of caregivers, burden was inversely proportional to resilience. In all groups, the association between spiritual support and

	caregiving burden-resilience relationship in a manner similar to caregiver social support; and to observe ethnicity, African American vs. Caucasian caregivers, in said moderation.				resilience was positive and direct. Social support did not moderate risk within either group. African American caregivers reported higher resilience than their Caucasian counterparts.
Wilks (2008a); Wilks & Croom (2008b)	**2008a** To evaluate psychometric properties of the shortened Resilience Scale among a sample of AD caregivers. **2008b** To examine whether social support functions as a protective, resilience factor among AD caregivers; to examine the relationship between risk (i.e., perceived stress) to mental and physical health, an outcome of resilience, and potential protective factors for resilience among caregivers.	Two large AD care conferences, one held in a large urban area and another held in a rural locale	The Shortened Resilience Scale	5.5 (1.3)	**2008a** Results confirmed the RS15 to be a psychometrically sound measure that can be used to appraise the efficacy of caregiving adaptability among the sample. **2008b** The sample reported moderate-high resilience. Perceived stress negatively influenced resilience and accounted for 43% of variance in resilience scores. Social support positively influenced resilience, and caregivers with high family support had the highest probability of elevated resilience. Social support is a protective, mediator of resilience.
Anderson, Daher, & Simpson (2019)	To integrate related explanatory (personality, coping) and mediating (hope, resilience, self-efficacy), and caregiver outcome (burden, psychological distress, quality of life) variables into a larger model and to test the role of resilience, hope, and self-efficacy among family caregivers of persons with TBI.	Six regional inpatient and community rehabilitation centres	The Connor-Davidson Resilience Scale	76.23 (12.3)	The model accounted for 63% of the variance in resilience. Resilience had a direct effect on positive affect in caregivers. There was a strong positive association between general self-efficacy and resilience. Problem-focused coping had a direct positive effect on resilience. Resilience was indirectly associated with caregiver burden when mediated through social support. Resilience demonstrated a direct effect on hope which is associated with positive mental health. Resilience was associated with reduced morbidity.
Hayas, Arroyabe, & Calvete (2015)	To develop the Questionnaire of Resilience in Caregivers of Acquired Brain Injury (QRC-ABI) and explore its psychometric properties.	The Federation of ABI Associations and public day care centers specializing in ABI	Questionnaire of Resilience in Caregivers of Acquired Brain Injury	43.24 (11.3)	The QRC-ABI showed good reliability and validity. Convergent validity was supported through positive correlations of the QRC-ABI with QOL, positive aspects of caregiving, and posttraumatic growth, and a negative correlation with perceived burden.

Vatter et al. (2018, 2020)	**2018** To explore the factor structure of the Zarit Burden Interview (ZBI) in life partners of people with Parkinson's related dementia and to examine the relationships among the emerging factors and the demographic and clinical features. **2020** To explore and compare levels of mental health, care burden, and relationship satisfaction among caregiving spouses of people with mild cognitive impairment or dementia in PD (PDD) or dementia with Lewy bodies (DLB).	Nation-wide post or as part of a larger study (ref)	The Brief Resilience Scale	24.97 (11.9)	**2018** Five factors of the ZBI (i.e., social and psychological constraints, personal strain, interference with personal life, concerns about future, and guilt) all negatively correlated with resilience. Lower resilience and higher negative strain and feelings of resentment were contributors to burden. **2020** Over 75% of respondents reported good resilience. ZBI scores correlated with resilience. Caregivers who were dissatisfied with their relationship reported lower resilience. Burden, stress, resilience, relationship satisfaction, quality of life, anxiety, depression, and mental health levels did not differ between spouses of people with PDD and DLB.
Ledbetter, Carr, & Lynn (2020)	To investigate how individual and contextual factors (i.e., caregiving tasks, resilience, timing of the SCI) moderate the extent to which receiving social support predicts psychosocial distress among SCI caregiving romantic partners.	Online groups targeted at SCI caregivers	The Brief Resilience Scale	4.05 (0.8)	Resilience inversely predicted psychosocial distress in both the pre-injury and post-injury groups. Findings revealed the benefits of resilience. Receiving high-quality support and timing of the injury moderated resilience effects. Injuries sustained after relationship initiation threatened wellbeing and closeness and altered the extent to which support and resilience were associated with health and relationship benefits.
O'Rourke et al. (2010)	To examine the three facets of psychological resilience (i.e., perceived control, commitment to living, challenge versus stability) as predictors of depressive symptoms over time among spousal caregivers of PwAD.	Clinic for AD and related disorders at a regional university hospital	The Dispositional Resilience Scale	NR	Resilience was associated with depressive symptoms among caregivers. Challenge and perceived control predicted depressive symptoms one year later. An increase in challenges over time predicted lower levels of depressive symptoms at Time 2. Commitment was not associated with depressive symptoms at any time point.
Rivera-Navarro et al. (2018)	To validate the Caregiver Abuse Screen (CASE) as an instrument for detecting the maltreatment of people with dementia in Spain.	Local associations of relatives of people with AD and other dementia and	The Connor-Davidson Resilience Scale	73.6 (13.4)	High CASE scores were associated with greater burden, lower social support, and lower resilience of caregivers. Resilience scores were negatively correlated with interpersonal abuse and neglect/dependency. The consistent negative

