

Alzheimer's Disease: The Resilience Approach to Making the Family Care of People Living with Alzheimer's Sustainable

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Introduction

With critical reliance on primary family carers of people living with Alzheimer's disease (PWA) at an all-time high and set to increase markedly over the next few decades an urgent question concerns how this growing army of family carers will be supported in the future? The uniqueness and complexity of Alzheimer's disease (AD) compared with other diseases and the myriad challenges it presents for family carers make such carers particularly vulnerable to the debilitating effects of chronic stress and its sequelae. The biopsychosocial pathways responsible for carer health deficits resulting from chronic exposure to the care environment are discussed. Further, a new epidemiological framework is introduced that attempts to capture how the dynamics at work within the AD care environment might lead it to become epidemiological in the sense that chronic exposure to it can uniquely generate carer disease outcomes. If the family care of PWA can potentially create an environment and dynamics within this that may be injurious to carers themselves, leading to premature cessation of informal care, a central issue for policy-makers and service providers concerns 'who will care for the carers and how?'

Although the present article primarily focuses on family carers of PWA, the knowledge that carers' health has a relatively direct impact on the capacity to carry out caregiving, as well as influencing the levels of harmony or disequilibrium that exists within the care environment, crucially means that carers' health also impacts on the wellbeing of PWA as part of a closely knit reciprocal relationship—they are mutually bound.

Further, while there is evidence to indicate that some family carers of PWA appear able to overcome the many challenges and potential attrition long-term care of a PWA can inflict on their own health, a further key question concerns how such

carers manage despite adversity? What characteristics, assets and resources do these carers possess that perhaps sets them apart? Are there valuable lessons we can learn concerning how the family care of PWA might be made optimal while safeguarding family carers' own health? This represents an important question since the vast majority of family carers, and moreover their care recipients, hope and desire to spend their final years, months, days together as a family rather than see their family member consigned to a formal institution. This article therefore argues the case for urgent public health action against the backdrop of the rising tide of AD globally.

Presently, there is a lack of any clear consensus concerning how more productive care environments might be created that better safeguard both family carers' health and by association PWA's health. Moreover, there is a need to move beyond syntheses of findings from the available literature that are limited to descriptive accounts based on 'outcomes' and towards a deeper analysis of 'process,' i.e. by focusing on what intrinsically 'works' to support family carers of PWA and how these processes might be generated. In response, the present authors recently conducted a comprehensive Realist review of the current literature. How this review was conducted is briefly described, as are the broad findings that lead to the proposal of a new model of family care of PWA. The strengths and weaknesses of existing hypotheses are discussed for how carers can counteract the challenges to their own health that care of PWA can bring and a new hypothesis is proposed based on a Resilience approach to family care of PWA that links with humans' 'fight or flight' response to stressors.

Alzheimer's disease: a serious global health issue

Alzheimer's disease (AD) represents the most common form and cause of dementia [1]. Currently, global estimates place the

number of people and the families affected by dementia at 47.5 million of whom up to 33.25 million have AD (**Figure 1**)[2,3]. AD has been described as ‘the dementia time-bomb’ and for very good reason since over the course of the next few decades global prevalence of the disease is predicted to triple to 135.5 million people by 2050, of which up to 70% will receive the more specific diagnosis of AD potentially affecting up to 95 million people as well as the families who care for them [2]. Developed countries continue to struggle to combat AD, e.g. while rates for several other major causes of mortality have fallen over the past

10 years in the U.S. a main concern is that AD demonstrates the reverse of this trend, having increased by a substantial 71% over the same period [4]. Similarly, in parts of Europe such as England and Wales AD has recently overtaken ischemic heart disease as the primary cause of mortality [5]. Although the global patterns of prevalence appear to affect developed countries more profoundly (**Figure 1**), in the coming decades AD is also set to have a significant impact on the rapidly growing number of dementia carers emerging in low and middle income countries as prevalence of the disease in these countries rises sharply [2].

