Caregiver burden: Support needed for those who support others and the National Health Service

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Recommended Citation

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Abstract

This literature review focuses on the complexities and inequalities of informal caregiving in the UK and was inspired by the story of the following individual: EL is a 68-year-old Caucasian lady who attended Movement Disorder Clinic and was diagnosed with Parkinson's Disease Dementia following many years of symptoms. The diagnosis came as a big relief to EL and her daughter (SL) who were eager to get treatment started as soon as possible. EL lives alone with SL and solely relies on her for care and support. SL does not have children and devotes her daily routine to looking after her mother, never spending more than a few hours away from her. SL has found this situation very challenging, while EL has felt she has lost her independence. This frustration on a background of mutual love and concern was evident from both parties during the appointment. Informal carers play a crucial role in looking after individuals and provide massive relief to healthcare systems but are often left without support. This puts themselves and the people they care for at risk of poor physical and psychological outcomes. The number of informal carers continues to rise but staggering rates of burnout are still observed. By understanding the complexities and emotional impact of this role, together with the inadequacies of current social care policies, we can strive to reveal areas of improvement that can grant carers the support they deserve to carry on performing their invaluable roles.

Introduction

Across the UK over 6.5 million people spend multiple hours a week providing care for friends and family at no cost.[1] These informal carers provide vital services to members of society and save the National Health Service (NHS) nearly £193 billion every year[2] yet are left suffering negative health outcomes and often feel overlooked by healthcare professionals and services.[3,4] Not only do they carry an increased risk of physical health comorbidities and complications such as strokes,[3] but their emotional health and quality of life can be immensely impacted.[1,5-8] This often leads to "caregiver burden" whereby an individual's caregiving responsibilities severely compromises their wellbeing, leading to anxiety and depression.[9] This can also have devastating implications on the care being provided and therefore on care-recipients in the form of increased mortality and likelihood of hospitalisation.[6,10,11]

This is a worrying situation if we consider that the number of informal carers rose by 600,000 between 2001 and 2011 and will continue to grow to assist an ageing UK population with complicated long-term needs.[12] Even more worrying is the fact that the informal care burden is greatest in some of the most vulnerable groups in society and not only exacerbates the struggles they face but highlights the inadequacy of the current social care system.

Young individuals, "sandwich carers" (people caring for children as well as older individuals), Black and Asian Minority Ethnic (BAME) communities as well as underprivileged groups save the NHS millions each year at their own expense but do not receive the support they need to carry out their care duties.[13] Their stories and the stories of individuals such as SL need to be heard to inform carer assistance strategies moving forward.

This essay will underline the challenges faced by informal carers considering existing inequalities and critically evaluate the current strategies that exist to alleviate burden by making recommendations on how to optimise them.

Definitions and Considerations

As a concept caregiver burden encompasses both objective and subjective interpretations of strain that relate to the wellbeing of carer and care-recipient.[9,14] Consequently, circumstances may directly predispose an individual to burden such as financial instability[15] and restricted social engagement,[16] but self-perception will interplay with these to direct health-seeking behaviours. One study showed that while half of carers in a cohort reported experiencing high levels of burden, a quarter denied that this was negatively affecting their daily lives.[17] Therefore, certain populations will have a higher threshold

for adversity and may only present to healthcare services at stages of burnout whereby continuing to care is no longer a suitable or safe option.[18] As a result, an integrated approach must be taken when evaluating carer needs.