		neurology outpatient clinics			association of CASE scores with resilience is indicative of this advantageous characteristic.
Tyler et al. (2020)	To validate a theoretical structural equation model whereby social support is associated with higher levels of resilience in PD caregivers and increased resilience is related to decreased mental health symptoms.	PD clinics associated with academic university institutions in Mexico and the PD and Movement Disorders Center at a regional medical centre in the USA	The Brief Resilience Scale	NR	The model explained 11% of the variance in resilience. Higher levels of social support were associated with higher resilience, which in turn was associated with lower mental health symptoms. Resilience partially mediated the effect of social support on mental health symptoms.
Quantitative, intervention studies (*n* = 4)					
Ghaffari et al. (2019)	To determine the effectiveness of resilience education in the mental health of family caregivers of elderly patients with AD.	Referrals from regional hospital and neurologist offices	The Connor-Davidson Resilience Scale	NR	Resilience education promoted the mental health of family AD caregivers by decreasing somatic symptoms and social dysfunction.
Lavretsky, Siddarth & Irwan (2010)	To examine the potential of an antidepressant drug (escitalopram) to improve depression, resilience to stress, and quality of life in family dementia caregivers in a randomized placebo-controlled double-blinded trial.	NR	The Connor-Davidson Resilience Scale	60.2 (16.7)	Measures of depression, anxiety, resilience, burden and distress, and quality of life improved on escitalopram compared with placebo groups.
MacCourt et al. (2017)	To assess the structure and effectiveness of a grief management coaching intervention with caregivers of individuals with dementia.	Local social media and referrals from regional AD society	The Resilience Scale	**Spouse** T1: 67.9† T2: 68.9† **Adult Child** T1: 66.6† T2: 71.1†	For the intervention group, grief, coping, empowerment, and resilience scores improved post-intervention. The intervention group exhibited greater resilience at Time 2. Time 1 resilience scores predicted greater resilience at Time 2.
Pandya (2019)	To report the impact of a long-term meditation program for enhancing self-efficacy and resilience of home-based caregivers of older adults with AD.	Network of agencies linked to older adults, geriatric clinics and units in private hospitals.	The Resilience Scale for Adults; The Caregiver Resilience Scale	**RSA** **Control** Pre: 99.2 (8.3) Post: 100 (8.3) **Intervention** Pre: 100.31 (9) Post:187.93 (14.2) **CRS**	Post-test RSA and CRS scores of the intervention group were higher than the control group and their own pre-test scores. Caregiver women, spouses, Hindus, middle class, with college and higher education, homemakers, who attended at least 75% of the meditation lessons and regularly practiced meditation at home reported lower post-test perceived caregiving burden, higher self-

				Control Pre: 30.28 (4.4) Post: 31.03 (5.3) **Intervention** Pre: 31.21 (4.9) Post: 58.71 (6.8)	efficacy, and resilience. Meditation was effective for increasing resilience.
Mixed-methods studies (*n* = 4)					
Maneewat, Lertmaharit, & Tangwongchai (2016)	To develop the Caregiver Resilience Scale (CRS) for Thai caregivers of older persons with dementia and to examine its validity and reliability.	Memory Clinic, Neurological Clinic, or Geriatric Clinic in the Outpatient Department at a regional hospital	The Caregiver Resilience Scale; Semi-structured interviews	NR	The final version of the CRS was composed of 30 items within six domains: physical competence; relationship competence; emotional competence; cognitive competence; moral competence; and spiritual competence. The 30-item CRS was considered a valid and reliable instrument.
Bull (2014)	To describe family caregivers' level of resilience and psychological distress and to describe strategies that family caregivers use to persevere in their caregiving role despite challenges encountered in caring for a family member with dementia.	Five adult day centres located in city setting	The Resilience Scale; Narrative interviews	154.3 (15.8)	Participants had high resilience and low psychological distress. The use of self-sustaining strategies explained the high scores on resilience and low levels of psychological distress. Caregivers used four strategies to sustain the self: drawing on past life experiences that dealt with difficult situations, nourishing the self, relying on spirituality, and seeking dementia-related information.
Jones, Killett & Mioshi (2019)	To explore discrepancies and congruency between definitions of resilience in the academic literature and carers own conceptualisations; to assess differences and similarities in conceptualisations of resilience between carers with high, medium and low resilience scores; and to compare carers' perceived level of resilience with the level of resilience when measured on a standardised tool.	Theoretical sampling recruited from participants in previous study (Jones et al. 2018)	Brief Resilient Coping Scale; Semi-structured interviews	NR	Under half (46%) of carers were low resilient. Carers' definitions of resilience were concordant with clinical and academic definitions; however, they extended the concept and placed greater value on the role of self-compassion. Carers recognised that the appearance of resilience may have negative consequences in terms of securing support from others. Resilience scores did not always match carers' own perceptions of their level of resilience.
Kidd, Zauszniewski, & Morris (2011)	To test the effectiveness of a poetry writing intervention for family caregivers of elders with dementia and to examine outcome variables	Support groups, churches, and agencies	The Resilience Scale; Interviews	NR	Women were lower in self-transcendence and resilience, and higher in depressive symptoms and burden. Older caregivers scored higher than younger caregivers on the study variables of self-