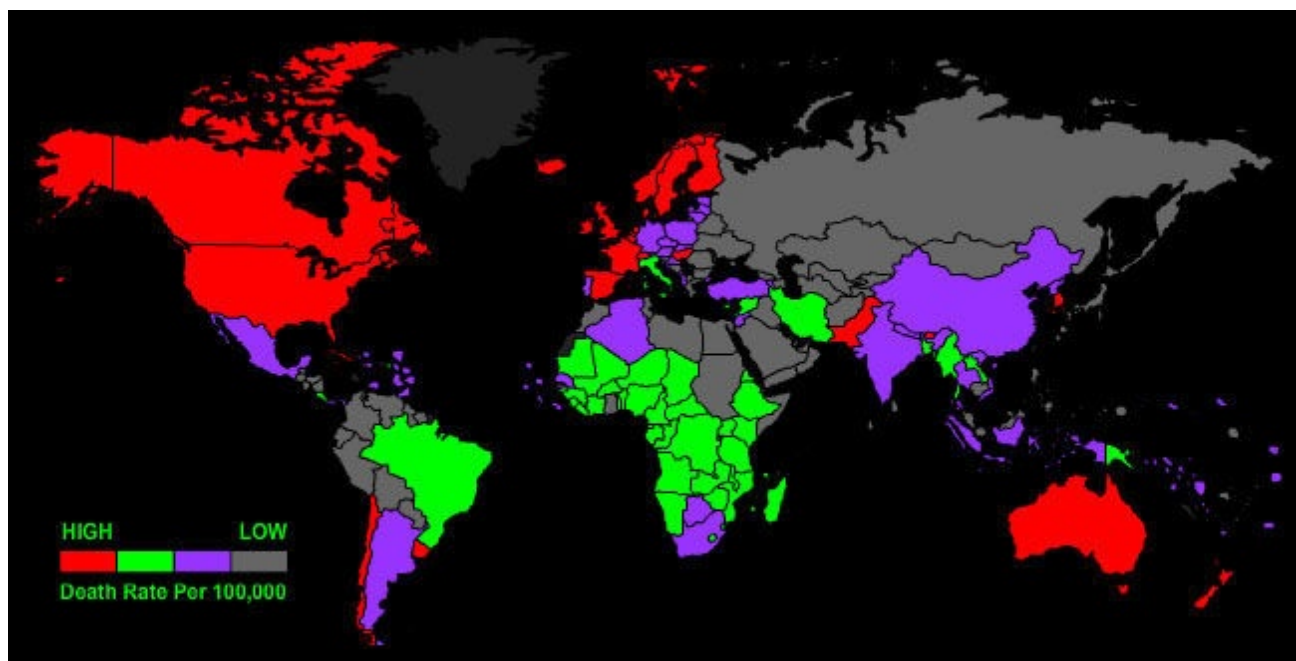


Figure 1 Prevalence of Dementia/Alzheimer’s disease globally. WHO (2014). Schematic produced by Le Duc Media illustrating World Rankings Calculations for Deaths by Dementia/Alzheimer’s Disease based on WHO (2014) population data [3].

Increasing longevity together with advances in medicine mean that many more people are surviving life-threatening diseases but susceptible to life limiting diseases such as dementia, i.e. more people are living long enough to become vulnerable to diseases such as AD [6]. For example, prevalence of the disease in the U.S. is set to soar in the near future as the post 2nd World War ‘baby boom’ generation reach the age of 65, [4] the age at which the risk factor for developing AD becomes marked. In general, the risk of contracting AD increases significantly with age, particularly once adults reach the age of 65. A notable example of this is illustrated by recent figures released for AD prevalence in the U.S. where four percent of people living with AD (PWA) are aged 65 with the risk factor rising rapidly with age so that by the age of 75 the number affected rises more than tenfold [4]. At present, AD remains both incurable and irreversible and is increasing in prevalence throughout many global populations [7]. It constitutes one of the most serious challenges facing families and health and social care services globally. Although there is growing realisation of the need to act on AD as a health priority a significant setback has been inertia in the global response to this crisis until relatively recently, some 40 years on from Katzman’s (1976) groundbreaking research which first revealed AD as a ‘major killer’ within populations [8].

Critical reliance on primary family carers of PWA

Even among relatively affluent nations such as the U.S. and the U.K. there is already heavy reliance on unpaid family carers who provide the majority of AD care with the number of carers set to rise exponentially over the forthcoming decades. For example, in the U.S. almost 16 million carers currently provide unpaid care to PWA, representing an estimated \$221.3 billion if this care was provided by the State, while in the U.K. a total reliance on formal care provision is estimated to amount to £119 billion which exceeds the entire 2015/16 National Health Service budget for the U.K., set at £93 billion [9-11]. Presently, reliance on state care of PWA remains untenable with formal care services insufficiently equipped either financially or logistically to assume full responsibility. Moreover, family care largely represents the preferred method of care for the majority of PWA and the family carers who provide for them. Wholesale reliance on formal care provision is often perceived to be a last resort, to be postponed or avoided where possible [12].

Potential obstacles faced by primary family carers of PWA

The current demographic trend in many developed countries towards smaller family units and diminished contact with extended relatives also means that family carers face the prospect of being increasingly isolated with a correspondingly larger share of the caregiving role [13,14].

