

Key health impacts and support systems for informal carers in the UK: A thematic review

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Abstract

Introduction: The economic contributions made by informal carers in the UK per year mount up to £132 billion. This is equivalent to the total amount of the health care costs, yet the health and wellbeing of carers are often not prioritised. This review paper aims to determine the key health impacts of informal caregiving and evaluate support/control methods in the UK.

Methods: This thematic review was conducted in accordance with an adapted version of the PRISMA guidelines for systematic reviews. Of the 6,482 articles identified through Pubmed/Medline, CINAHL, SpringerLink, Summon, and grey literature, 38 studies were included in the review.

Results: The key health impacts of being an informal carer were identified as musculoskeletal disorders and psychological issues (such as depression, stress and anxiety), which were categorized as 'high-risk impact' areas. The review further identified cardiovascular disease and early mortality as 'low to moderate risk impact' areas and a thematic area that revolves around positive impacts on health of informal carers. Financial help, proper respite care, availability and accessibility of information and advice, provision of equipment in a timely manner and adequate support networks were found to be key factors useful in minimising musculoskeletal and psychological disorders.

Discussion and Conclusions: There is a need for policy makers and program implementers to recognize and accommodate the ever-changing role of carers on different stages of caring. There is also a need to review key health policy documents to include informal carers' needs and improve support systems available. The lack of evidence-based research on the psycho-physical impacts of caring and the lack of evaluation of services that impact the health of carers also needs to be addressed with priority.

KEY WORDS: Caregivers; control methods; informal carers, UK, health policy; systematic review; support systems; public health.

Riassunto

Introduzione: Il contributo economico dei lavoratori che prestano assistenza in modo informale nel Regno Unito ammonta a 132 bilioni di sterline l'anno. Questo è l'equivalente del totale annuale dei costi sanitari, tuttavia la salute ed il benessere di tali lavoratori spesso non sono considerati prioritari. Questa revisione ha l'obiettivo di determinare le aree di impatto chiave per la salute ed i metodi di controllo e di supporto per tali lavoratori nel Regno Unito.

Metodi: Questa revisione tematica è stata condotta seguendo una versione adattata delle linee guida PRISMA per le revisioni sistematiche. Dei 6.482 articoli identificati attraverso Pubmed/Medline, CINAHL, SpringerLink, Summon e la letteratura grigia, sono stati inclusi in questa revisione 38 studi.

Risultati: Sono state identificate come aree di impatto chiave per la salute i disturbi muscolo-scheletrici e psicologici (come la depressione, lo stress e l'ansia), classificati come aree di impatto ad alto rischio. La revisione ha inoltre identificato le malattie cardiovascolari e la mortalità precoce come aree di impatto per la salute con un grado di rischio basso-moderato ed un'area tematica riguardante gli aspetti che impattano positivamente sulla salute di tale categoria di lavoratori. Aiuto finanziario, appropriate strutture di sostegno, disponibilità ed accessibilità di informazioni e consigli, fornitura di attrezzatura in modo tempestivo ed adeguate reti di supporto sono fattori chiave utili per minimizzare l'impatto negativo dei disturbi muscolo-scheletrici e psicologici.

Discussione e Conclusioni: È necessario che i decisori politici e gli attuatori dei programmi riconoscano e tengano in considerazione il ruolo in continua evoluzione di tale attività lavorativa nelle differenti fasi dell'assistenza. C'è anche necessità di rivedere i documenti chiave di politica sanitaria per includere i bisogni degli assistenti informali e per migliorare i sistemi di supporto disponibili. La mancanza di ricerca basata sull'evidenza relativa agli aspetti assistenziali che impattano a livello psico-fisico e la mancanza di valutazione delle attività che hanno conseguenze negative sulla salute di tali lavoratori necessitano anche di essere affrontati in via prioritaria.

TAKE-HOME MESSAGE

Informal carers in the UK contribute much to the society, yet their well-being is not often prioritized. There is an urgent need to improve support systems already available as well as research and implement new support structures.

Competing interests - none declared.

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INTRODUCTION

There are over 6.5 million carers in the UK (10% of the population) [1], who provide care for a family member, relative or a friend who may need assistance due to an illness or disability. It is very likely that the responsibilities of being a carer will touch most families [2]. Carers are often referred to as informal caregivers and they are unpaid, unlike the professional caregivers who are paid for their services [3]. A recent European study, estimated caregivers in the UK to be much higher – around 30.2% of the population and intensive caregivers around 8.2% [4]. Carers are one of the most important workforces needed to deliver health care services, however experts argue that they are disregarded, overlooked and not given due recognition or support [5]. Carers' contributions are not always monetized to be included in healthcare economic evaluations. This has repercussions like dismissing or reduction of interventions that could benefit carers [6]. Carers are providers of care within a hidden health care system that the formal healthcare system is highly dependent on [7]. With the National Health System (NHS) resources reducing, the healthcare system relies on informal carers to take on more responsibilities [5, 8]. It is estimated that they economically contribute around £132 billion pounds a year, which is equivalent to the total expenditure of the NHS [1]. Moreover, they save the NHS an estimated £67 billion or more annually [5]. There would be an immense strain on the NHS without the contribution of the carers [8].

From the Census 2001 to 2011 there has been an 11% increase in the carer population in the UK [9]. This significant increase can be attributable to an ageing population that is catalysed by the changes in the demography and improved medical techniques. The rates of survival for the elderly and people with complicated illness are much higher than ever before. The well-being of people who need care depends on the capability of carers to provide care. It is crucial to the healthcare system that the caregivers are acknowledged as partners in care, provided with adequate support and

more importantly looked after physically and mentally [8].

Key research [10–12] has shaped our current understanding of the health impacts of caregiving. Widespread and hugely accepted views are that caregiving is burdensome and demanding causing high risk to the carer's own health. Caring can take a toll on the caregiver's physical and psychological health, they are also likely to show poor health behaviours. In literature, the recognised health impacts from caregiving concern physical and psychological health as well as poor health behaviours.

The physical impact of caring has been studied less than mental impact but from what we know, caregiving can be stressful, and distress has been associated with immune functioning problems, which can lead to higher risk of developing cardiovascular diseases [13]. Many carers find it difficult to maintain a healthy and balanced lifestyle and as a result, have poor health behaviors. Carers are highly likely to put off medical treatment, have a poor diet and reduced amount of sleep [14, 15]. Common poor health behaviours seen among carers such as smoking, poor nutrition, obesity and physical inactivity also put them at high risk for musculoskeletal disorders, cardiovascular diseases and diabetes [1, 16]. And besides, the impact on health - caring can be mentally taxing. Carers who care for illness especially mental illness often have to cope with challenging and irrational behaviour from the person they care for, which can cause immense stress and can impact the health of the caregiver. Some carers also have to handle aggressive behaviours of the care recipient such as verbal and physical abuse due to the nature of certain diseases, which can make them feel isolated, trapped and unappreciated [3, 10]. Many carers are experiencing social isolation, inability to maintain personal relationships and restrictions in freedom of mobility [1, 16]. Caring also puts a significant number of carers in socio-economic turmoil, 42% of carers in the UK reported not receiving any financial help due to lack of proper advice. As a result, almost half of them had to

cut down on essentials like food and heating. Almost one-fifth of them found it difficult to afford housing [17].

Nevertheless, asserting that caring is an entirely burdensome experience and hazardous to one's health would be taking a restrictive view and ignoring the positives. It is human nature to maintain caring relations with their loved ones. An unbiased view looking at other dimensions of caregiving such as pro-social behaviour and altruistic motives would be beneficial [18], as the number of people who are available to provide care are scarce and is said to be outnumbered by the number of people who need care. This is a growing crisis for the policymakers, the government and the healthcare system [2]. Painting a non-dire picture would mean that people would be heartened to take up the responsibility of being carers and the sick would be able to live in their communities longer [18]. Although the positive benefits of caregiving are seldom reported, a recent study has found that carers who had some strain had better longevity than carers who had no strain, possibly due to increased self-efficacy as well as increased resilience. But highly strained carers still had high risk of all-cause mortality compared to no strain and some strain caregivers [19].