	of self-transcendence, resilience, depressive symptoms, and subjective caregiver burden.			transcendence and resilience. Poetry writing was an effective intervention that may promote resilient outcomes.
Qualitative studies (*n* = 7)				
Author (year)	**Purpose**	**Recruitment setting**	**Means of resilience assessment**	**Key Results**
Bekhet & Avery (2018)	To identify components of resilience theory (i.e., risk factors, protective factors, overlapping factors) from the perspective of caregivers of PWD.	Regional AD Association early stage programs	Open-ended questions on written questionnaires	The experience of dementia caregiving involved a combination of risk factors and protective factors, suggesting that caregivers may feel conflicted. Risk factors included experiences of stress and difficulties, demanding tasks, frustration, lack of social support, exhaustion, and negative feelings. Protective factors included feeling rewarded and serving a purpose. If protective factors were more predominant, then caregivers became more resilient and experienced associated positive health outcomes.
Roberts & Struckmeyer (2017)	To examine family caregiver perspectives on how respite programming impacts their resilience and ability to better handle the demands of their responsibilities.	Recruited as part of a larger study[b] through respite providers	Semi-structured interviews	Several themes emerged describing the path to caregiver resilience which included family dynamics, isolation, financial struggles, seeking respite, and acceptance. The road to acceptance became a critical factor in the development of resilience.
Han et al. (2019)	To identify challenges, possible solutions as resources for resilience, and expected consequences from the perspective of family caregivers of hospice patients with dementia.	Two large hospice agencies recruited as part of a larger clinical trial	Deductive content analysis of secondary clinical trial data	Resilience resources were identified at the individual, community, and societal levels. Resources included knowledge, self-control and appraisal, self-care, using visual materials, having options to choose a good care facility with exemplary providers, family or friends' support, involving in volunteer activities, legislative support, public awareness, and health insurance. Identified challenges were difficulties in communication, providing care and decision-making, lack of knowledge, emotional challenges, concern about care facility selection, death with dignity, and lack of public awareness.
Liu et al. (2020)	To investigate the resilience of a growing but largely underserved and understudied population—Chinese American dementia caregivers, whose experience is embedded in their development throughout the life span, process of migration, and sociocultural contexts.	Local agency providing services for dementia caregivers with a representation of Chinese clients	Semi-structured interviews	Main themes fit within two categories, challenge and resilience, in each of the four principles—time and place, timing in lives, linked lives, and agency—of the developmental life course perspective. Physical and emotional exhaustion was the most frequently mentioned challenge theme, followed by limited knowledge of dementia, navigating the healthcare system, and limited time for self-development. Three aspects of resilience—sense of mastery, access to formal and informal support, and commitment to care—were salient among caregivers.

Donnellan, Bennett & Soulsby (2015, 2017, 2019)	**2015** To assess whether spousal dementia carers can achieve resilience and to reveal which factors and resources facilitate or hinder resilience within the ecological framework.	Two local dementia support groups and a care home	Semi-structured interviews	**2015** Carers achieve resilience via a complex multidimensional process. A resilient carer was someone who stayed positive, who maintained their relationship and loved one's former self, who were knowledgeable, well supported, and who were engaged with respite services. Facilitating community factors included friendships with common experience and social participation. Individual hindering resilience factors were negative outlook and perceived social isolation.
	2017 To explore social support as a key component of resilience and to identify the availability and function of support provided to older spousal dementia carers.			**2017** Social support is not always sufficient to facilitate resilience, as negative perceptions of support may moderate the effect of support on resilience. Family and friends served a wide range of functions, but were equally available to resilient and non-resilient participants.
	2019 To use qualitative longitudinal methods to examine trajectories of resilience and which assets and resources are associated with resilience and care status transitions in spousal dementia carers.			**2019** Five participants remained resilient, three remained non-resilient and four participants became resilient. Only one participant became non-resilient. Stable resilience was characterised by continuing individual assets and community resources. Carers who became resilient returned to previous resources or gained new resources.

[a] Authors divided participants into 'low' (BRCS 0-13), 'medium' (BRCS 14-16) and 'high' (BRCS 17+) resilient groups, with no inclusion of total mean resilience scores.

[b] Reference for large study not provided.

[†] SD for resilience scores not reported.

NR, not reported; ABI, Acquired Brain Injury; AD, Alzheimer's Disease; PD, Parkinson's Disease; PWD, Persons with Dementia; QOL, Quality of Life; SCI, Spinal Cord Injury; SMV, Service Member Veteran; TBI, Traumatic Brain Injury

Table 4. Operationalized definitions of resilience by article included in the review.