A further setback is that the lack of knowledge concerning 'what works and how' for family carers of PWA, let alone the finer grained detail of 'for whom and when' means family carers of PWA must frequently resort to carrying out the role with a great deal of reliance on 'trial and error' approaches [15,16]. Further, while the official mantra stating that for AD 'every case is different' is no doubt true, arguably this provides very little clear guidance for the carer, leaving care outcomes more to chance and leaving carers fraught with doubts and uncertainty that are compounded by inevitable wrong turns. Arguably, this calls for the establishment of a clearer framework upon which to base guidelines in support of carers of PWA first and foremost. The next step would be to produce more tailored guidelines that meet the needs of diverse groups of carers of PWA.

Moreover, a fundamental issue concerns the general level of ignorance or oversight that persists about AD, particularly with regard to its scale and impact, with the result that other health priorities tend to attract greater attention instead, e.g. in the U.S. emphasis appears to be mainly towards the prevention and treatment of the disease with the goal of finding a cure by 2025. While this goal is both crucial and laudable it shifts attention away from those who are already affected by the disease, the numbers of whom are already rising sharply [2]. Further, this ignorance or oversight appears to reinforce and perpetuate a gross assumption that family carers are already well equipped to take up the care needs of PWA. The reality is that AD is a very

complex and challenging terminal illness whose symptoms extend far beyond memory deficits to include more profound disabilities including impairments to speech, feeding and walking as well as profound personality changes that combine to present real challenges to the health of family carers themselves [17]. Carers of PWA are twice as likely as carers of people with other diseases to suffer emotional and physical difficulties that disrupt their emotional and psychological balance [18]. The chronic nature of these assaults means that their accumulated effects threaten to compromise carers' own health [19]. For example, almost 60% of carers of PWA in the U.S. report high or very high levels of emotional stress with around 40% suffering from depression, while almost 75% of carers of PWA report concerns about their own health becoming jeopardized as a result of caregiving [7,20]. More globally, a robust relationship between dementia caregiving and negative effects on psychological health has been demonstrated in numerous studies with rates of carer depression varying between 23% and 85% in developed countries [21-25]. For a review see Brodaty and Donkin [26]. In general, family carers' experience of greater health inequalities (H.i.s) present an additional determinant of health problems, ranging from clinical levels of anxiety and depression to insomnia [27]. These symptoms are often exacerbated by general fatigue and social isolation [28].

Pathways to disease for carers of PWA

It is possible to draw up several separate causal chains, each of which provide a plausible account for how family carers might feel ultimately that the family carer role can no longer be maintained. However, one pathway in particular that emerges from a review of the literature describes how the accumulation of daily challenges posed by the care of PWA over time might lead to the premature cessation of family care:

unique challenges posed by dementia for the carer → erosion of carer control → chronic stress → anxiety → burnout → depression → earlier entry of PWA into hospital/residential care [21-25,29-33].

Figure 2 Pathway by which the family care of PWA potentially creates a unique epidemiological environment in which the accumulation of chronic stress becomes increasingly injurious to carers themselves, leading to premature cessation of informal care.

Although this pathway is depicted in a linear fashion it is important to note that cessation of family care may sometimes involve some rather than all of these steps. Further, these steps should be viewed as bi-directional, i.e. admit the possibility of health improvement and subsequent reversals, e.g. where the care context changes to become more manageable. While various models and approaches exist to explain these findings and explicate the underlying mechanisms that might operate, the model adopted here closely follows the pathway described above, i.e. it is derived from biopsychosocial models that account for how assaults to carer health are created via the individual perception of stress emanating from a chronically stressful social context/environment [34]. This remains

consistent with the well-established links between family care of PWA and chronic stress and how the subsequent psychosomatic effects generated can impact on individuals' physiological response [24-26]. To summarise from Bartley [34]:

(A) The S.A.M. (Sympathetic-Adreno-Medullary) Axis is essentially a 'stress circuit' and most closely associated with a 'fight or flight' response in humans. The sympathetic nervous system is activated in response to extreme stimuli resulting in the medulla producing adrenaline and the sympathetic nerves releasing noradrenaline. Problems occur however when this circuit is constantly activated, e.g. via frequent daily stressors encountered within a chronically stressful environment. Over-

activation of the S.A.M. circuit can lead to dysregulation of blood pressure thresholds, effectively resetting these to a higher homeostatic 'setting'. This has long-term implications for cardiovascular disease (cvd) and other cardiovascular related illnesses.

(B) The H.P.A. Axis (Hypothalamic-Pituitary-Adreno Cortical Axis) represents a further Stress circuit.