Considering this backdrop, the aim of this paper is to review the main health impacts (physical and mental) of being an informal carer and mostly importantly evaluate the current control methods in place in the UK.

METHODS

This review is a thematic analysis of papers that explore the health impacts of being an informal carer. Thematic analysis allows for a systematic review that can identify themes within the data corpus and, also collate results from various study methods. The descriptive nature of themes also allows for incorporation of both qualitative and quantitative studies [20].

Literature search strategy

A literature search was conducted for studies that explored the health impacts of being

an informal carer in the last 17 years (2000 – 2017) for this review. The time period of 17 years provided this review with most recent evidence of health impacts of caregiving. However, relevant grey literature (independent surveys done by organisations) were also included as there was a dearth of literature that showed the physical impact of caring.

Databases searched

The main electronic databases searched for relevant research were Cardiff Metropolitan University's electronic library 'Summon', Pubmed/Medline, SpringerLink, CINAHL and Science direct. Grey literature search was conducted on some main carers support organisations such as Carers UK, Carers trust, Independent Age, Age UK, Macmillan cancer support, Alzheimer's society, Arthritis UK and UK Gov.

Inclusion criteria for the review

We only included:

1. Research published/available in English.
2. Research that focused on the health impacts of caregiving.
3. Both qualitative and quantitative studies.
4. Studies on informal caregivers who care for any disease.

There were only a limited number of studies that explored the health impacts of informal caregiving within the UK population. Hence the review included research studies published in the last 17 years from all over the world. However, evaluation of control methods to minimise these health impacts was discussed later on in the context of the UK population only.

Search terms

Some key words searched with varying combinations were: 'Carers', 'caregiving', 'Informal carers', 'Health impacts', 'policy', 'mortality', 'morbidity', 'support mechanisms', 'support systems' and 'UK'. Studies for this thematic review were identified, screened for eligibility and included in accordance with adapted PRISMA guidelines [21]. Figure 1 illustrates

a PRISMA flowchart for the inclusion of the studies.

All 38 studies were analysed for their quality. Each study was analysed on the following criteria: The suitability of the study design for the study objective; the representativeness of carer group; the acceptability of control group if present; quality of the data collected and the outcomes; accountability of bias, confounding and reliability. The criteria used to assess the quality have been adapted and modified from Spencer and colleagues [22]. The criteria assessment has also been informed by few other studies that have used similar templates [23,

24]. Overall, none of the studies included in the thematic analysis had major flaws to disregard the findings. A detailed table of the quality assessment is given in Table 8.

RESULTS

Past research has shown that the health impacts of caregiving can manifest either physically, mentally or through modified health behaviours which ultimately affects the overall health. Table 1 gives a snapshot of already recognised health impacts in the literature.

The studies ($n = 38$) included in this review impacted carers in the following 5 health are-

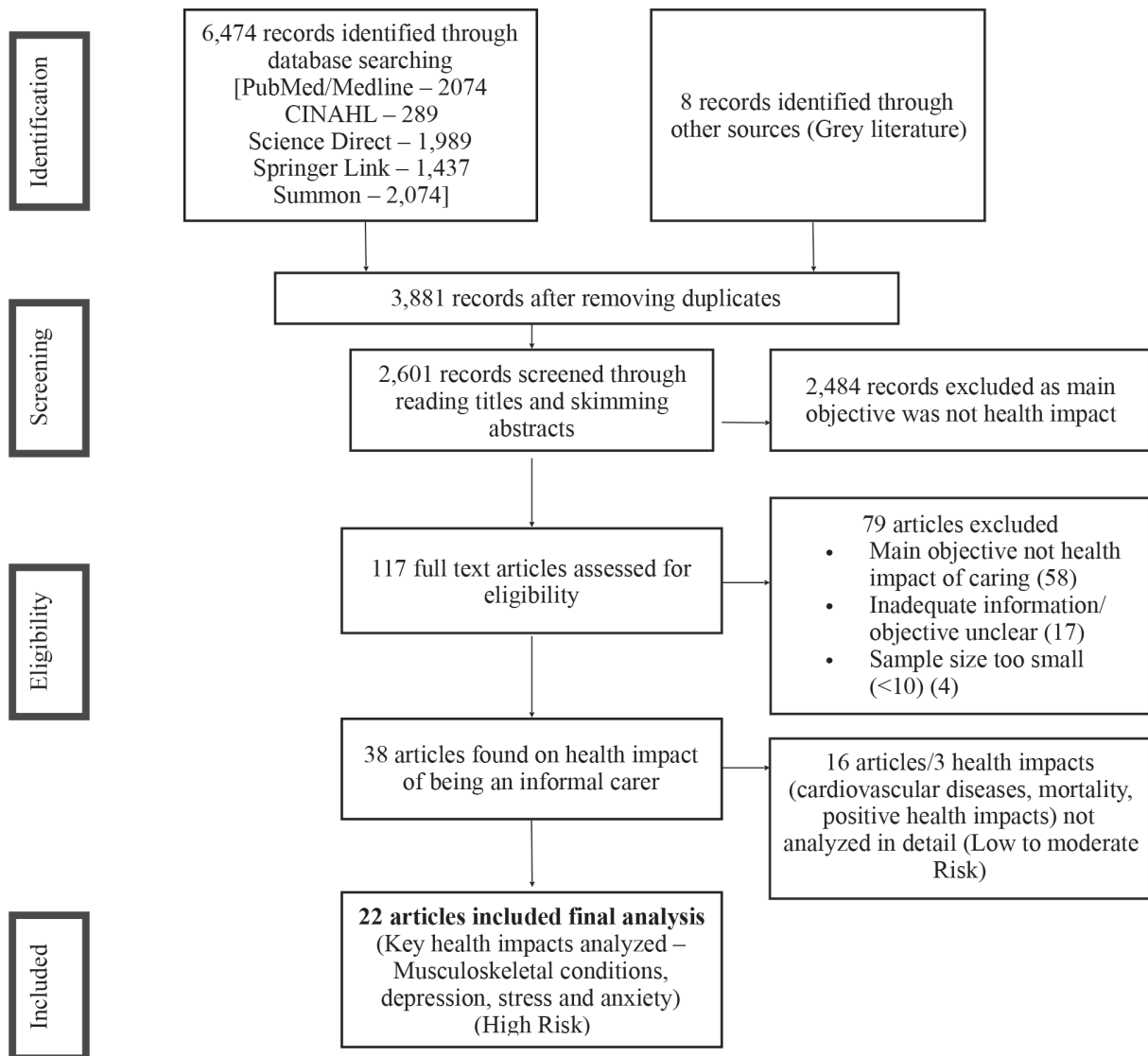


Figure 1. PRISMA flowchart of included studies.

Table 1. Previously recognised health impacts of being a carer [1, 10, 13–16]- Table Adapted from [16].

| Physical Health | Psychosocial Health | Health Behaviours | Overall health |
|--|---|---|---|
| <ul style="list-style-type: none"> • Increased risk of cardiovascular diseases • Increased risk of musculoskeletal problems • Increased risk of high blood pressure, diabetes, back problems and mobility issues • Decreased immune system | <ul style="list-style-type: none"> • Increased risk of depression • Increased risk of stress-strain • Increased risk of anxiety and distress • Carer burden | <ul style="list-style-type: none"> • Poor Diet • Ignoring one’s own health • Reduced physical activity • Insufficient sleep | <ul style="list-style-type: none"> • Poor self-reported health • Reduced self-efficacy • Reduced overall health and quality of life • Increased risk of early mortality |

as: 1) Musculoskeletal disorders; 2) psychological disorders including depression, stress, and anxiety; 3) cardiovascular diseases; 4) early mortality; and 5) positive health impacts. Risk for the four negative health impacts have been categorized on prevalence rates (Tables 2 to 6). These rates have been used previously to categorize risk levels by WHO studies [25, 26]. If a health impact had a prevalence of 0 – 9% it was categorized ‘low’, 10 – 19% as ‘moderate’ and 20% or over ‘high’. If prevalence was not reported in the study other measures used such as risk ratio and association that was based on statistical significance was used. For the positive health impacts, we have identified reported satisfaction rates and arbitrarily classified them as 0 – 20% ‘low’, 21 – 69% as ‘moderate’ and 70% or over ‘high’. Most of the studies retrieved by our review impacted on two health areas, i.e. musculoskeletal disorders, and psychological issues such as depression, stress and anxiety (Tables 2, 3 and 4). These were found to be the key health impacts of being an informal carer that had the most potential to inform and influence the most urgent intervention strategies to minimize ‘carer burden’. We have categorized them as ‘high-risk impact’ areas ($n = 22$ studies). These high-risk areas were analysed and explored in detail to identify themes and sub-themes. The review also explored the effectiveness of support systems available to reduce these impacts.