Author (year)	Resilience Model	Operationalized definition of resilience
Quantitative, cross-sectional or longitudinal studies (*n* = 35)		
Castellano-Tejedor & Lusilla-Palacios (2017)	Hybrid (Trait-Process)	A range of thoughts, feelings and behaviors and a dynamic process encompassing positive adaptation within the context of significant adversity; also considered a personality characteristic that moderates the negative effects of stress and promotes adaptation.
Senturk, Akyol, & Kucukguclu (2018)	Trait	The ability of a person to successfully overcome and adapt to negative conditions despite the difficult circumstances; satisfaction with social network and social support, psychological well-being, strength, and healthy life.
Garity (1997)	Trait	A personality trait or characteristic that moderates the negative effects of stress and promotes adaptation; persons who display courage or adaptability in the face of adversity.
Scholten et al. (2020)	Trait	Psychological factor related to psychological distress.
Brickell et al. (2020)	Process	Core concepts of adversity and personal adaptation; the concept of personal adaptation allows for resilience to be a flexible process rather than fixed and may be modified over time as the individual adapts.
Simpson & Jones (2013)	Process	A multidimensional construct constituting a range of thoughts, feelings, and behaviours; a dynamic process encompassing positive adaptation within the context of significant adversity.
Cousins et al. (2013)	Trait	The characteristic way that people approach and cope with life events, described in terms of three related tendencies: commitment, where behaviour is influenced by the meaning and purpose seen in a situation; control, the ability to make one's own choices in a situation; and challenge, the tendency to perceive life events as opportunities for development, rather than threats.
Elnasseh et al. (2016)	Process	A psychological phenomenon characterized by effective coping and adaptation in the face of loss, hardship, or adversity; a protective factor; personal strength.
Ertl et al. (2019)	Trait	An individual's ability to adapt, persevere, and maintain emotional equilibrium despite adversity; psychological strength
Fitzpatrick & Vacha-Haase (2010)	Hybrid (Trait-Process)	Resilient individuals are able to confront a crisis successfully and engage in positive behavior to adjust coping strategies for effective adaptation to the situation; a multi-dimensional construct, involving not only psychological traits, but also the individual's ability to use external sources to facilitate coping.
Kimura et al. (2019)	Hybrid (Trait-Process)	A dynamic and complex construct that involves the interaction of both risk and protective factors, internal and external to the individual, which act to modify the effects of an adverse life event; a protective factor that enhances health by buffering the deleterious effects of stress.
Ruisoto et al. (2020)	Hybrid (Trait-Process)	A control-related intrapsychic variable which may promote a more successful adaptation to care demands; personality trait, but broader approaches underline the importance of relational and situational contexts for resilience behavior.
Scott (2013)	Process	A characteristic or developmental process in individuals that, when activated, aids in thwarting the effects of social conditions that can lead to impaired daily functioning.
Pessotti et al. (2018)	Trait	One's capacity for successful adaptation when faced with the stress of adversity; not invulnerability to stress, but, rather, the ability to recover from negative events.

Wilks & Vonk (2008)	Trait	Implies a track record of successful adaptation in the individual who has been exposed to stressful life events, and an expectation of continued low susceptibility to future stressors; reflects an outcome strength; that is, the ability to recover from the stressor successfully.
Rosa et al. (2020)	Trait	One's capacity for successful adaptation when faced with the stress of adversity.
Chan, Yap & Khalaf (2019)	Trait	Successful adaptation and competence that results in effective functioning in the face of stressful situations.
Dias et al. (2016)	Trait	One's capacity for successful adaptation when faced with the stress of adversity; facilitates adaptation by enabling one to identify what is stressful, realistically appraise one's capacity for action, and solve problems effectively; considered as a personality characteristic.
Serra et al. (2018)	Trait	The abilities and personal resources of individuals that allows them to successfully deal with adverse situations.
Sutter et al. (2016)	NR	Relates to positive coping strategies, lower depressive symptoms, and positive psychosocial variables.
Jones, Killett & Mioshi (2018)	Process	The process of adaptation to distress and is associated with the caregiver's ability to draw on personal assets in combination with the availability, suitability, and use of community and societal resources.
Jones, Killett & Eneida (2019a); Jones, Woodward & Mioshi (2019b)	Process	**2019a** Multidimensional concept that embodies personal qualities and external support systems that enable one to thrive in the face of adversity.
	Process	**2019b** Positive adaptation to stressful situations and encompasses both individual characteristics and extrinsic factors, including social support from their family and the wider community.
Wilks et al. (2011, 2018)	Trait	**2011** Implies adaptational success; a characteristic of psychological well-being, referring to the ability to recover from negative life events, leading to hope and expectation of success in the face of future adversity; reflects post adversity strength boosted by protective factors.
	Trait	**2018** The positive pole of the ubiquitous phenomenon of individual difference in people's responses to stress and adversity; reflects an outcome strength, recovery and hardiness post-adversity.
Wilks (2008a); Wilks & Croom (2008b)	Trait	**2008a** An adaptational outcome success; suggests overcoming the odds, adapting to high risk (adversity), and recovering from adversity by adjusting successfully to negative life events.
	Trait	**2008b** Viewed as being augmented by protective factors and defined as a psychological phenomenon referring to effective coping and adaptation although faced with loss, hardship, or adversity.
Anderson, Daher, & Simpson (2019)	Hybrid (Trait-Process)	The ability to adapt in the face of tragedy, trauma, adversity, hardship, and ongoing significant life stressors; a multi-dimensional construct comprising a mix of personal skills and attributes, social competence, social resources and spirituality, which may be associated with reductions in morbidity and increased positive wellbeing.

