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Review of the international evidence on support for unpaid carers

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Abstract

Globally and locally, ongoing demographic, socio-cultural and economic changes have implications for unpaid carers. For those who provide unpaid care, particularly at higher intensities, there is substantial evidence of negative effects on employment, health and wellbeing, with associated individual and societal costs. For these reasons, there is increasing policy emphasis on supporting unpaid care in the UK, mirrored, and in some cases exceeded, internationally. This paper aims to provide an overview of the international evidence on effective support for unpaid carers. This evidence synthesis finds an extensive literature on a wide range of potentially effective interventions to support unpaid carers under the broad categories of indirect support (services for the care-recipient), direct support (such as psychological therapies), work conditions, and combinations of these. However, there are significant gaps in the evidence base with regards to interventions, outcomes and types of caring situation studied, with a dearth of evidence on cost-effectiveness and few evaluations of key recent policy initiatives.

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Evidence is strongest and most consistent for formal care services for people with care needs (so-called 'replacement' or 'substitution' care); flexible working conditions; psychological therapy, training and education interventions; and support groups. In many cases it may be that a combination of interventions is most effective. These findings have implications for social care policy and practice which aims to support carers, particularly in the context of the changing landscape of global macro-level processes and recent policy, legislative and funding changes for local authority and voluntary sector providers of support and services for carers in the UK.

Keywords: unpaid care, support for unpaid carers, social care services, work conditions, cash benefits, review.

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Introduction

Globally and locally, ongoing demographic, socio-cultural and economic changes have implications for unpaid carers. Global ageing of the population and more years lived with disability mean that the number of people in need of long-term care (LTC) is increasing substantially (ONS, 2014; Burchardt et al., 2016; Pickard, 2015; Scheil-Adlung, 2015). In England, this is taking place in a context of a history of underfunding of social care exacerbated by substantial cuts to adult social care budgets since 2009/10, with an accompanying reduction in the numbers of adults receiving publicly funded care services (Fernandez et al., 2013; HSCIC, 2015; ADASS, 2016; Burchardt et al., 2016; Glendinning, 2016).

At the same time, other socio-demographic and cultural changes are impacting on the availability of unpaid care. Most prominent in policy terms is the continuing rise of female labour force participation (Colombo et al., 2011; Pickard, 2015), and drives towards increasing this participation (DWP, 2014a; European Commission, 2015) and towards increases in state pension age. Reconciliation of unpaid care and employment is thus an increasingly important societal, economic and equality issue, both in the UK and internationally (Fine, 2012; Eurofound, 2015). So too is the projected 'care gap' between demand for unpaid care and supply of unpaid care, which is expected to increase rapidly over the coming decade and beyond (Pickard, 2015).

For those who provide unpaid care, there is substantial evidence of poor outcomes, particularly for those providing long hours of care. Unpaid carers are less likely to be in paid employment (e.g. Carmichael et al., 2010; Lilly et al., 2010; Colombo et al., 2011; Van Houtven et al., 2013; Department of Health, 2014; Department of Work and Pensions, 2014; Nguyen & Connelly, 2014; Bauer & Sousa-Poza, 2015; Nazroo, 2015; Pickard et al., 2015; Scheil-Adlung, 2015; Aldridge & Hughes, 2016; Glendinning, 2016), in some cases through early retirement (Jacobs et al., 2014). There are difficulties with re-entering employment after caring finishes (Spiess & Schneider, 2003; Carmichael et al., 2008; Glendinning et al., 2009; Michaud et al., 2010; Van Houtven et al., 2013). The longer that a carer is out of paid work, the harder it is for them to return to it (Hirst, 2005; Buckner & Yeandle, 2011). Intensity of care hours is a significant factor in whether carers remain or are in employment (e.g. Carmichael & Charles, 2003; Heitmueller, 2007; Lilly et al., 2007; Glendinning & Bell, 2008; Carmichael, 2011; King & Pickard, 2013; Jacobs et al., 2014; Bauer & Sousa-Poza, 2015). Numerous UK government, European Union (EU) and Organisation for Economic Co-operation and Development (OECD) reports come to the same conclusion (e.g. Colombo et al., 2011; Rodriguez, 2013; DWP, 2014a; Hoff, 2015; Nazroo, 2015; Bouget et al., 2016; Glendinning, 2016).