Manifestations and Implications of Burden

Research and polling have consistently revealed that informal carers experience worse mental and physical health on a background of unmet needs for themselves.[19] Specifically, caregiver burden has been associated with feelings of burden,[20] depression,[21] anxiety,[22] stress and a reduced quality of life.[22,23] Premature mortality is also a prominent feature in unpaid caregivers,[24] along with an almost doubled risk of disease development.[25] Nonetheless, despite the prevalence of chronic health conditions in these individuals,[26] surprisingly low levels of pharmaceutical uptake has been observed.[19] This points to the idea that self-neglect and poor health-seeking behaviours are present in carers[27] potentially due to limitations in available free time.[28] It has also been hypothesised that "physiological burnout"[29] may be at play in caregivers whereby chronic stressors lead to increased Hypothalamic-pituitary-adrenal axis[30] and sympathetic activity.[31] This results in the sustained release of adrenaline and pro-inflammatory molecules[32] which overwhelm and tire the body with stress signalling.[29]

However, each carer has an inherently different set of responsibilities and will objectively be caring for someone with a unique set of requirements. For example, the finding that distress is higher than average in carers of cancer survivors[22] may not be applicable to carers of individuals with other conditions. On the other hand, there is a lack of insight into caregiver burden in Alzheimer's disease[9] and this limits the scope and validity of current interventions. Many studies also fail to set out objective, comparable measures for the severity and

prevalence of their observations. This highlights a self-admitted gap in the literature whereby incompatible data from dissimilar populations with contrasting chronic conditions is lumped together and compared.

Determinants of Health

Due to the undeniable impact that unpaid care has on physical and mental health, it has been proposed as a direct social determinant of health and health inequalities (19). Additional frameworks from the WHO[33] and Dahlgren and Whitehead (1991),[34] reveal the host of health impacting social determinants that predispose to burden but that can also be negatively affected by caregiving.

The WHO points to several factors (Table 1) such as poor financial status which exacerbates carer stress but can also be the result of relentless caring costs.[13] Inadequate social amenities and inclusion can also be generated by caring but similarly worsen burden,[16] something which also occurs when cultural barriers to accessing healthcare exist. Meanwhile, being a young carer impacts on both development and future social opportunities.[4]

In the Dahlgren and Whitehead (1991)[34] model, certain factors are highlighted which both predispose to caregiver burden and may be caused by caring (Figure 1). Unemployment and poor educational attainment may occur due to caring responsibilities,[13] while social exclusion may also be a consequence of caring and has been shown to provoke feelings of burden.[16] Inadequate social and healthcare support, as well as cultural barriers can also worsen burden. Furthermore, certain groups are also disproportionately impacted by caring and at greater risk of burden, such as younger and older individuals as well as females.

Table 1. WHO Social Determinants of Health in the Context of Caregiver Burden[33]

WHO Social Determinants of Health Categorised			
Financial Status	**Younger Age**	**Social Factors**	**Ethnic Factors**
Income and social protection	Early childhood development	Housing, basic amenities and the environment	Access to affordable health services of decent quality
Unemployment	Education	Social inclusion	

Figure 1. Dahlgren and Whitehead Model of Health Determinants Relating to Caregiver Burden[34]
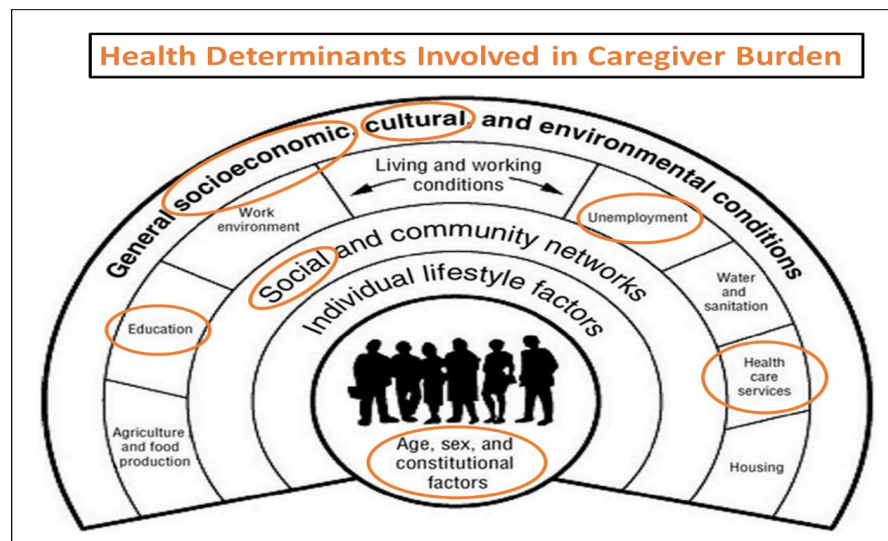
By gaining a better understanding of the social and cultural factors which interplay to create and perpetuate caregiver burden we can take a more informed and wholistic approach to addressing the problem.