Hayas, Arroyabe, & Calvete (2015)	Process	The process of positive adaptation in the face of adversity, trauma, tragedy, threats, or significant sources of stress; a dynamic process in which psychological, social, environmental, and biological factors interact to enable an individual at any stage of life to develop, maintain, or regain his or her mental health despite exposure to adversity.
Vatter et al. (2018, 2020)	Trait	The ability to bounce back from stress.
Ledbetter, Carr, & Lynn (2020)	Hybrid (Trait-Process)	An individual's successful adaption to adversity or stressful experiences, informed by both elements of their personality and the contextual, ongoing situation in which adversity occurs but is frequently measured at a discrete point in time; a combination of both personality and situational factors that inform how individuals cope with stress and adversity.
O'Rourke et al. (2010)	Process	The process of adaptation in response to adversity, threats, or significant stress such as the diagnosis and care of a family member with a major illness.
Rivera-Navarro et al. (2018)	Trait	Protective factor
Tyler et al. (2020)	Process	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.
Quantitative, intervention studies (*n* = 4)		
Ghaffari et al. (2019)	Process	Describes a situation in which a caregiver improves social performance and overcome difficulties, despite experiencing high mental pressure.
Lavretsky, Siddarth & Irwan (2010)	NR	NR
MacCourt et al. (2017)	Trait	A positive personality characteristic that enhances individual adaptation, preserving balance and harmony.
Pandya (2019)	NR	NR
Mixed-methods studies (*n* = 4)		
Maneewat, Lertmaharit, & Tangwongchai (2016)	Process	A process of growth and adaption with a multi-dimensional structure; a holistic and dynamic development that encompass the ability to cope with stress and serious situations.
Bull (2014)	Process	A dynamic process that fluctuates across time and situations and enables individuals to adjust or cope successfully despite stress or adversity.
Jones, Killett & Mioshi (2019)	Process	A dynamic and interactive phenomenon, which is triggered by an antecedent event and developed through the interplay of risks and resources.
Kidd, Zauszniewski, & Morris (2011)	Trait	Human beings are engaged in goal-directed movement which has unified patterns and utilizes creative power (resilience) to overcome obstacles; resilience is a positive psychological resource.
Qualitative studies (*n* = 7)		
Bekhet & Avery (2018)	Trait	When homeostasis is restored after adversity which includes new insight and growth from a disruptive experience.

Roberts & Struckmeyer (2017)	Hybrid (Trait-Process)	The ability to maintain normal or enhanced functioning during times of adversity and consists of two components: the first is thriving and succeeding; the second is exhibiting the competence in difficult situations or a situation where others often do not succeed.
Han et al. (2019)	Trait	To be able to restore balance and harmony when they encounter negative circumstances, which may be achieved by enhancing inherent adaptation.
Liu et al. (2020)	Process	The process of effectively negotiating, adapting to, or managing 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; across the life course, the experience of resilience will vary.
Donnellan, Bennett & Soulsby (2015, 2017, 2019)	Process	The process of effectively negotiating, adapting to, or managing significant sources of stress or trauma; assets and resources within the individual, their life, and environment facilitate this capacity for adaptation or bouncing back in the face of adversity.

NR, Not Reported.

Table 5. Description and psychometrics of resilience measures included in the review.

Scale	Author(s)	Country of Origin and Language	Target Population	Number of Dimensions (items)	Cronbach's alpha (α)	Retained Studies that Assessed Scale Reliability (CNC population)
The Connor Davidson Resilience Scale (CD-RISC)	Connor & Davidson (2003)	USA/ English	Adults	5 (25)	.89 -.93[†] .87	 Ghaffari et al. 2019 (AD)
The Connor Davidson Resilience Scale (CD-RISC)	Cambell- Sills & Stein (2007)	USA/ English	Young adults	1 (10)	.85[†]	
The Resilience Scale (RS)	Wagnild & Young (1993)	Australia/ English	Adults	2(25)	.91[†] .80 .94	 Kimura et al. 2019 (YOAD) Scott 2013 (AD)
The Resilience Scale (S-RS; Shorted version of RS)	Neill & Dias (2001)	Australia/ English	Adults	14-15	.91[†] .96	 Wilks 2008a (AD)
The Brief Resilience Scale (BRS)	Smith et al. (2008)	USA/ English	Adults	1(6)	.80 - .91[†] .73 .82 .89	 Ertl et al. 2019 (PD) Ledbetter, Carr, & Lynn 2020 (SCI) Tyler et al. 2020 (PD)
The Resilience Scale for Adults (RSA)	Friborg et al. (2003)	Norway/ Norweigan	Adults	5 (36)	.67 - .90[†]	
The Resilience Scale for Adults (RSA)	Friborg et al. (2005)	Norway/ Norweigan	Adults	6 (33)	.76 - .87[†] .96 .92 .82	 Elnasseh et al. 2016 (dementia) Pandya 2019 (AD)

						Senturk, Akyol, & Kucukguclu 2018 (dementia)
TBI-QOL Resilience Short Form	Tulsky et al. 2016	USA/ English	TBI	1(27)	.95†	
The Dispositional Resilience Scale	Bartone et al. (1989)	USA/ English	Adults	3 (45)	.78†	
The Brief Resilient Coping Scale (BRCS)	Sinclair & Wallston (2004)	USA/ English	Adults with Rheumatoid Arthritis	1(4)	.69†	
Questionnaire of Resilience in Caregivers of Acquired Brain Injury (QRC-ABI)	Hayas, Arroyabe, & Calvete (2015)	Spain/ Spanish	Family caregivers of persons with ABI	1(31)	.88†	Hayas, Arroyabe, & Calvete 2015 (ABI)††
The Caregiver Resilience Scale (CRS)	Maneewat, Lertmaharit, & Tangwongchai (2016)	Thailand/ Thai	Family caregivers of persons with dementia	6 (30)	.87† .87	Maneewat, Lertmaharit, & Tangwongchai 2016†† Pandya 2019 (AD)

† Indicates alpha value reported in original scale development and validation.