Cardiovascular diseases and early mortality studies are issues that are addressed as well, and their description is given in Tables 5 and 6. We have categorized them as ‘low-moderate risk impact’ areas ($n = 16$ studies). Studies about well-being and positive aspects among

carers are also described in Table 7.

‘High-risk impact’ health areas

Studies in this review show that the risk for musculoskeletal disorders is high for carers. Musculoskeletal disorders were found to be mainly dependent on the characteristics of the patient cared for. Patient characteristics such as functional capacity and cooperativeness of the patient were associated with risk of musculoskeletal injuries. The more physically dependent the patient was higher was the risk of carer developing musculoskeletal disorders, most frequently reported conditions were spinal injury with moderate to high pain levels, back pain, shoulder pain and pain in muscles and joints (Table 2).

Similarly, studies included in this review also showed high risk of psychological disorders among carers. The analysis also revealed some predictors of these distressing symptoms (Table 3,4). Stress and anxiety among carers were associated with both carers characteristics (lower trait Emotional Intelligence (EI), being female and being older) and patient characteristics (co-morbidities of the care recipient and higher dependency on the carer). Stress and anxiety were predicted by perceived burden of the carer, poor finances and greater responsibility (Table 3). Depression among carers was higher for those who had to care for patients with higher needs that require increased caring hours, patients with co-morbidities such as hypertension and CVDs and those with some illness characteristics such as physically challenged, dementia and elderly. Carer characteristics such as being female as well as being younger were associated with higher depressive symptoms.

Table 2. Musculoskeletal disorders (MSD) among carers.

| Author/date | Aim of study | Type of study/ Sample size | Main findings | Risk |
|-------------------------------------|--|--|--|------|
| Forbes <i>et al</i> , 2007 [41] | To study carer activity, carer burden and health in Multiple sclerosis caregivers in England | Quantitative Study. Postal survey spanning over 24 months (<i>n</i> = 257) cross-sectional | Greater carer activity corresponded to greater disease impact (Most frequently engaged activity recorded was lifting patient (74%). Moderate to severe back problems were reported by 38% of carers. | High |
| Geere <i>et al</i> , 2011 [42] | To study the physical health impacts of being a carer in Kenya | Mixed method (<i>n</i> =20) | Most commonly reported health condition spinal injury ranging from moderate to severe pain levels. All of the carers suffered from MSD (100%). | High |
| Shiue, 2015 [43] | To study care provision for Welsh adults regarding back problems | Quantitative Study. Analysis of Population data from Welsh health survey 2013 (<i>n</i> = 2,751) | Carers tend to be women of the age group 40-74 with poor education, high BMI, smokers and physically less active. Carers had a lower quality of life with or without back pain. Carers not being treated for MSD had worse quality of life, that could disrupt normal life. 22.9% of carers were treated for back pain when compared to 18.7% of non-carers. | High |
| Carers Week 2012 [14] | To explore health and well-being impacts of being a carer in UK | Quantitative Study (<i>n</i> = 3,387). Majority filled online survey | 36% of carers reported to having injuries back pain. 16 % of carers felt the need for more practical aid. 26% reported the deterioration of a present health condition. | High |
| Sharan <i>et al</i> , 2012 [44] | To study Musculoskeletal disorders in caregivers who care for children with cerebral palsy | Quantitative Study. Case control (<i>n</i> = 257) among carers of cerebral palsy and control (<i>n</i> = 117) carers of children with orthopaedic problems | 3 MSDs identified Myofascial Pain Syndrome (27.6%), Fibromyalgia syndrome (24.5%) and Thoracic Outlet Syndrome (23%). Cooperativeness of the care recipient was associated with reduced back pain among the study group. High prevalence of body pain of shoulders and back found in the study group. | High |
| Darragh <i>et al</i> , 2015 [45] | To explore musculoskeletal disorders in carers who care for physical disabled | Mixed methods (<i>n</i> = 46) | 94% of carers reported high levels of carer burden with high physical exertion and musculoskeletal discomfort. Most commonly reported was lower back pain. Higher physical dependency on the caregiver and physical environment identified as factors influencing the physical health of carer. | High |
| Alshammari <i>et al</i> , 2017 [46] | To determine characteristics, socio-economic status, psychological and physical impact for informal carers who cared for elderly in Riyadh, Saudi Arabia | Quantitative Study. Cross- sectional study (<i>n</i> = 315) | 31% of the patients had chronic health disorders and 66% of them were over 70 years old. 78% of carers suffered from musculoskeletal problems such as pain in muscles, bones and joints. 58% of the carers expressed the need for additional health services support for themselves. | High |
| Liu <i>et al</i> , 2017 [47] | To investigate caregiver burden among carer givers of prolonged ventilator –dependent patients in Taiwan | Quantitative Study. Cross-sectional study (<i>n</i> = 160) (80 home care and 80 chronic respiratory care ward) Burden Assessment Scale (BAS) scores used | Physical exhaustion and torso/ back pain statistically significantly higher among home care givers than chronic respiratory care ward carers. Improved clinical and professional support needed for home caregivers. Torso pain statistically significant and higher for home carers (3.29 BAS score for home carers and 2.63 BAS score for respiratory care ward) | High |

Table 3. Stress and Anxiety among carers.

| Author/date | Aim of study | Type of study | Main findings | Risk |
|------------------------------------|---|--|---|----------------|
| Jacome et al, 2014 [48] | To study psychological health in carers who care for Chronic Obstructive Pulmonary diseases | Quantitative Study. Cross-sectional study, data collected from the family carers and their care recipients. Face to Face interview. Total No of carers and their respective care recipient = 203, Age range of carers 43-73. | Anxiety symptoms that were clinically significant found in 63.5% of carers. Some predictors of anxiety were care recipient's co-morbidities and perceived burden of the carer. Other factors like being a female and being older were also associated with distressing symptoms | High |
| Weaving et al, 2014 [49] | To study if Trait (EI) emotional intelligence does impact anxiety in carers who care for dementia | Quantitative Study. Cross-sectional study of 203 carers. Questionnaire used. | 49.2% reported to clinically significant symptoms of anxiety. Lower levels of Trait (EI) predicted higher levels of anxiety and perceived carer burden and poorer self-reported health. Multivariate analysis shows trait EI is a statistically significant predictor of anxiety among carers | High |
| Perz et al, 2011 [50] | To study the impact of gender difference in psychological distress in carers who care for cancer | Qualitative study (mixed methods study). Total participants= 329 (245 women and 119 men) Hospital Anxiety and Depression scale | Women carers reported high levels of anxiety and burden of care than men. Gendered role of women was related to carer burden and unmet needs which resulted in higher levels of anxiety. Women had statistically significant higher score of 10.20 than men 9.20 on the HADs scale | High for women |
| Carers UK, 2017 [1] | To study the impact of caring | Quantitative Study. Cross-sectional study of over 7000 carers. Mode of data collection =survey | 78% of carers reported suffering from stress and 72% reported to feeling more anxious, 69% reported poor quality of sleep and 45% reported difficult to maintain a balanced diet | High |
| Drutyte et al, 2014 [51] | To study the characteristics associated to carer stress symptoms in carers who care for Parkinson's Disease | Quantitative Study. Cross-sectional data, Survey of 1881 carers of Parkinson's Disease | 58.5% carers reported feeling anxious, 63.8% had trouble sleeping and 21.4% memory problems. Higher limitations of the care recipient, greater responsibilities of the carer and poor economic conditions were associated with increased stress symptoms | High |
| Greenwood and Mackenzie, 2010 [52] | To determine the anxiety levels in carers of stroke survivors | Longitudinal study 45 carers filled in HADs (Hospital Anxiety and Depression scale) questionnaire after one month and three months of discharge | Increased scores for anxiety than for depression. At both point in time around half the carers scored for high levels of anxiety. 51.1% reported being anxious in the first month compared to 48.9% in the third month. 31.1% reported depression in first month compared to 28.9% in the third | High |

Loss of control in life, less social support and perceived stagnant personal growth increased the risk for depressive symptoms. Support systems like domiciliary care and financial support were seen to reduce depressive symptoms (Table 4).