Inequalities in Social Care Burden

Black, Asian and Minority Ethnic (BAME) Communities

BAME carers make up over half a million individuals and despite providing proportionately more care than White British carers, are left facing unequal levels of isolation in health and employment.[35] As a group they also more likely to be struggling financially and more likely to be providing care for over 20 hours a week[36] which are major risk factors for burden. However, despite increased help needs,[37,38] they are less likely to employ the help of support services.[39]

Hypotheses for this phenomenon have been that BAME carers may be less likely to view themselves as being carers based on cultural norms and family relationships.[40,41] Moreover, reports have shown that barriers to accessing aid exist such as misconceptions surrounding available care,[42] language, cultural insensitivities,[43] stigma and a sense of duty.[44] As a result, there are delays in BAME carers accessing services[45] and once accessing them they are more likely to report being dissatisfied due to insensitivity, inflexibility and financial costs.[46-48] One study looking at stroke, a condition that BAME individuals are at increased risk of,[49] confirmed these findings and echoed the need for cultural considerations in care-package development.[50]

Financial Status

Caring brings with it a host of additional expenses as well as forfeited income[13,51] with surveys showing that nearly a third of carers face losses of 20,000 pounds in household income annually.[52] Therefore, it unsurprising but still concerning that carers are more likely to live in poverty[53] and that 39% of carers describe "struggling to make ends meet."[54] Additionally, 43% report suffering adverse health outcomes due to financial pressure.[55] This is a dangerous situation if we consider that individuals who are already financially struggling may be thrust into poverty as new carers, and as a result will be disproportionately disadvantaged. However, financial support remains a difficult intervention to critique as many individuals may not access available financial benefits (40% of carers reported missing out on financial help due to misinformation).[56] Furthermore, different financial support frameworks exist in different countries, and this makes cross-comparison unadvisable. Nonetheless, this data highlights the inequalities and inadequacy of the current social care system.[57]

Age

It has been repeatedly shown that the youngest and oldest carers of society are at the greatest risk of developing burden, but for different reasons. Young carers (under 18) have been shown to face social isolation, bullying[58] and poor health outcomes as well as reduced educational attainment and employment opportunities.[59-61] This is an extremely unfair situation, and this burden must be alleviated to allow these individuals to develop with the same opportunities and freedom as non-carers. On the other hand, older carers (over 65) are more likely to be suffering from their own chronic conditions and disabilities and therefore provide care at the expense of their own health and wellbeing.[8,62,63]