†† Designated original scale validation article also retained study in review.

ABI, Acquired Brain Injury; AD, Alzheimer's Disease; PD, Parkinson's Disease; YOAD, Young-Onset Alzheimer's Disease.

Table 6. Demographic information and resilience levels of participants.

***n* = 24**	**Mean (*SD*)**	**Min**	**Max**
Age	56.9 (14.6)	31	80
Duration of Assistance (in years)	13.7 (9.6)	1	30
Minutes of Assistance Per Day	183.8 (176.5)	10	600
CD-RISC[a]	67.0 (11.1)	52	94
	Median (*IQR*)	**Min**	**Max**
PDDS[b]	5 (4)	0	7
	n	**%**	
Gender			
Male	11	45.8	
Female	13	54.2	
Race			
European descent	11	45.8	
North American descent	11	45.8	
Other Asian descent	1	4.2	
Unknown	1	4.2	
Relationship to PwMS			
Spouse/Common Law partner	20	83.3	
Parent	2	8.3	
Adult child	1	4.2	
Sibling	1	4.2	
Marital Status			
Married/Common Law	21	87.5	
Separated/Divorced	2	8.3	
Widowed	1	4.2	
Highest Education Level			
High school/GED	3	12.5	
Technical or trade school	2	8.3	
College	1	4.2	
Bachelor's degree	8	33.3	
Master's degree	7	29.2	
Doctoral degree	2	8.3	
Unknown	1	4.2	
Employment Status			
Employed full time	8	33.3	
Unemployed	4	16.7	
Retired due to age or life course decision	11	45.8	
Retired due to medical reasons/disability	1	4.2	

PwMS, Person with multiple sclerosis

[a] Connor-Davidson Resilience (CD-RISC) scale total scores.

[b]Patient Determined Disease Steps (PDDS) score >6 is a threshold for walking 25 feet with bilateral support.

Appendix 1. Systematic review MEDLINE search strategy.

Ovid MEDLINE(R) ALL <1946 to July 24, 2020>

Search history sorted by search number ascending

#	Searches	Results	Type
1	exp Dementia/	165450	Advanced
2	dementia*.ti,ab.	108724	Advanced
3	alzheimer*.ti,ab.	145080	Advanced
4	exp Epilepsy/	111335	Advanced
5	epilep*.ti,ab.	136236	Advanced
6	seizure disorder*.ti,ab.	3825	Advanced
7	Headache Disorders/	2339	Advanced
8	(headache* adj3 disorder*).ti,ab.	3854	Advanced
9	migraine*.ti,ab.	34642	Advanced
10	exp Multiple Sclerosis/	58749	Advanced
11	multiple sclerosis.ti,ab.	74395	Advanced
12	exp Parkinsonian Disorders/	80433	Advanced
13	parkinson* disease*.ti,ab.	92687	Advanced
14	exp Stroke/	134533	Advanced
15	stroke*.ti,ab.	247120	Advanced
16	exp Brain Injuries, Traumatic/	14562	Advanced
17	(trauma* adj3 brain injur*).ti,ab.	36593	Advanced
18	concussion*.ti,ab.	8249	Advanced
19	brain damage, chronic/ or brain injury, chronic/	13989	Advanced
20	(brain adj2 (damage* or injur*) adj2 chronic*).ti,ab.	608	Advanced
21	Amyotrophic Lateral Sclerosis/	18856	Advanced
22	Amyotrophic Lateral Sclerosis.ti,ab.	23016	Advanced
23	("Gehrig* Disease" or "Lou Gehrig* Disease").ti,ab.	133	Advanced
24	exp Brain Neoplasms/	151466	Advanced
25	(brain adj2 (tumo?r* or neoplasm* or cancer*)).ti,ab.	48231	Advanced
26	Intracranial Neoplasm*.ti,ab.	1139	Advanced
27	Cerebral Palsy/	20582	Advanced
28	cerebral pals*.ti,ab.	22469	Advanced
29	Dystonia/	6362	Advanced
30	dystonia*.ti,ab.	14827	Advanced
31	huntington disease/	12087	Advanced
32	huntington* disease*.ti,ab.	15451	Advanced
33	tourette syndrome/	4302	Advanced