Neurotransmitters / Hormones → Hypothalamus → Pituitary Gland → Adrenal Cortex → Cortisol release into the bloodstream → *Short-term increases in energy via the release of reserves of sugars and fats into the bloodstream.*

Figure 3 Brief overview of H.P.A. Axis (Hypothalamic-Pituitary-Adreno Cortical Axis) pathway and how its chronic over-activation can culminate in cardio-vascular disease (cvd) and related health problems (adapted from Bartley, 2004) [34].

While the S.A.M. and H.P.A. axes serve important and vital functions in humans, a key point here is that chronic over-activation of these two circuits in particular via their continual engagement over time can lead to cvd and related health problems. It has also been shown to compromise immune system functioning, further increasing vulnerability to cvd and increasing susceptibility to clinical conditions such as anxiety, depression and insomnia [34]. This is particularly relevant to older people who represent a sizeable proportion of those who are carers of PWA and for whom the risk of developing cvd or succumbing to stress related illnesses is heightened due to age [35].

Although carers' experiences will differ from one individual to the next and the reasons for any cessation of family care may vary, the stress pathways described nevertheless serve to emphasise the health risk factors that exist for people exposed to prolonged, long-term stress within a relatively high stress environment such as the care of a PWA. Without adequate support such carers are especially vulnerable to risks to their own health and wellbeing that can simultaneously undermine carers' capacity to continue caring for the PWA. In order for family caregiving of PWA to remain viable, with formal care providing an adjunct to this, urgent action is required to bolster carers' own health and wellbeing [36]. Arguably, the current situation in which the genuine needs of family carers of PWA are not properly understood or addressed is unsustainable.

Carers of PWA facing greater health inequalities (H.i.'s)

The challenges family carers of PWA face give rise to salient health inequalities, over and above those experienced by non-carers [28,37]. Family carers of PWA represent a disadvantaged minority compared with non-carers [28]. A main point that needs to be better understood and taken into account with regard to carer support is how caring for a PWA is in itself a determinant of carers' health and wellbeing [28].

AD presents unique challenges to family carers that may exceed those for other diseases [38-39]. The lengthy time course of AD, the inevitability of an irreversible decline in health for PWA, the unpredictability of how the disease will manifest itself from day-to-day and the high level of disability and dependence generally associated with AD present novel and distinct

challenges to family carers in comparison to other non-communicable diseases such as cancer [40-41]. A further challenge is that many carers of PWA are aged 65 or over [35] and therefore reaching an age where they are becoming more vulnerable to health problems themselves.

This calls for greater appreciation of family carers' of AD staunch efforts. They often provide the linchpin for care despite immense challenges. Better understanding of the increased health risks family carers of AD face and fuller recognition of the need for improved support to ensure their own health and wellbeing is safeguarded as a prerequisite to effective long-term AD care is long overdue.

Addressing the different levels of H.i.'s experienced by specific carer groups within populations

Although the present discussion and the review it is based on focus on family carers of PWA in general it is also acknowledged that family carers of PWA are far from being homogenous. Rather, they represent a diverse group of people [28] distinguishable by a wide range of factors including gender, age, ethnicity, socio-economic background, the locum of caring, level of social isolation, the type, severity, duration and experience of the disease, the intensity of care, the emotional involvement of the carer and not least, the resources and support available to the carer. While the scope of this article will remain on family carers of PWA in general it is important that future research examines how key contextual factors, e.g. socio-economic status and culture and ethnicity, may mediate care situations with possibly differential effects on family carers [42,43]. For example, a recent WHO report highlights the economic hardships associated with dementia care and how these can augment levels of carer stress [2]. While economic hardship affects those carers of PWA living in developed countries, in the future it is also set to have a profound influence on the rapidly growing number of dementia carers emerging in low and middle income countries as prevalence of the disease in these countries escalates [2]. Differentiation of carer groups would permit the tailoring of resources and interventions to meet specific carer needs and also facilitate greater prioritisation of resources with particular emphasis on targeting the most vulnerable carer groups. Currently however, there appears to be a lack of awareness of the needs of different groups of carers [36,44].

The link between epidemiology and primary carers of PWA

Although epidemiology is a branch of medical sciences that deals primarily with the incidence, distribution, and control of disease in a population, it has some application to explaining family carers of PWA research. A novel way of approaching how the biopsychosocial pathways linked to family carer health deficits via chronic exposure to stress in AD care may be to examine it within an epidemiological paradigm. Thus, a new framework is introduced here that attempts to capture the dynamics at work within the AD family care environment, including how this environment may or may not become epidemiological in the sense that chronic exposure to it can uniquely generate carer disease outcomes.