Figure 2. Pathway of Progression to Caregiver Burnout with Opportunities for Interventions
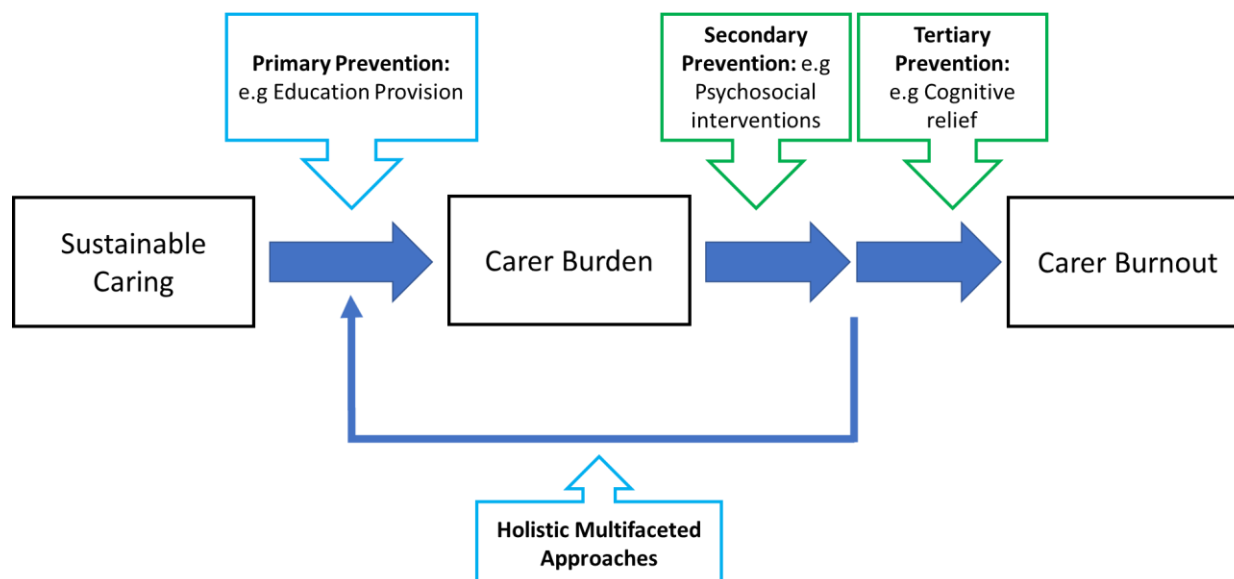
The evolution from carer that is in control of their responsibilities to burden, and burnout can be halted at various points. Primary prevention may arrest this progression and promote carer empowerment, for example through provision of appropriate information and training. Meanwhile, secondary and tertiary prevention strategies may help prevent burnout but because they are implemented at a later stage the patient is likely to continue suffering to a degree. Additionally, multidimensional approaches could theoretically help reverse the progression and give individuals a new lease on caring.

Gender
In the UK females are more likely to be carers than males (58% compared to 42%) and generally provide more hours of care a week, which predisposes to burden.[1,64] Furthermore, a predominantly female group of individuals (68% of 1.25 million) called "sandwich carers" are tasked with providing care for both older individuals as well as young children. 78% of them still manage to undertake paid work at great sacrifice to their own personal health.[65-67] Studies have shown that these carers are more likely to experience psychological, physical, social and financial burden[65-67] and since this population is heavily skewed toward females, support strategies must address this inequality.

Strategies to Prevent and Manage Caregiver Burden

Various approaches aimed at relieving carer burden have been studied, however many of these are aimed at secondary and tertiary disease prevention whereby burden has already started and may be well-established at the time of intervention. This delay in acting will undoubtedly impact on the reported effectiveness of outcomes. With the evidence that extraordinary fatigue and mental strain without relief can result in physical and emotional abuse of care-recipients,[68,69] interventions should come at an early

stage to prevent the progression of burden to burnout. Therefore, primary interventions should be prioritised along with multi-targeted approaches since they have the potential to alleviate hardship by granting carers greater control of their responsibilities (Figure 2).

Targeted Strategies
Systematic reviews of psychosocial interventions in the form of supported self-help therapies,[70] stress reduction support with combined yoga and meditation,[71] and group support therapies,[72] revealed mixed results on factors such as carer depression, stress, anxiety and mindfulness.[70-72] From an education provision perspective, one study looking at web-based support through question answering, training in relaxation and information sharing by healthcare professionals also failed to reveal any improvements in outcomes.[70]

Another study aiming to provide cognitive relief through calendar and note-taking training did show some benefits to carer mood but not "carer burden."[73]

Therefore, while many of these mentioned strategies have a theoretical basis in promoting health, their effectiveness has not been categorically demonstrated. This could be due to the inappropriate timeframe in which they are being introduced, inconsistent implementations of strategies and

measurement of outcomes, or that simply they may be unhelpful in isolation. Nonetheless, further research could build-upon this by measuring quantitative burden as a more objective outcome before and after the intervention of interest. This could be done using the Zarit Burden Interview which is a 22-question form that yields a carer burden severity score. Its reliability has been demonstrated in evaluating caregivers of dementia[74] and heart failure patients,[75] but further research needs to be done to establish its applicability across further conditions.