34	(tourette* adj2 (disorder* or syndrome*)).ti,ab.	4984	Advanced
35	exp Hydrocephalus/	23496	Advanced
36	Hydrocepha*.ti,ab.	26363	Advanced
37	exp Muscular Dystrophies/	26642	Advanced
38	(Muscular adj2 Dystroph*).ti,ab.	23625	Advanced
39	exp Spinal Cord Injuries/	48630	Advanced
40	(spinal adj2 (cord or column) adj3 (trauma* or injur* or transection* or laceration* or contusion*)).ti,ab.	42875	Advanced
41	exp Spinal Dysraphism/	8269	Advanced
42	spina bifida.ti,ab.	7040	Advanced
43	(malnutrition and neurologic* disorder*).ti,ab.	89	Advanced
44	(chronic adj3 pain adj3 neurologic* disorder*).ti,ab.	33	Advanced
45	neuroinfection*.ti,ab.	497	Advanced
46	or/1-45	1278513	Advanced
47	exp Adaptation, Psychological/	126933	Advanced
48	Resilience, Psychological/	5732	Advanced
49	social adjustment/	23254	Advanced
50	(resilienc* or hardiness or empowerment or rebound*).ti,ab.	54539	Advanced
51	((healthy or positive) adj2 function*).ti,ab.	7908	Advanced
52	(psychological adj2 (resilienc* or adaptation or wellbeing)).ti,ab.	2672	Advanced
53	((coping or adaptive) adj2 (skill* or behavio?r*)).ti,ab.	11774	Advanced
54	or/47-53	212699	Advanced
55	marriage/ or parents/ or spouses/	94296	Advanced
56	(spous* or "domestic partner*" or partner* or wife or wives or husband? or "significant other*" or marriage or marital or married).ti,ab.	257691	Advanced
57	or	543565	Advanced
58	Caregivers/	36638	Advanced
59	(caregiv* or care-giv*).ti,ab.	73074	Advanced
60	carer*.ti,ab.	14612	Advanced
61	or/55-60	865609	Advanced
62	46 and 54 and 61	3616	Advanced
63	exp animals/ not humans.sh.	4720580	Advanced
64	62 not 63	3615	Advanced

Appendix 2. Systematic review PRISMA 2020 checklist.

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	26
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	21
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	22-26
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	26
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	27-28
Information sources	6	Specify all databases, registers, websites, organizations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	27
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix 1 (132)
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	28-29
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	28-29
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	29
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	29
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	N/A
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	28-29
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	29

Section and Topic	Item #	Checklist item	Location where item is reported
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	N/A
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	28-29
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	29, Figure 2
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	N/A
Study characteristics	17	Cite each included study and present its characteristics.	29-36 Tables 2,3,4
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	N/A
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	29-36
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	N/A
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	36-41

Section and Topic	Item #	Checklist item	Location where item is reported
	23b	Discuss any limitations of the evidence included in the review.	41
	23c	Discuss any limitations of the review processes used.	41
	23d	Discuss implications of the results for practice, policy, and future research.	36-41
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	26
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	26
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

Appendix 3. Research ethics board approval for interview study.

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

H-02-20-5338 - REG-5338 - Certificat d'approbation éthique / Certificate of Ethics Approval

(English message follows)

Cher/Chère Afolasade Fakolade,

Veuillez trouver ci-joint le certificat d'approbation éthique pour le projet intitulé «A longitudinal study of Resilience Among multiple sclerosis Caregivers over Time (ReACT). ».

Le certificat est valide jusqu'au : 17-03-2021

Recherche financée : veuillez faire suivre une copie du certificat au Service de gestion de la recherche.

Si vous avez des questions, n'hésitez pas à communiquer avec le Bureau d'éthique à ethique@uottawa.ca ou en composant le 613-562-5387.

Vous pouvez voir votre demande en vous connectant à votre compte eReviews.

Cordialement,

Kim Thompson
Responsable d'éthique en recherche

Ceci est une réponse automatisée, merci de ne pas répondre à ce courriel.

Dear Afolasade Fakolade,

Please find attached the certificate of ethics approval for your research project titled "A longitudinal study of Resilience Among multiple sclerosis Caregivers over Time (ReACT). ".

This certificate is valid until: 17-03-2021

Funded research: A reminder that you must provide a copy of this certificate to Research Management Services.

If you have any questions, please contact the Ethics Office at ethics@uottawa.ca or by telephone at 613-562-5387.

You can view your project at any time by logging into eReviews.

Best regards,

Kim Thompson
Protocol Officer

This is an automated message. Please do not reply directly to this email.

Attachement(s) / Attachment(s)
approvalLetter1584532570273.pdf

550, rue Cumberland, pièce 154 550 Cumberland Street, Room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie I www.recherche.uottawa.ca/ethics

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

H-02-20-5338 - MOD1-5338 - Modification approuvée / Modification Approved

(English message follows)

Cher/Chère Afolasade Fakolade,

Merci d'avoir soumis une demande de modification pour votre projet de recherche intitulé «A longitudinal study of Resilience Among multiple sclerosis Caregivers over Time (ReACT). ».

Ces modifications ont été approuvées et sont assujetties au certificat d'approbation éthique (voir la version révisée du certificat en pièce jointe), valide jusqu'au 17-03-2021.

Research Team: Ms. Odessa McKenna has been added to the project.

Research design: An interview component has been added to Wave 1 to explore how MS care partners experience resilience, particularly during stressful situations, like the current COVID-19 pandemic. Approximately 20 people will be randomly selected from survey participants who agree to take part in the interviews. Copies of the modified survey, the interview guide and the consent forms have been appended.

Si vous avez des questions, n'hésitez pas à communiquer avec le Bureau d'éthique au ethique@uottawa.ca ou au 613-562-5387.