'Low-moderate risk impact' health areas

The overall risk of carers developing CVDs was found to be moderate in the studies included in this review [27–31]. The review has

also identified 3 main predictors of CVD risk among the carer population. The first one being lifestyle behaviors such as lack of physical activity and higher Body Mass Index (BMI) especially among women, which lead to high blood pressure and obesity (known predictors of CVD) [28, 31, 32]. The second one being psychological distress such as depression and stress [28]. The last predictor is the relation to the care recipient, 2 of the studies also associated carers caring for a spouse

Table 4. Depression among carers.

| Author/date | Aim of study | Type of study | Main findings | Risk |
|----------------------------|--|---|--|----------|
| Loi et al, 2015 [53] | To study depressive symptoms in older carers caring for various conditions in Australia | Cross-sectional quantitative study (n = 202), Questionnaire, Carer aged 55 years or older | 43% of carers were depressed and 25% reported as being moderately or severely burdened. Hours cared for and the nature of care recipient's illness was associated with the depressive symptoms. Elderly carers who cared for physically challenged patients were at high risk | High |
| Chang et al, 2010 [39] | To study the impact psychological distress and carer burden on physical health of the carer | Cross-sectional quantitative study (n = 388) Aged 18 or over, Mode of collecting data: Questionnaire | Increased hours spend for caring was associated with poor mental health and lower emotional support, higher physical exertion and increased carer burden. Good emotional support was associated with self-reported improved mental health and fewer illnesses. Median burden score 23.9 on 49 | High |
| Resch et al, 2012 [54] | To determine the rate of depression among parents who care for children with disabilities | Age range 27- 68, No of carers (n = 110). Cross-sectional quantitative study. Mode of data collection: Online survey | 19.1% of carers were depressed. Influential factors of depression were poor physical health of the carer, inability to resolve problems and lower family satisfaction of the parent | Moderate |
| Valimaki et al, 2009 [55] | To determine the impact of sense of coherence to depression in spouse caregivers of Alzheimer's disease | Cross-sectional quantitative study. Carers (n = 170) were asked to fill the SOC (Sense of Coherence) Questionnaire, HRQoL, Beck depression and general health questionnaire scale | Low SOC scores was a predictor of depression. 37% of carers reported depressive symptoms. Men had higher scores of SOC than female caregivers. Depression was associated with low Health related quality of life. Being a female and have low stress were the main predictors of high Health related quality of life. Carer are more vulnerable at early stages of caring | High |
| Aggar et al, 2011 [56] | To study depression and anxiety in carers in relation to self esteem | Cross-sectional quantitative study of (n = 119) carers above 70 years of age. Questionnaire | 68% of carers had positive caring experiences but Carers who resent their caring where more likely to be anxious and depressed. 14.3% of carers showed border-line depressive symptoms and 8.4% were highly depressed | High |
| Rosness et al, 2011 [57] | To explore the quality of life and depression in carers caring for early onset dementia | Cross-sectional quantitative study (n = 49) Quality of Life – Alzheimer Disease scale (QoL-AD) and Geriatric Depression Scale – 15 items (GDS-15) questionnaires used | Higher depressive symptoms were associated with having children with the patient, being married and caring for dementia with co-morbidities like CVD and hypertension. Increased age of carer and knowing the patient well was associated with better quality of life for carer. Domiciliary care when offered reduced depressive symptoms. 14 carers (28.6%) showed depressive symptoms | High |
| Jorgensen et al, 2009 [58] | Study the effects of care giving in New Zealand | Mixed methods (n = 287) | 56 % of carers showed signs of depression (n = 162) Lack of respite, information available and finances were associated with carers being frustrated. | High |
| Cameron et al, 2016 [59] | To study caregiver and patient characteristics to determine characteristics that are associated with caregiver health outcomes | Prospective quantitative study (n = 280) Data collected 7 days, 3, 6 and 12 months after discharge | 67% of carers reported depressive symptoms initially and 43% at the 12-month period. Over time depressive symptoms decreased partially in 84% of carers but remained the same in 16%. Being younger and less social support, control over life and personal growth were significantly associated with depressive symptoms | High |

Table 5. Cardiovascular diseases (CVD-CHD) among carers.

| Author/date | Aim of study | Type of study/Sample size | Main findings | Risk |
|----------------------------|--|--|--|---|
| Mausbach et al, 2007 [27] | To study the impact psychological distress of care giving on developing CVD and measure onset time on dementia caregivers | Longitudinal prospective quantitative study. Total time period of 18 months. Follow up every 6 months. Assessed by Interviews (n = 643) | Increased depression and distress were associated with the early onset of CVD. Over the 18-month period 5% (n = 32) reported a diagnosis of CVD. Low risk but carers are at risk for early development of CVD and early mortality | Low |
| Aggarwal et al, 2008 [28] | To study the impact of care giving on CVD risk and lifestyle on CVD caregivers | Randomised controlled trial. Participants did not have established CVD patients were not included (n = 263) | Care givers were more likely to be women, be over 50 years of age unemployed have higher waist circumference with less physical activity. Carer givers were at higher risk of developing CVD due to suboptimal lifestyle and psychosocial risk factors such as stress and depression. association between caregivers of cardiac patients and inflammatory risk factors for CVD | Moderate |
| Horwitz et al, 2009 [32] | To study the impact of care giving and CVD risk for grandparents who care for orphaned children by measuring Framingham risk scores. | Case control quantitative study age (n = 386) | No significant relationship found between CVD and care giving for both male and female caregivers and non-caregivers. However higher BMI was associated with higher CVD risk. | Low |
| Lee et al, 2003 [29] | To study the impact caregiving has on CVD incidence | Quantitative Study (n = 54,412). Registered female nurses in US aged 46 -71 at baseline (1992) with no diagnosis of CVD, stroke or cancer (1996 - follow up) | 321 incidence cases of CVD (231 nonfatal, 90 deaths) Being a carer for ill or disabled was not associated with increased risk of CVD, however caring for a disabled spouse was associated with increased risk of CVD (RR = 1.82). | Higher only for carers who care for spouses |
| Capistrant et al 2012 [30] | To estimate the relationship between CVD onset and caregiving in older American spouses | Quantitative Study. The respondents at baseline had no history of CVD, were married and over 50 (n = 8,472) followed upto 8 years | Caring for a spouse was significantly associated with CVD incidence with a hazard ratio of 1.35. Long term CVD was associated with twice the risk HR = 1.95, however it varied with race (p<0.01). CVD onset risk for white HR = 2.37 and non-white = 0.28 | Higher for carers who care for spouses |
| Von Kanel et al, 2008 [31] | To test if Framingham CHD score is higher in caregivers who care for dementia | Case control quantitative study (n = 64) caregiver spouses who cared for dementia and 41 non-caregivers. Subjects did not have any history of CHD | CHD risk score was higher in caregiving group than non-caregiver. Most significant being the higher blood pressure in caregiving population. Probability of a randomly selected caregiver having higher CHD risk than a non-caregiver was 65.5% | High |
| Haley et al, 2010 [60] | To study the association between carer strain and stroke and CHD | Participants of REGARDS study where scored for Framingham Stroke Risk (n = 716) and Framingham CHD risk score (n = 607) | High care giving strain was associated with 23% higher risk for stroke. However, no associations were made between carer strain and CHD scores | Low |

se to be at a higher risk of developing CVD. This is possibly because of increased emotional investment and responsibility the spouse feels - unlike carers who care for children or parents who are likely to share responsibility and the burden [29, 30] (Table 5).