Multi-targeted Approaches

The simultaneous use of multiple complementary approaches to target caregiver burden is not something that has been studied in detail, or widely implemented, despite reported benefits. One such approach called the Care Navigation Service was developed in Gateshead. This programme provides support directly to carers and patients through regular calls and meetings and indirectly by pointing them in the direction of appropriate resources and services. This is especially important if we consider that only 66% of carers feel that they are appropriately directed to supportive services by healthcare professionals.[76] Collected data showed that assistance was provided in creating 396 care plans, 40 carers were connected with services and post-discharge support helped reduced the need for further GP appointments and hospital admissions.[77] Therefore, by providing carers with continuous support, multi-dimensional services may halt the onset of burden and progression to burnout (Figure 2).

Interventions Addressing Inequalities

Financial

Interventions aimed at reducing financial burden and inequality should be explored. As it stands carers may qualify for a £69.70 weekly carers allowance if they are over 16, spend at least 35 hours looking after someone and only if they do not earn over 132 pounds a week after deductions.[78] This is not adequate financial support if we consider that the National Living Wage dictates that a weekly rate of 356.40 pounds is the minimum someone over 23 should earn for a 40-hour work week before deductions.[79] Therefore, a carer who qualifies for a carers allowance will most likely exceed 40 hours of combined caring and work a week yet will only be compensated a maximum of 201.70 pounds. This is incredibly low considering the costs of caring and the allowance should in turn be raised significantly.

Notwithstanding, the means-tested social care threshold in England is too easily surpassed by care recipients to the point where individuals often must spend thousands of pounds before being entitled to free care.[80] This makes them extremely dependent on informal care. As a result, a strategy to alleviate reliance on informal carers could include adopting the Scottish model whereby personal care

for individuals over 65 is not means tested but rather needs tested. This would entitle the majority of individuals who need care to free services, which is an important strategy considering social care funding has been shown to prolong life expectancy.[81] As a result, providing individuals with free care and caregivers with financial support could help benefit both parties.

Cultural

Interventions aimed at carers in different ethnic groups should be personalised and account for individuals' day-to-day needs and understandings.[81] This would be consistent with findings that carer interventions are not "one size fits all"[81] and therefore keeping this in mind can help tailor interventions that are sustainable and empowering.

For example, simply translating leaflets from English to other languages and disseminating them in communities is not sufficient but rather enlisting the help of community groups fluent in the different languages could allow for deeper understanding and potentially better engagement.[35] Additional strategies could involve sitting with carers and helping to organise budgets, healthcare appointments and schedules as well as providing help with transport.[81] However, challenges in providing personalised care include the limited information available on intervention success within specific ethnic groups[82] and struggles in recruiting and engaging ethnic minority individuals in helping to test and develop programmes.[83] Many studies also require individuals to speak English to be able to participate which limits the external validity of reported results. Consequently, research should be conducted that is specific to certain cultural groups and engages with them on an individual level.

Nevertheless, support projects that involve culturally tailored approaches have shown to be beneficial. One such project involved constructing a culturally sensitive dementia support team to help provide physical and social care to individuals from diverse ethnic communities, and saw carers being more likely to access community help services.[84] Therefore, culturally inclusive interventions should be adopted to provide personalised care to groups that are often at greater risk of carer burden.

Respite as an Important Intervention

Respite care can be defined as any supportive measure which provides informal carers with a break. This can involve either taking over their care responsibilities at home or in the community with both options having the benefit of relieving them of their duties for a few hours or days at a time. Home-based respite involves external carers making home visits to tend to care-recipients, while community care includes any outdoor excursions (e.g., park visits) or care in the community (e.g., in care homes).

These approaches can be implemented in carer groups across ethnicity, financial status, and care-recipient condition, thus making it an important intervention to analyse and implement.