Vous pouvez voir votre demande en vous connectant à votre compte eReviews .

Cordialement,

Kim Thompson
Responsable d'éthique en recherche
Président(e) : Daniel Lagarec
CÉR : Comité d'éthique de la recherche en sciences de la santé et sciences / Health Sciences and Sciences Research Ethics Board

Ceci est une réponse automatisée, merci de ne pas répondre à ce courriel.

Dear Afolasade Fakolade,

Thank you for submitting a modification request for your research project titled "A longitudinal study of Resilience Among multiple sclerosis Caregivers over Time (ReACT). ".

These modifications are now covered under the certificate of ethics approval (see updated version attached), valid until 17-03-2021.

Research Team: Ms. Odessa McKenna has been added to the project.

Research design: An interview component has been added to Wave 1 to explore how MS care partners experience resilience, particularly during stressful situations, like the current COVID-19 pandemic. Approximately 20 people will be randomly selected from survey participants who agree to take part in the interviews. Copies of the modified survey, the interview guide and the consent forms have been appended.

If you have any questions, please contact the Ethics Office at ethics@uottawa.ca or 613-562-5387.

You can view your project at any time by logging into eReviews .

Best regards,

550, rue Cumberland, pièce 154 550 Cumberland Street, Room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie I www.recherche.uottawa.ca/ethics

Appendix 4: Complete interview guide utilized to guide semi-structured interviews.

ReACT Interview Guide

Introduction

I would like to thank you for participating in this interview to explore how MS care partners, like you, manage the challenges of caregiving, especially during difficult times like the COVID-19 pandemic. As I ask you to describe your opinions and experiences, please keep in mind that there are no right or wrong answers to these questions, since people have a lot of different views on these topics. I'm simply interested in what you think about these different issues. I don't know exactly what it's like to "be in your shoes" or to deal with the challenges that care partners like yourself are confronted with every day, so I am looking forward to learning more about these experiences from your perspective. Thank you for giving me your time. This interview should take around 45 minutes to one hour.

Before we begin, do you have any questions pertaining to the study?

Answer any questions

If at any time you have questions or something that I say is not clear, please let me know and I'll try to clarify.

Restate permission to record the interview.

Warm-up/building rapport

Before we start talking in detail about the topic, I would like to first know a little about you. Pretend that you are someone close to you, like your best friend or family relative, and you are talking to someone who has never met you. Describe to that person who you are. Give as much or as little detail as you feel comfortable telling me—this is just a way for me to get to know you better so that I will know how to best ask you the other questions in this interview.

Thanks for sharing a little bit about what's going in your life right now. Now, I'd like for us to begin talking about resilience, caregiving, and the impact of the current pandemic on your life as a care partner.

Begin recording at this point (let participant know that recording is starting)

Section 1: Resilience

1. What does having resilience mean to you?
    - Probes:
        - What comes to your mind when you hear this word?
        - If you were to explain resilience to someone else, how would you explain it?

2. Tell me about some of the challenging situations that you have experienced as a care partner?
    - Probe:
        - Tell me about some of the challenging situations that you have experienced as a care partner in relation to the COVID-19 pandemic?
        - Has anyone in your immediate household been diagnosed with COVID-19?
3. How did you initially react when these things (mentioned above) happened?
    - Probe:
        - How did you react to situations related specifically to COVID-19?
4. How have you adapted your caregiving protocols, plans, and activities over the years?
    - Probes:
        - How have your caregiving skills/strategies changed in response to the current pandemic?
5. If you were talking with other care partners of people with MS, what would you tell them with respect to what has helped you to develop resilience during this pandemic?
    - Probes:
        - How has your community (e.g., local programs or services) helped you to develop resilience?
        - How has your social network (e.g., friends or family) helped you to develop resilience?
        - How about personal factors or personality characteristics about yourself that have helped you to develop resilience?
6. What factors have hindered you from developing resilience during this pandemic?

<u>Section 2: Health and Wellbeing</u>

Now we will be moving on to questions related to your personal wellbeing throughout the course of this pandemic.

7. How did the COVID-19 pandemic impact your ability to engage in health behaviours (e.g., healthy eating, limiting substance use, maintaining an active lifestyle, positive social engagement)?
8. What is the most challenging element of this pandemic for maintaining your health and wellbeing (physical, mental, or emotional)?
    - Probe:
        - How did these challenges impact your ability to be a care partner?
        - What new or alternative strategies (e.g., remote online tools, support lines, recommendations) have you used during this time in order to maintain your health and wellbeing?

<u>Section 3: Disaster Preparedness</u>

Now we are going to explore another dimension related to your resilience experience during this pandemic.

9. How prepared did you feel for a pandemic of this nature and its impact on your ability as a care partner?

Closing questions

Is there anything else that you would like to tell me about your experience of stress or difficulties as a care partner during this pandemic?

Are there any experiences of resilience as a care partner that you want to elaborate on?

Thank you for sharing your insights with me today. As you know, the purpose of this interview is to generate further insights about resilience among care partners of people with MS, and how care partners cope with challenging and stressful situations, like the COVID-19 pandemic. The insights that you have shared with me with today may inform the development of programs to enhance and sustain resilience among care partners of people with MS.