The risk of early mortality was low in all the 5 studies in the review especially for mid-le-

vel strained carers [11, 18, 19, 33, 34]. Mid to moderate level of strain among carers is associated with survival benefits; moreover, it is seen to be associated with increased self-efficacy and resilience [11, 19]. Only one study found highly burdened carers to be at risk for early mortality for the first 3 years but not after that. This study also found carers with

Table 6. Mortality among carers.

| Author/date | Aim of study | Type of study | Main findings | Risk |
|---------------------------|--|---|--|---|
| Brown et al, 2009 [33] | To explore if care giving behaviour is associated with decreased risk of mortality among married couples | Quantitative survey (n = 3376), participants were couples who both were able to take part in survey. Age 70 or older at baseline. Survival time calculated for 7 years | Participants who provided at least 14 hours of care per week for a spouse had decreased mortality rates than those who did not provide care. However, those whose spouse were in poorer health had higher mortality than those whose was healthy. | Low |
| O'Reilly et al, 2015 [34] | To determine the relationship b/w care giving and mortality risk | Quantitative Study. Census 2011 - 2013 Aged 25 and over. Time period = 33 months. Total participants = 1,122,779, carers among them = 183,842 carers who cared 50 hours or more= 51,927 | Total number of deaths = 29,335, deaths among carers = 2,443, Mortality risk for carers were much lower than non-cares HR= 0.72 with 95%CI. Higher caring hours was associated with lower mortality risk. Even carers who had poor health had decreased mortality. Decreased risk of mortality for most causes. | Low |
| Perkins et al, 2012 [19] | To study care giving strain to all-cause mortality | REGARDS population-based quantitative study. Age 45 years and older. Study population (n = 3,710). Time period 5 years | Carers who reported high care giving strain had higher all-cause mortality risk when compared to no strain and some. However, carers with some strain predicted longer longevity. Mid-levels of stress possibly associated with increased self-efficacy and resilience. | Low for mid-level strained carers but high risk for highly strained |
| Fredman et al, 2010 [35] | To study the impact of stress and care giving status on mortality in elderly women. | Case control study. Time period = 8 years. Aged 65 or over. Care giver sample 375 and non-caregivers 694 | Lower mortality rates were found in carers. Higher mortality risk in carers who had higher stress for the first 3 years but not later. High stressed caregivers and non-caregivers were found to have higher mortality risk. Low stress caregivers were found to have decreased mortality rates than non-caregivers. | Low |
| Roth et al, 2013 [11] | To determine if care giving is associated with greater mortality risk | Study population from REGARDS quantitative study. Case control. (n = 3,503) individually matched. Age 45 and over (6-year follow-up period) | Carers had a significantly lower mortality rate. 7.5 % carers died and 9.0% non-caregivers died during the 6 period follow up. Proportional hazards ratio model indicates 18% reduction in mortality rates for caregivers. Care giving was associated with survival benefits. | Low |

lower stress to have decreased mortality than non carers [35] (Table 6).

Positive aspects of caregiving

Positive aspects of caregiving were mostly self-reported and associated with the carer and the care recipient interactions as well as interactions with the social circle including healthcare professionals and family members [36–38]. Carers who had a good relationship with the care receipt and those that took initiative to provide care found caring more satisfactory [36, 38]. Carers who were able to

interact meaningfully with their healthcare professionals by sharing/receiving information and those that had support systems like family and social groups found caregiving positive [39]. Self-esteem of the carers was also seen to be an important contributor to satisfaction, even those that were highly burdened found caring satisfactory if they had high self-esteem [40] (Table 7).

DISCUSSION

This review has highlighted some key health impacts of being an informal carer. We have

Table 7. Well-being and positive aspects among carers.

| Author/date | Aim of study | Type of study | Main findings | Satisfaction |
|------------------------------------|--|---|--|--------------|
| Lopez et al, 2005 [36] | Determine the predictors of positive aspects of care giving | Cross-sectional quantitative study on 111 carers of elderly. Mode of data collection – Questionnaire and semi structured interview. Caregiving Satisfaction Scale | Some predictors of positive impacts were associated with the carer taking the initiative to provide care, having recreational time, working from home and previous positive caring experience. Caregivers experienced high levels of caregiving satisfaction (mean = 22.38; SD = 5.39) | High |
| Chen et al, 2004 [37] | To determine the influence of social support on carer gains/Positive experiences | Cross-sectional quantitative study. Interview done on 560 carers of schizophrenia | Support from health care professionals and social groups like friends and family had a positive impact on the carer mental well-being and carer gains. Information sharing and interactions with the health care professional especially mental health seen to promote positive experiences. Over 50% reported caring responsibilities helped them gain clarity for priorities in life and greater inner strength. 36.8 % reported increased self-confidence | Moderate |
| Sanchez-Izquierdo et al, 2015 [38] | To determine the positive aspects of family caregiving of elderly | Quantitative study of 140 caregivers who cared for elderly Questionnaire or interview | Caregiver satisfaction and quality of life above average. Level of dependence was associated with problems in quality of life however increased dependency showed greater level of satisfaction. Good relation with the care recipient was associated with more satisfaction. Caregivers satisfaction in our study was above average (mean = 25.01, SD = 7.02) with high quality of life | High |
| Kruihof et al, 2012 [40] | Study positive caregiver experiences | Cross-sectional quantitative study of 121 carers. Mode of data collection – Questionnaire | High self-esteem and high burden were associated with higher life satisfaction than for those who perceived high burden and low self-esteem. Approximately 49% were satisfied with life as a whole, 72.9% satisfied with family life | Moderate |

identified two key areas of high risk: - i) Musculoskeletal disorders and ii) Psychological issues (stress, anxiety and depression). With respect to these key areas we also evaluated the best support and control mechanisms in place to minimize these impacts in the UK. Although there is a lack of evaluation of quality of interventions to support carers, we have pooled them and critically evaluated a few relevant existing interventions strategies.

Musculoskeletal disorders (MSDs) among carers

Many studies conducted on formal healthcare providers like nurses have established the high prevalence of MSD in professional settings, however fewer studies have been done

on informal caregivers [44]. Among carers, musculoskeletal injuries can occur as a result of physical exertion such as lifting patients and other strenuous physical tasks. Over time these can cause strain in muscles, injuries to joints and skeletal systems, low back pain, joint pain arthritis, chronic pain and discomfort [44, 62].

The studies included in this review showed that two patient characteristics may have the most significant impact on the carers developing MSDs: a) Functioning capability of the care-recipient, and b) cooperativeness of the care recipient.

Decreased functional capability and higher physical dependency of the care recipient was associated with musculoskeletal disorders in

Table 8. Quality evaluation of studies included ($n = 38$).

| Author | Is the study design apt for objective? | Is the study sample representative of the carer population? | Is the control group acceptable? | Quality of data collection and outcomes? | Reliability (Has bias, confounding and chance been accounted for?) |
|--------------------------------------|--|---|----------------------------------|--|--|
| Forbes et al, 2007 [41] | S | PS | NA | S | S |
| Geere et al, 2011 [42] | S | PS | NA | S | S |
| Shiue, 2015 [43] | S | S | S | S | PS |
| Carers Week 2012 [14] | S | S | NA | PS | NA |
| Sharan et al, 2012 [44] | S | PS | S | S | PS |
| Darragh et al, 2013 [45] | S | S | NA | PS | S |
| Alshammari et al, 2017 [46] | S | S | NA | S | PS |
| Liu et al, 2017 [47] | S | S | S | S | PS |
| Jacome et al, 2014 [48] | PS | PS | NA | S | S |
| Weaving et al, 2014 [49] | PS | PS | NA | S | PS |
| Perz et al, 2011 [50] | PS | PS | S | S | PS |
| Carers UK, 2017 [1] | S | S | NA | S | PS |
| Drutyte et al, 2014 [51] | S | PS | NA | PS | S |
| Greenwood and Mackenzie 2010 [52] | S | S | NA | PS | PS |
| Loi et al, 2009 [53] | S | S | S | S | PS |
| Chang et al, 2010 [39] | S | S | NA | S | PS |
| Resch et al, 2012 [61] | S | S | NA | S | S |
| Valimaki et al, 2009 [55] | S | S | NA | S | PS |
| Aggar et al, 2011 [56] | PS | S | NA | S | PS |
| Rosness et al, 2011 [57] | S | S | NA | PS | S |
| Jorgensen et al, 2009 [58] | S | S | NA | S | PS |
| Cameron et al, 2016 [59] | S | S | NA | S | S |
| Mausbach et al, 2007 [27] | S | PS | NA | PS | S |
| Aggarwal et al, 2008 [28] | S | PS | NA | S | S |
| Horwitz et al, 2009 [32] | S | PS | S | PS | PS |
| Lee et al, 2003 [29] | S | S | S | S | PS |
| Capistrant et al, 2012 [30] | S | PS | NA | S | S |
| Von Kanel et al, 2008 [31] | S | S | S | S | PS |
| Haley et al, 2009 [60] | S | S | NA | S | PS |
| Brown et al, 2009 [33] | S | S | PS | S | S |
| O'Reilly et al, 2015 [34] | PS | S | S | S | S |
| Perkins et al, 2012 [19] | PS | S | NA | S | S |
| Fredman et al, 2010 [35] | S | S | S | S | PS |
| Roth et al, 2013 [11] | S | S | S | S | S |
| Lopez et al, 2005 [36] | S | PS | NA | S | S |
| Chen et al, 2004 [37] | PS | S | NA | S | PS |
| Sa ´nchez-Izquierdo et al, 2015 [38] | S | S | NA | S | PS |
| Kruihof et al, 2012 [40] | S | PS | NA | S | PS |