The epidemiological triad consisting of (a) an external agent (symptoms/needs generated by AD) (b) a host-primary family carers who possess greater or lesser degrees of resilience (+/- resilience in carer) that is at least partly dependent on the level of supportiveness offered by the environment in which the care takes place [45]. The host and agent are brought together within this environment. The unique dynamic that exists between host and agent in such circumstances can result in disease causation via the 'stress circuits' and pathways described earlier. However, a main contention made here is that an important mediator and protective buffer against stress-related disease may lie in the host's capacity for resilience at an individual level combined with the level of support to bolster resilience that is received from the external environment. Recently, Kent et al. stated that a main drawback to our current understanding of how resilience might operate to promote adult health is that we have yet to uncover the biological and behavioral mechanisms that drive human resilience in the same way as we now comprehend how human 'stress circuits' function [46]. However, Kent et al. go on to make an interesting point, that there may be some plausibility to the suggestion that those biological mechanisms involved in human 'fight or flight' responses may also share links with our capacity for resilience as part of an overarching adaptive system designed to deal with threats or challenges. Although as yet unproven, this hypothesis makes intuitive sense and would help to explain how some individuals possess the capacity to override extreme emotional responses via 'top down' cognitive intervention that prevent 'stress circuits' from becoming 'overloaded.' If proved correct then the links between chronic carer stress and its potential mediator in resilience may be far closer than previously supposed. Moreover, this may reinforce the notion that humans perhaps possess greater cognitive ability to regulate the impact of stress than is often assumed. Solms and Panksepp suggest that sustained positive affect and a positive outlook, despite adverse circumstances, may be key to instilling resilience, with potential biological correlates in the maintenance of dopamine levels [47]. Conversely, sustained negative affect accompanied by a negative outlook may have biological correlates in dopamine depletion and become manifest in depression. This may be highly relevant to family carers of PWA who are especially vulnerable to suffering from depression [23].

However, this should not detract from the need to ensure that those who are exposed to chronic stress, such as family carers of PWA, will often require effective and timely external support to bolster resilience also. As Waugh contends, what perhaps separates those who are resilient from those who are less so is the opportunity to experience positive emotions despite exposure to stress [48]. It should not therefore be automatically assumed that all carers of PWA are entirely self-sufficient or benefit from the same opportunities. A main contention made here is that particularly in such potentially prolonged and high stress situations as dementia care, resilience relies on a combination of intrapersonal agency and strategically implemented external resources to support this, a point previously emphasised by Lazarus and Folkman over thirty years ago. Resilience benefits from the additive and cumulative effect of combining effective resources [49,50]. Moreover, optimising intrapersonal agency may still demand some important external input, e.g., training in CBT or Mindfulness that include emotion regulation strategies.

Critique of existing hypotheses concerning how carers of PWA might deal with stress

(A) The Wear and Tear hypothesis of caregiving (Townsend et al.) maintains that the longer care is provided, the more psychological strain on carers, i.e. long-term chronic exposure to stressors is more debilitating than limited exposure [51]. This is measured by comparing subjective caregiving stress with perceived caregiving effectiveness to provide an indicator of carer 'wear.' Meanwhile carer 'tear' or health deficits are measured by comparing indices of depression with those for affect balance. Carer 'wear and tear' is deemed likely to be more pronounced where the care recipient's health steadily deteriorates over time rather than remains relatively stable. While factors that relate to self-efficacy and quality of life (helping to regulate affect balance) are cited as important mediators of carer stress there is nevertheless a somewhat fatalistic assumption that carers' risk of depression will nevertheless increase the longer the care continues and that this will correlate with carers' increasing perception of care as 'burden.' However, a central issue concerns whether such negative outcomes remain inevitable or preventable.

(B) An alternative view presented by the Adaptation hypothesis contends that as the dementia advances carers develop adaptive strategies that assist the management of the care situation [52]. However, some of the strategies outlined by this hypothesis may be more adaptive than others. For example, 'Psychological Distancing' by carers may help to create an important psychological buffer that protects carers against potentially counter-productive feelings of guilt and overwhelming sense of duty that can lead to an inability to find a healthy balance between constantly managing the care situation and allowing time to recuperate via personal engagement in pleasurable activities that enhance carers' quality of life (QOL). As an adaptive carer strategy the focus of 'Psychological Distancing' is on the practical and pragmatic necessities of the carer role while dwelling less on the negative aspects of caring.