To date research has shown that respite may give carers a new lease on caring by reducing burden, alleviating stress and giving them the time to carry out personal and social tasks.[85,86] Affording carers this opportunity gives them an escape which they often find beneficial and re-energises them for their caring responsibilities.[87-90] Through this mechanism respite has been shown to decrease anxiety, loneliness and burden in general also leading to improved sleep quality and mood.[91-93] It has also been shown lead to better and more understanding relationships between carers, care-recipients and family members.[94] These factors are vital if we consider the nature of caregiver burden and the negative effects it can have on carer wellbeing as well as care-recipient outcomes (Figure 3).

However, the benefits of respite care are not straightforward and often favourable correlations have not been found.[19, 95-97] Moreover, most of the research that has found benefits is qualitative rather than quantitative and has been undertaken in a dementia care setting, making extrapolation and interpretation of results difficult. It has also been hypothesised that respite care may not be sufficient to have a direct effect on mental health as it is not addressing the more pressing needs that a carer may be experiencing.[19] Instead, it simply provides some free time and relief as a secondary prevention strategy (Figure 2). The implementation of respite care also presents many barriers including cost, feelings of guilt and difficulty in setting up respite visits.[85, 98-102] Many carers also view respite as a tool to improve the treatment of the care-recipient which means that trust and cultural considerations are at play when evaluating how respite care is viewed by carers.[50, 103] Respite care is also extremely variable in nature and while in-home is often preferred,[85,89] it is important to consider individual preferences especially when it comes to different ethnic groups.[104] Nonetheless, many of these barriers can be accounted for by alleviating cost concerns through wider government funding and working closer with different groups to achieve more personalised, culturally-sensitive care that suites both carer and care-recipient. This would require providing tactful education and undergoing detailed discussions rather than simply presenting available options with no context.

Therefore, the inclusive nature of respite care, the flexibility it affords carers and the benefit it has shown to yield makes it a valuable tool to combat burden. However, further research is needed to definitively demonstrate its worth and multiple barriers must be addressed to maximise its benefits and to allow for its widespread uptake.

Conclusion

Informal carers are a large group in the UK that make immense sacrifices for their loved ones and provide enormous relief to the NHS, at a great cost to their own health and wellbeing. Despite this they are not supported adequately and often internalise their struggle to the point where they burnout and can no longer carry on caring. Therefore, caregiver burden is a worrying problem as it

Figure 3. Overview of Variables Involved in Caregiver Burden
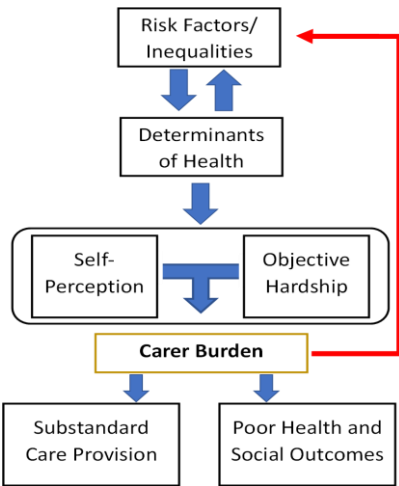
Risk factors such as age, ethnicity, sex and financial status interact with social determinants of health to push carers toward burden in disproportionate ways. However, for someone to admit to experiencing burden and seek help both subjective and objective interpretations must be considered. Nonetheless, once burden is established, a plethora of negative outcomes have been reported to occur, many of which exacerbate existing inequalities.

affects some of the most vulnerable groups in society and does not only impact their health but also diminishes the quality of care they can provide. Inherent societal risk factors also leave certain carer groups at heightened risk of burden in a positive feedback loop that further disenfranchises them (Figure 3).

Intervention strategies must however be implemented in a timely manner to prevent burden onset and progression (Figure 2) and must also consider individual circumstances and inequalities to be more targeted and effective. Respite is one such approach which is flexible and beneficial, but just like other approaches it may not be adequate in isolation or implemented early enough. Therefore, early-interventions and multi-targeted approaches may provide more holistic relief and could stand to benefit millions of carers and care-recipients once introduced.

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