S – Satisfactory; PS – Partially Satisfactory; UN – Unsatisfactory; NA- Not Applicable

the carers, most common being lower back pain. Carers who care for physically disabled patients or patients with lower mobility reported increased caregiving activities like lifting or moving that would require high physical strength. The availability of support equipment like grab rails and hoist have been shown to reduce the physical exertion required by carers and increase the patient's independence [14, 41, 45].

Cooperation of the patient was linked to reduced risk of MSD among carers. This view was expressed in only one study that was done among caregivers of children with cerebral palsy. Even though younger care recipients weigh less, repetitive bending and lifting among carers are suggested to cause compression in the low back area that worsens over time; this repetitive action is also linked to contraction of the neck muscles that damage soft tissue muscles like nerves and blood vessels. Some MSDs the paper links to the cooperativeness of the patient are: Myofascial Pain Syndrome, Fibromyalgia syndrome, and Thoracic Outlet Syndrome [44]. This carer characteristic was not explored in any study among caregivers of the adult population, however, we can suppose that patient cooperativeness among the adult population is also linked to MSDs for highly dependent care recipients.

Therefore, our findings show that provision of partial aid around the house could help reduce injuries like low back pain among carers. Equipment like grab rails, walking stick, wheelchairs stair lift and hoist can reduce the physical exertion of carer and would make the patient more independent. In addition, training in safe transferring, manual handling and supporting equipment that will help lift and carry patients like mechanical stairs and hoist are control measures that will reduce MSDs among carers [14, 42].

Evaluation of key factors to minimise MSD

Occupational therapy (OT) services

Occupational therapy services for the care recipient can be seen as a support mechanism that can elevate the physical burden of caring.

Most patients who get referred to OT services faced delays in assessments and receiving adequate support equipment. Equipment as grab rails, ramps and stairs are often categorized as less urgent which causes a delay in OT assessments. This can also cause accidents and hospitalization that are preventable. Lengthy weighting time and lack of funding are added causes for concern [63, 64]. There is limited data to draw upon for allied health professional recruitment, retention and turnover in the UK much less for occupational therapists, however from limited data, there is evidence of shortage for occupational therapists. One recent report found that in the capital, London there is a crisis in occupational therapist recruitment. Occupational therapy vacancy rates (by service) ranged from 11.5% in children's only services to 20.2% in adults only services. Vacancy rates by specialty showed above 20% for services like elderly care, accident and emergency, end of life care and medical and surgery [65]. Shortage of occupational therapists and in general, physicians may cause overwork and more MSDs rates [66]. Anecdotal evidence suggests that delays in OT assessments and lack of availability of healthcare equipment at the proper time increases the risk of carers developing MSDs and for carers who are older and already have a pre-existing condition. However, there seems to be a lack of research and evaluation that can support this view [64]. The shortage of occupational therapists, coupled with the lack of funding makes it very difficult for carers to find support. In other words, informal carers are finding it difficult to get timely advice on safe healthcare practices and are having to face long waiting times to get even simple healthcare equipment. This is bound to affect and in a lot of cases exacerbate the impact on the physical well-being of those who care. Delay in the provision of equipment is not only a health risk but it can be draining on finances as some of them would have to buy equipment for themselves. It is also a cause for added stress-strain when carers are in difficult financial situations [3, 63, 67].

There is also some evidence to also suggest

the lack of training among carers on manual handling, safe moving and equipment use can have a physical impact on carer's health. Currently, the local authorities are meant to provide training courses for carers or they are to provide financial support that will enable carers to take those courses but unfortunately most often this is not the case [64]. Although information is sparse there are reported accounts of carers being unable to use the hoist and other equipment when available, as they do not feel competent or trained enough to use them, some carers are also uncertain how to access training. All these lead to the carer manually handling the patients incorrectly increasing the risk of MSDs [68]. Due to the long waiting times, high referral rates, lack of resources and OT personal the effectiveness of support measures that will help carers are struggling to cope with demand and retention. Improvements to the system that will hasten provision of equipment and assessment are to be considered with at most importance [65, 67].

The carer's assessment

A carer's assessment is for adult carers over the of age 18. During a carer's assessment the local council and the carer identify support and services that a carer might need. The assessment will delve into how caring affect the carer physically and mentally and if the carer is able to continue/willing to provide care [69]. It is an important support tool, as much of the help and support that carers receive is materialized after a carer's assessment. An assessment can lead to: i) financial, emotional and practical support; ii) information and advice; and iii) provision of equipment. After an assessment, the support worker draws out a care or support plan with the carer to ensure they are well supported [70]. Many carers do not have these assessments and are consequently not well supported. In a survey conducted by Macmillan in 2011 in the UK (on 386 cancer carers) 44% of carers were unaware of carers assessment and have never heard of it before. 33% of them have heard of it before and only 5% have actually had an assessment [71]. Some carers are hesitant to have carers

assessment as they don't see themselves as carers and yet others might be unwilling to ask for help [70]. The inability of these services to reach carers and fewer carers having the assessments done, question the effectiveness of reach of carers assessments as a support tool. Some speculated reasons for delay and ineffectiveness of the assessments are the scarcity of social care service workers available, uncertainty among some healthcare workers regarding procedural and policies and lack of coordination between caseworkers and resource allocations. There is an urgent need for improvement and increased resources like personnel and funding to improve efficiency [72, 73].

A large barrier to carers not utilizing carers assessment is the notion that there won't be any outcomes. Approaches whereby the carer can foresee possible positive outcomes would encourage more carers to take part in carers assessments. Lack of communication and coordination before and after the assessment was also seen to be a barrier in effectively carrying out the process [3].

Carers assessments are also seen as a very rigid process lacking flexibility. The process fails to consider the complexities of carer needs. There are also concerns that not enough information is gathered during these assessments to develop a tailored care plan [73]. Carers have previously reported the assessments to lack sensitivity and flexibility to meet their specific needs. Support services need to be mindful of the ever-changing role of carers in their different stages of caring, the system must be flexible to accommodate and respond accordingly [74]. Room for flexibility and consideration of broad aspects of the carers life in assessments could ensure a more positive outcome.

Policy context

Much more recent legislative responses like the Care Act 2014, which partly came to effect in April 2015, in England have made efforts to make it easier for carers easier to have an assessment. Previously only carers who provided continuous care could have an assessment. The new act allows the assessments to consider the needs of the whole family and

not just the primary carer. This includes younger carers as well. Under the Act local authorities are expected: i) to ensure that carers with a need for information and advice about care and support are able to access it; ii) to take responsibilities for carers need by assessing 'appearance of need'; and iii) to enable carers to undergo eligibility assessments, access to information, respite care and employment and financial assistance. The Act recognizes and highlights the importance of ensuring carers themselves do not develop needs of their own, which is a positive forward step. However, translation of an act into action requires resource allocation, strengthening of support systems and structures. Besides initial assessment reports, there have been no evaluatory reports on increased resource allocation or the impact the act has had on carers [61].