By contrast, the development of several other carer strategies identified by the Adaptation hypothesis may arguably be more maladaptive than adaptive. For example, 'Social Regression' represents a strategy by which the carer and care recipient become increasingly isolated. While this can increase 'carer-PWD' interdependence it has the potential to lead to greater strain long-term, particularly for the carer, due to distancing from external support. A further potentially maladaptive strategy described by the Adaptation hypothesis is 'Role entrenchment' in which the carer role takes precedence over all other tasks and responsibilities. While such a strategy 'works' to maximize carers' resources towards the care of the PWA it runs the risk of instilling the conviction that self-sacrifice is a necessary part of the care arrangement, paving the way for the exclusion of all other interests, including QOL activities that promote positive affect. This may be maladaptive in terms of stifling regular engagement in activities that promote carers' positive affect that might otherwise provide an antidote to the frequent experience of negative affect and may in turn provide an important buffer against carer depression [53-54].

The case for developing new hypotheses and approaches concerning how carers of PWA cope

Despite the significant challenges faced by family carers of PWA, a recurring theme in family carer research is the polarity of carer response to the challenges of taking on the role [28]. While some carers become overwhelmed by the experience others appear to not only maintain stability but may even report improvements over time [28]. Several main questions remain therefore: (a) what works to support those carers who succeed in maintaining and sustaining long-term care of PWA (b) how can this knowledge be used more widely to benefit family carers of PWA (c) how can all carers of PWA, successful or otherwise, be supported still further.

Spiralling numbers of dementia diagnoses together with the insupportability of fully funding formal care means greater reliance than at any previous time on family care to provide the backbone for the majority of AD care. If family care is to remain at the heart of the care of PWA then there is a burgeoning need to make the best of a less than ideal situation. Arguably, this means refocusing on family carers' strengths and capabilities by framing their role within a positive paradigm that fosters a 'can-do' attitude. Presently, a main obstacle to such an alternative view achieving any real world impact lies in the current predominance of the Medical model of dementia, as well as hypotheses such as The Wear and Tear hypothesis of caregiving, which continue to frame the disease within a sickness paradigm [51,55-56]. A main contention is that by reinforcing the notion of long-term and life limiting diseases such as AD as incurable 'lost causes' for which nothing can be done and within which family care is perceived as 'burdensome,' unsustainable and destined to be quickly superseded by formal care is that such a view does a major disservice both to the capabilities of family carers of PWA and the capabilities of the State to be able to provide adequate support that enables family carers to carry out the role well. While the 'burden of care' paradigm remains consistent with the dependency culture that has come to dominate

medical care over the past seven decades, it remains incompatible with the notion of recognising and supporting the role of family carers as the primary long-term caregivers [57-58]. Models of family care of PWA that shift perceptions towards a more positive outlook and successful outcome for family carers in terms of maintaining and sustaining long-term family care have therefore become both expedient and essential.

To address these challenges the present authors embarked on a Realist review of the current literature [59]. Although the focus of this review was on dementia, AD was foremost in the authors' minds since this form of the disease comprises almost two thirds of all cases of dementia [2]. The review covered over a thousand documents, the majority of which were published within the past decade.

Method

Adhering to the approach established by earlier Rapid Realist Reviews (RRRs) [60] and in accordance with the Realist Publication Standards [61], the review comprised five key steps:

Step 1: Developing and refining a purpose statement and research questions;

Step 2: Searching and retrieving information;

Step 3: Appraising the evidence;

Step 4: Synthesizing information;

Step 5: Interpreting information: theory derived from the evidence and inspired to explain the evidence via hypotheses that can be tested.

Step 1: purpose statement and research question: 'What works to support family carers of people living with dementia (PWD)?' with particular emphasis on interventions and strategies that might promote the maintenance and sustenance of family care of PWD.

Step 2: (i) scoping review to identify relevant abstracts from published articles to establish the extent of the existing knowledge related to the research question. This confirmed that the evidence base was relatively narrow. (ii) Search of the literature to obtain relevant abstracts using: ISI Web of Science, Northumbria University Research Articles database, Applied Social sciences Index and Abstracts, Social Services Abstracts and PsycARTICLES to provide comprehensive and complementary indexing of relevant literature. This search also included grey literature such as voluntary sector reports as well as additional databases including the Cochrane database, Department of Health and N.I.H.R. To achieve breadth and relevance searches were filtered to only include those articles dating from 1st October, 2005 to 31st December, 2014. However, this did not preclude the inclusion of pre-2005 findings where these were deemed pertinent to the research question. Titles and abstracts were screened using inclusion criteria, with documents meeting any of the inclusion criteria retrieved for full text screening. Full text articles meeting inclusion criteria proceeded to full extraction while those not meeting any of the above criteria were excluded from the results.

Step 3: Review of all extractions to identify the common denominator among all the themes and domains with particular emphasis on what works to promote the maintenance and sustenance of family care of PWD. Retroductive inquiry, including exploration of a range of potential middle range theories (MRTs), was conducted to establish how this specific outcome might be generated [62].

Initially, central factors previously associated with maintaining equilibrium despite adverse circumstances were mooted, including personality factors such as 'hardiness'. Although such factors are likely to be instrumental to care outcomes, their relative fixity in adulthood makes them unsuitable as a target for interventions [63]. This presented a major obstacle to placing personality constructs at the heart of any proposed models of care.

'Fear' of the ramifications of premature termination of family care and subsequent institutionalization was also mooted as a potential motivating force underpinning carers' drive to maintain and sustain family care of PWD. However, the concept of 'Fear' as being central to models of care runs counter to efforts to prevent the chronic accumulation of stress that is often a precursor to cessation of family care.

Ultimately, the contention was raised that the common denominator among all the themes and domains underpinning 'what works to promote the maintenance and sustenance of family care of PWD' was 'carer resilience' where 'resilience' is operationalised as 'resilience bolstered by assets and resources that combine to provide a cumulative buffer against adversity,' 'as well as by supportive behavioural choices and actions' [64,65]. This definition emphasises how those key resources that remain external to the family carer, such as principal social assets and key service support resources, combine with intrapersonal carer resources, such as carers' physical health and psychological wellbeing, to promote resilience. This is in turn hypothesised to facilitate the successful continuation of family care of PWD.

Thus, a 3rd string literature search was conducted using the PubMed database to establish how 'resilience' might be related to interventions and strategies designed to support family carers of PWD. This subsequently confirmed that relatively strong links could be found between the two.

Step 4: Synthesis of the main findings from all the literature searches culminating in a basic hypothesised Resilience model of family care of PWD.

Step 5: Formulation of context-mechanism-outcome configurations (CMOs) based on the review's findings, leading to a more expansive Resilience model of family care of PWD and accompanying Programme Theories (PTs).

There is only scope here to provide brief details of the review. However, fuller details concerning how the review was conducted, the results and their discussion, which culminated in a proposed Resilience Model of Care, can be found in an earlier publication [59].

Discussion

The Resilience approach to family care of PWA

While previously 'resilience' was considered more a trait-like attribute that was sufficiently malleable in childhood and adolescence to be targeted to promote health, the general consensus was that its potential in terms of promoting adult health was limited due to the relative fixity of resilience as a trait in adulthood. However, recent interpretations of 'resilience' crucially emphasise its role as a 'process' [46]. Moreover, it is increasingly recognised as a process that develops across the lifespan [66]. Further, as adults continue to develop cumulative strength and knowledge based on their many experiences of adapting to changing circumstances and new challenges, adult resilience may already represent a relatively mature, sophisticated, yet still adaptable set of resources that can be exploited to strengthen and empower adults, enabling them to overcome life challenges [67]. This is borne out by Bonanno et al. in his research demonstrating that adults aged 65 or over possess a capacity for resilience that may be up to three times higher than that for people aged 18 to 24 [50]. This is significant for carers of PWA, a sizeable proportion of whom are aged 65 or over [35].

While several of the adaptive strategies developed by carers described earlier may be maladaptive, resilience by contrast represents a positive adaptation that can promote wellbeing [46]. Recent research also singles out resilience as a potentially key mediator of the 'allostatic load' that can accumulate as a result of chronic stress [68].

The Resilience approach to family care of PWA seeks to frame carer health challenges within a positive, salutogenic paradigm that emphasises what can be achieved rather than what cannot [59,69]. This represents a paradigm shift away from the majority of health-based research that focuses on illness and sickness [70]. By identifying and embodying factors that promote resilience and its contingent resilience building, it may become possible to construct tailored models of support that are specific to AD. Considering how this support could be provided takes the debate beyond individual carers -to how the environment can be shaped to allow carers to develop resilience, overcome isolation, learn from peers and experts, and share lived experiences that inform more adaptive ways of coping with the demands of being a carer. While there is a role for voluntary and other community based organisations to help shape such an environment, this is unlikely to be sufficient to deal with the current and projected prevalence of AD and the many challenges this poses to family carers' health and wellbeing. The needs of carers of PWA also go beyond the traditional provision of respite care. Indeed, there is a strong case for galvanising national support, including stepping up campaigns to raise awareness as well as prioritising the mobilisation and co-ordination of efforts and resources to support carers of PWA. An even bigger question concerns the role of healthcare providers and the coverage they offer for preventative agendas rather than direct care and treatment. Moreover, these issues not only reflect the needs of carers of PWA but could apply to carers of people with other long-term conditions.