Similarly, the government's mandate to NHS England for 2016- 2017 gives little to no consideration to the well-being of carers. A consultation response from Carers UK in November 2015 voiced concerns over the same highlighting the fact that under the Care Act 2014 the NHS is an important partner in improving the outcome for carers, however not considering carers with high importance can have serious negative health implications on the carer's health [9].

On a similar note, considerable focus and attention is currently being given to the health policy MECC (Making every contact count) where healthcare professionals aim to encourage the population to make better and healthier lifestyle changes [75]. The likelihood that carers are in contact with healthcare professional because of the person they care for is high. This could be an opportunity for healthcare providers to enquire about the carers health and well-being in addition to the person they care for. The health care provider could encourage carers to eat healthy and exercise more and if carers are seen to be struggling and signpost them to support services they need. Having said that, time and resources could be a barrier for this. There is no evidence in policy documents of MECC that support this view that carers can be hel-

ped through MECC or if carers are being considered. The inclusion of carers and their issues in relevant policy documents could ensure that struggling carers do not fall through the net.

Psychological distress among carers

Stress and anxiety

The psychological impacts of being a carer have been well studied and documented for over 3 decades. Alarming high rates of stress and anxiety are observed among carers. In a survey conducted among 7,000 carers, 78% of carers reported high stress and 72% reported to feeling more anxious after taking roles as carers [1]. These disturbingly high levels of stress and anxiety could be due to lack of time, poor finances, challenging behavior from the patient, higher care needs, lack of information on how to provide care, decreased social support and lack of respite care [76].

The present analysis revealed 3 influencing factors that impact stress and anxiety among carers: a) personality traits and perceived burden; b) gendered roles; and c) higher care needs.

Trait EI (Emotional Intelligence) is a personality trait by which humans perceive their emotions. People who have High Trait EI are known to handle difficult situations well and have greater self-efficacy. Trait EI has been linked as a predictive factor of anxiety and stress among carers. Similar to, Trait EI is perceived burden (how difficult the carer perceives the caring situation to be) has also been linked to carer anxiety [48, 49]. Interventions that aim to minimize stress and anxiety levels in carers would benefit from considering the individual's personality. For instance, when providing advice and counseling, an understanding of how stressful a carer perceives a situation to be can help provide or direct the course of treatment.

The analysis also showed the gendered role of women to be linked to higher levels of anxiety in female carers. In society, caring is mainly established as a woman's role, leading women

to take up caring roles compulsively and sometimes hesitantly in order to nurture and please everyone. While men when positioned as carers viewed it stoical leading to more satisfaction. Women also feel pressured to hold high standards of care unlike men [50].

Finally, higher care needs and increased co-morbidities of the care recipient was associated with higher level of stress among carers. Carers who care for certain diseases such as Parkinson's or severe dementia have patients with higher care needs who are highly dependent on the caregiver. These groups of carers were highly vulnerable and had higher burden [48, 51].

Carers are more likely to suffer from anxiety than depression. However, anxiety is less frequently diagnosed in carers. One reason is the overlap and strong relation between the two illnesses. Anxiety causes excessive panic, fear and worry whereas depression is lower positive interests. Anxiety is also seen to resolve on its own. Moreover, prolonged stress not only deteriorates mental health but can manifest as physical illnesses as well [52]. Stress and anxiety can have an impact on the caregiver's social life including employment and work place relationships. According to literature, psychosocial risks associated with mental health disorders such as anxiety, depression and burnout include shift work and work-life imbalance, violence and threat of violence, emotional demands, and shortage of occupational therapists may aggravate heavy workload and time pressure leading to higher levels of work-related strain [66]. Identification of carers who are most vulnerable (e.g., highly burdened women) to mental distress is key. Interventions like self-help groups, support groups and classes on relaxation techniques and coping mechanisms have been successful in the past [77].

Depression

The present analysis of the studies revealed five influencing factors that predict depression in carers: a) care recipients with high care needs (increased caregiving hours and nature of illness cared for); b) being a female and

being younger or older in age; c) poor respite; d) lack of information available; and e) poor finances.

Carers who have care recipients with high care needs that require longer hours are more likely to be affected by depression, particularly carers who care for long-term illness such as dementia [10, 62].

Being a female and being younger or older in age was also associated with higher depression levels [55, 59]. These findings could be key in the light of identifying the most vulnerable carers. Carers who had less social support and those who felt no personal growth and a loss of control in life were also highly likely to be depressed [59].

Provision of respite care (e.g., domiciliary nursing care) has been known to reduce depression in carers. Short breaks from caring can help carers pay attention to their own physical health as well as recuperate mentally [57]. Many carers miss hospital appointments and ignore their own health due to lack of time. Having some time to themselves can help them have a life of their own. Some examples of respite care are having the care recipient stay at residential care temporarily or the carer having a short break/ holiday [1]. Advice and information in a timely manner is an important factor that can reduce strain among carers. Information needed can depend on the type of illness cared for and the severity of the illness. For instance, someone caring for a newly diagnosed illness would need support accessing information regarding the side-effects and advantages of the treatment, likely physical needs of the recipient, financial support and welfare benefits they might be entitled to, how it could affect their working life and what support services can be accessed. But someone caring for terminally ill patients might need more information about what to expect in future, the severity of the illness, how to manage symptoms and whom to contact in emergency situations [58].

Being a carer can put the carer in immense financial pressure as the carer would have to incur with the increased costs related to caring. Having to compromise on matters relating to

employment as a result of caring have a direct effect on their finance and can cause depression [16, 58]. In a recent survey, 39% of carers reported that they struggle with finances and find it difficult to pay bills or make ends meet and 43% of carers had to give up work due to increased stress and inability to juggle both work and caring [1].

Prolonged stress, pressure to meet demands and juggle many responsibilities can cause carer burnout wherein the carer suffers from physical, emotional and mental exhaustion. This may cause changes in attitude where the carer feels unattached and unconcerned. This happens mostly when carers do much more than they are able to. Burned out caregivers may experience other psychological disorders such as stress, anxiety, and depression [79]. Most research done on burnout is in the formal healthcare settings where burnout is caused by stressors of the occupation that coupled with shortage of physicians in the healthcare setting accelerates burnout amongst healthcare professionals [66, 80]. The impact of burnout is much more for healthcare professionals who provide informal care along with their normal job in the healthcare industry [81]. One very recent study conducted amongst informal carers in Spain associated burnout to increased caring hours, patient's health status, severity of disease and degree of dependence of the patient [82]. Burnout is often not official diagnosed and as a result there are limited access for carers to get treatment and opportunity to recover [80, 83]. Although constructs are distinct psychological disorders especially depression is closely associated with burnout. It is vital that carers with burnout are identified in a timely manner and are provided with diagnosis and treatment.

Evaluation of key factors to minimize psychological distress

Carer's allowance

Many carers who take care of people with high care needs are forced to stop working, this causes financial constraints on the family.

Carers Allowance (CA) is a support mechanism that aims to aid carers with financial assistance and subsequently reduce the stress and anxiety levels of carers who are struggling to make ends meet. There is an eligibility criterion on who can claim CA. One of them being the person cared for should be in receipt of disability benefit, PIP (Personal Independence Payment - an allowance for people who are disabled or have long-term illness). The 2016 budget has made changes to who can claim PIP by making the criteria stringent. A lot of people who receive PIP will be affected by either it being reduced or ceased. This will have a knock-on effect on carers as when some care recipients lose PIP, the CA will also stop. These changes made to Budget 2016 could have serious implications for carers as some of them will be worse off financially than before. This could have a negative impact on the carer's health, as stress and anxiety levels can increase due to financial hardship. On the other hand, the 2016 budget announced that carers are exempt benefit cap, which will be beneficial to a lot of struggling carers. In the 2017 budget as well there were no changes made and CA remains one of the lowest welfare benefits [86, 87].

Respite care

As mentioned above, a few days of respite care can have immense benefits for the carer. Currently in the UK carers who access respite care will have a carers assessment to assess if they need a break from caring. However, many carers have voiced their concerns over the quality of respite services. Lack of trust over the care provided or being unsatisfied with previous respite services has caused unwillingness among carers to use respite services [1]. Despite this, some other studies have shown that majority of carers are willing to use and are generally satisfied with respite care, which has also shown to reduce depression and stress levels while allowing them to recuperate physically as well [88]. Many voluntary organizations in the UK such as Macmillan and Family fund provide small grants for carers and their care recipient to

go on convalescent breaks. Most people referred to voluntary organizations find them very helpful for practical and emotional support, often hospitals refer patients to organizations like these. Therefore, it is necessary to coordinate activity between healthcare professionals and charity organizations. It was difficult to establish to what extent and how many carers are being helped to get respite care through the voluntary sector, as there were no formal evaluations or reports. Overall, although not all carers are satisfied with respite services in the UK, the majority of carers find respites services useful and to reduce psychological distress. There is a need for further exploration to fully understand the effectiveness of respite care in the UK and how best to utilize this service to reduce carer burden.

Online Information sources

This analysis also indicates that availability and accessibility to information and advice in a timely manner can minimize psychological health impacts such as stress and anxiety. In the last few years, the rapid growth of technology meant there is a lot of support available for carers online. Many websites like Carers UK, Carers Trust, Carers week and NHS have so much information (on how to care and what kind of support is available) that is easily accessible for carers. There are also carers forums on these websites where carers who go through similar experiences support each other. Many of these groups also have support groups and café meetups where they provide each other with support. That said, there are older carers, who do not use technology or do not have access to them. However, support lines run by these organizations can also be used as an effective alternative. The platform provides opportunities for carers to organize appointments, get help with symptom management as well as peer support from other carers who had similar experiences. Many carers share positive experiences of using online resources including reduction of distress [89]. There has been considerable evidence from studies conducted that show computer mediated interventions such as self-help pro-

grams and cognitive behavioral therapy can increase self-efficacy and reduce mental stress among carers. The effectiveness of these interventions is potentially high to minimize mental stress as they require less resource and can be accessed very easily anywhere anytime [90]. Again, it was difficult to establish the reach and extent of how many carers benefit from these services. There is a need to evaluate and explore the impact of technological advances as a support mechanism for carers, as this holds promising potential and can inform future help strategies.

CVDs and early mortality risk among carers

Most CVDs are preventable through modified lifestyle behaviors such as physical exercise, good diet and weight management [28]. The studies identified in this review suggest that carers are at a moderate risk of developing CVDs. Although the risk is on the lower side, this review points to important risk factors that are predictors of CVD among carers. Many carers display suboptimal health behaviors such as lack of exercise, poor nutrition and smoking which lead to high blood pressure and obesity and put carers at risk for developing CVDs [28, 31, 32]. It is vital that support systems encourage carers to lead a healthy life. It is also important that primary care clinicians monitor and advice carers on healthy lifestyle choices [31]. Psychological disorders such as stress and depression were also found to increase risk of developing CVDs among carers [27, 28]. Depression and stress in carers can cause molecular and vascular alterations (such as exacerbate catecholamine response and D-dimer reactivity) which can lead to risk of CVD. In this context, it is key that mental health issues in carers are treated in a timely manner so that it does not manifest into physical issues such as CVDs [27].

The risk of early mortality among carers is low especially if carers have only some or mild-levels of strain although comparatively highly strained carers are still at risk of mortality. When caregivers provide care willingly at a manageable level where they experience only

mid-level strain it is associated with self-efficacy, resilience and survival gains [11, 19, 34]. Altruism within families is suggested to have an evolutionary impact whereby it could improve physical health [11]. Moreover, caregiving tasks could help carers be more physically active which might be leading to lower mortality. Lower strain caregivers are also less likely to be caring for a spouse where there is higher responsibility and emotional involvement [33, 35]. These studies indicate the importance of keeping stress levels in carers low. Interventions such as mindfulness-based stress reduction programs and teaching carers approaches for adaptation and coping strategies can help improve the overall well-being among carers [35].

Positive aspects of caregiving

High-moderate satisfaction was reported by carers in the studies. Satisfaction with caregiving is influenced by many determinants such as the willingness of the carer to provide care, good relationship with the carer, good support from the social networks such as the friends, family and workplace as well as high self-esteem. A vast majority (4.1 million) of the carers belong to the working age group, highly burdened carers most often have to compromise on matters relating to employment – due to constraints like time and poor support [78]. Our studies in this review also represent the premise to develop workplace health promotion activities based on the concept of the ‘work engagement’. One study in our review reported higher level of satisfaction among carers who worked from home indicative of lesser juggle and burden among carer [36]. However, majority of carer have commitments of full-time employment and being able to stay in employment is suggested to be very beneficial for a carer - as it can reduce the burden of care by reducing poverty, social isolation and the facilitating the ability to maintain supportive relations outside caring [78]. Many carers aim to find a balance between their caring and work responsibilities. However, carers face barriers to achieving this balance such as lack of support

from the work place, affordable and adequate replacement care, and lack of local support network and system like hospitals and access to information [84, 85]. Work engagement (“positive motivational state of fulfillment that is characterized by the three components: vigor, dedication, and absorption”) that put carers at an optimistic state of mind is essential in reducing carer burden and burnout [83]. Supportive organizations that are caregiver friendly can promote work engagement. These organizations could enable carers to have flexible working schedule, control over the working hours and raise awareness and understanding supervisors and colleagues. Moreover, policies and guidelines that can promote work engagement among carers also need to be considered in organizations in the UK [91].

Limitations and strengths of the study

To our knowledge, this is the only study that has employed this methodology to provide a condensed snapshot of the health impacts of caregiving and the first study that has evaluated support systems for carers in the UK. This study also brings together the results of many studies to provide an overview of the health impacts and has recognized key ways to minimize them. However, we recognize that most of the studies done on informal carers are cross-sectional studies. There is a dearth of studies that explore health impacts in case-control settings, hence it would be difficult to make a solid conclusion that caregiving causes the health impacts identified by our review. Probably, the scientific community is either underestimating or overestimating the impacts of caregiving. Moreover, as there was a dearth in studies that explored the physical impacts of caregiving, we had to include some lower quality studies done among smaller sample sizes and some that have not accounted for bias and confounding. There is a need for more studies with rigorous methodology that can establish the true impact of caregiving. The present study only used online sources to find research papers there could have been papers with interesting findings that

were not included in the study due to limited accessibility and unknown sources. The findings of this review also point to the dearth and need for research on the physical health impacts of caring but most importantly the need for evaluation of support mechanisms for carers.

CONCLUSION

Carers are being acknowledged much more than ever before however, support services such as carers assessments, occupational therapy for the recipient, respite care and financial assistance all need improvements to accommodate the ever-changing role of carers on different stages of caring. The findings of this review also indicate the need for policy, research and practice to consider both physical and mental impact of caring and have a holistic approach while attempting to reduce the negative health impacts of caregiving. With the contributions made by carers annually to the healthcare system, it is only fair that the carers are well supported in communities so as to minimize any negative impacts of caregiving.

Recommendations for policymakers and future research

The healthcare system in the UK would be under immense strain if informal carers were not to provide care. There is a pressing need

to increase support for this hidden healthcare force, so that they do not reach breaking point. The evaluation of health impacts and support mechanisms in this review has uncovered some novel findings that require high-priority action. There is so much uncertainty over the impact of many carer interventions strategies in the UK. As discussed above, the impact of: i) delays in OT services and equipment provided for the care-recipient; ii) online resources; iii) voluntary sector help; and iv) manual handling training for the carers are practically unknown. All these services have immense potential to reduce carer burden. What is needed now is a detailed evaluation of these services, so as to explore how best can these be utilized to support carers. These evaluations could also bring to light other support mechanisms that can impact carers.

Although carers are being acknowledged in some policy documents, this has not translated into resource and fund allocation. There is now a need to not only recognize carer needs but also allocate resources and funds to ensure their overall well-being. Furthermore, an important area of research to be considered with priority is the physical impact of caring, these are not yet fully explored and there are gaps that need to be filled in. Moreover, there is also a need to fund case-control studies that will truly establish the hypothesized impact in both carer and non-carer populations.

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