The dominant issue is how to live well with an illness and how to accommodate the changes that the illness brings into the family unit, so that caring and support is integral rather than fracturing and negative. Enabling carers of PWA to capitalise on their innate capacity for resilience and its adjuncts—resourcefulness and adaptability—while also creating a supportive environment that promotes carer resilience, offers an antidote to traditional ‘burden of care’ models that pathologise the carer role and assume that most family carers will follow an inevitable, fatalistic pathway that leads to the collapse of family caregiving [71]. Arguably, close parallels exist between such deficit models of care and existing carer coping hypotheses such as the Wear and Tear hypothesis [51]. By contrast, models such as the Resilience model of care present an opportunity to improve support for carers to safeguard their health and wellbeing while also facilitating the retention and integration of PWA within our communities, allowing them to continue to experience a better quality of life than might otherwise be possible if they were institutionalized [59].

Conclusion

Globally, reliance on primary family carers of PWA is already high and is set to increase markedly over the next few decades. However, a main setback to both its continued viability and its optimisation in terms of caregiving effectiveness is that there needs to be greater awareness of the unique challenges presented by the family care of PWA. In particular, the unpredictability, longevity and irreversibility of AD make family carers vulnerable to the debilitating effects of chronic stress. These challenges make AD relatively unique compared with other diseases, giving rise to salient health inequalities (H.i.’s) for family carers. The magnitude of these health effects is now becoming better understood via improved knowledge concerning how ‘stress circuits’ and pathways can lead to health deficits. Related to this biopsychosocial view of disease causation is how the care environment and interaction between the carer and PWA within this can create a unique epidemiological environment that can be injurious to carers with negative consequences for the continuation of family-based care.

Responding to a lack of consensus concerning how carers of PWA can best be supported the present authors conducted a relatively comprehensive Realist review of over a thousand documents primarily published in the past decade. This led to a proposed Resilience model of care of people living with dementia (Parkinson et al; 2016) that strives to achieve a more coherent, strategic and adaptable approach, embracing a wider range of potential options to address dementia carers’ diverse needs. Main caveats include the fact that this Model remains to be empirically ‘tested,’ although this is in progress. Also, while current research has tended towards a focus on family carers of PWA in general rather than on specific family carer groups, future research will need to differentiate between different carer groups associated with AD care, not least to tailor resources and interventions to meet specific carer needs and facilitate greater prioritisation of resources to those carers who may be most vulnerable to H.i.’s. However, the present authors

responded to an initial need to establish a founding platform or model before subsequent focus on specific carer groups within populations could begin in earnest.

A main contention of the Resilience model of care is that it presents a means of mediating negative health outcomes, primarily by recognising and strengthening family carers’ own innate resilience, and also by bolstering resilience via effective external support [59]. Such intervention is deemed essential to prevent the AD care environment itself from becoming epidemiological in the sense that chronic exposure to it can uniquely generate disease outcomes for carers that also threaten to interfere with the quality of care, as well as precipitating the premature cessation of family care.

Existing hypotheses concerned with how carers can counteract the daily stressors associated with the long-term care of chronic conditions such as AD such as the Wear and Tear hypothesis may be counter-productive, serving to reinforce the current dominance of the Medical Model of dementia and associated ‘burden of care’ models that envision the inevitable failure of family-based dementia care [51]. In addition, The Adaptation hypothesis may be flawed due to its emphasis on maladaptive rather than productive carer strategies [52]. Arguably, recent recognition of ‘resilience’ as a lifelong process presents an opportunity to harness and strengthen a set of largely under-represented carer resources, that if properly supported could be exploited to promote carer strength and empowerment that leads to better carer health outcomes, enhances the level of AD care provided and prevents the early termination of family care of PWA. The Resilience approach to family care of PWA that is outlined here, set within a novel epidemiological paradigm, offers a fresh perspective concerning how some of the core issues relevant to the family care of PWA (not least how to tackle the chronic stress frequently associated with the family care of PWA) might be addressed.

AD represents a rapidly escalating global health issue. It is also a double headed health concern since it leaves family carers also vulnerable to serious health problems. Arguably, we have already reached a crossroads at which point we either allow the health attrition caused by AD to effectively be doubled by continuing to allow primary family carers to become included among the casualties of the disease or we can act decisively to redouble efforts to safeguard the health and wellbeing of family carers of PWA by ensuring they are equipped with the resources to build resilience and can in turn maintain and sustain effective family caregiving in support of care recipients. A main question concerns the role of healthcare providers and the coverage they offer for preventative agendas rather than direct care and treatment. Moreover, these issues not only reflect the needs of carers of PWA but could apply to carers of people with other long-term conditions. It is a debate that needs to start now.

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