Carers are more likely to work reduced hours than non-carers (Lilly et al., 2007; Bolin et al., 2008a, 2008b; Leigh,

2010; Kotsadam, 2011; Meng, 2012; Van Houtven et al., 2013), although it is still the case that carers, particularly those caring for ten or more hours a week, are more likely to leave employment than to reduce their hours (Colombo et al., 2011; Age UK and Carers UK, 2016). Reducing working hours is also related to intensity of caring (Casado-Marín et al., 2011; Heitmueller, 2007; Glendinning et al., 2009; Age UK and Carers UK, 2016). Provision of care has other effects on work including disruption, missing hours or days of work and sickness absence (Colombo et al., 2011; Schneider et al., 2011; Carers UK, Her Majesty's Government & Employers for Carers, 2013; Ugreninov, 2013; Department of Health, 2014; Bauer & Sousa-Poza, 2015; Nazroo, 2015).

Although some research finds a positive effect of caring on health and wellbeing (e.g. Evandrou & Glaser, 2003; Young & Grundy, 2008), especially when it is done voluntarily, is of short duration, and can be carried out alongside other productive roles (Hinterlong, 2006), there is substantial research that shows that provision of unpaid care is associated with poorer mental and physical health and quality of life, particularly at higher intensities of caring. There is also evidence that psychological and physical health consequences continue once caring has ended (e.g. Larkin, 2009).

Several meta-analyses find associations between caring and psychological ill-health, mainly depression, anxiety and poorer wellbeing, including stress and burden (e.g. Pinguart & Sörensen, 2003, 2006; Savage & Bailey, 2004; Cooper et al., 2007). Similar findings are reported in other academic papers (e.g. Lamura et al., 2008; Coe & Van Houtven, 2009), OECD reports (Colombo et al., 2011) and carers' surveys (e.g. Carers UK, 2016). There is much less research on the impact of caring on physical health, but the evidence that is available shows that caring is associated with poorer physical health. Meta-analyses and reviews show that carers have worse physical health than non-carers (e.g. Vitaliano et al., 2003; Pinguart & Sörensen, 2007; Legg et al., 2013; Social Protection Committee, 2014).

Intensity of caring, and relatedly co-residence, are significantly associated with poorer health (e.g. Lamura et al., 2008; Schultz & Sherwood, 2008; Coe & Van Houtven, 2009; Glendinning et al., 2009; Mentzakis et al., 2009; Colombo et al., 2011; Legg et al., 2013; ONS, 2013; Rodriguez et al., 2013). Furthermore, Coe & Van Houtven (2009) found that duration of care provision has a significant effect specifically on the physical health of the carer.

There are costs to the state, employers and individuals of reduced labour force participation and poorer health. Individual costs accumulate from reduced income over the lifecourse (Colombo et al., 2011; Keating, 2014) with implications for pensions and savings (Evandrou & Glaser, 2003; Keating, 2014). For employers, there are costs associated with recruitment and non-retention, absenteeism, and reduced productivity (Mazanec et al., 2011; Ugreninov, 2013; Keating, 2014). For society, costs result from lower tax revenues and lower social security contributions, increased

welfare benefits and lost productivity and therefore reduced contribution to GDP (e.g. Social Protection Committee, 2014; Carers UK, Her Majesty's Government & Employers for Carers, 2013; Hoff, 2015; Schneider et al., 2011; Age UK, 2012; Casey, 2011). It was recently estimated that the public expenditure costs of carers leaving employment in England are £2.9 billion a year (Pickard et al., 2017).

In England, there have been a series of Carers Strategies and Acts of Parliament which have sought to support carers in various ways, but in particular with their health, wellbeing and employment (Her Majesty's Government, 2008; Her Majesty's Government, 2010; Her Majesty's Government, 2014; Care Act, 2014). These have included workplace support such as the right to flexible working, direct and indirect support for carers and increasing rights for carers, most notably in the 2014 Care Act. Of the six countries that Eleftheriades and Wittenberg considered in their review of international practice on assessment and eligibility in adult social care, England appeared to be the only country whose planned provisions (subsequently enacted in the Care Act 2014) gave unpaid carers a clear entitlement to an assessment of their own needs in their own right (Eleftheriades & Wittenberg, 2013). The increasing policy emphasis on carers seen in England is mirrored, and some cases exceeded, internationally (Yeandle, 2016).

We aimed to scope and synthesise evidence on the effectiveness and, if available, the cost-effectiveness, of different interventions to support unpaid carers of older people, in order to inform policy discussion and strategy on unpaid carers. We aimed to focus in particular on evidence about the impact of such interventions on areas in which there are known negative consequences of providing unpaid care: carers' employment, health and wellbeing.

Methods

We carried out a scoping and synthesis of the evidence. While we recognise some of the limitations of this method compared to, for example, systematic review, we utilised this type of review methodology as the most appropriate to inform time-limited and emergent policy decision-making (Arksey & O'Malley, 2005). The review concentrated on identifying international evidence on interventions and policies aimed at supporting unpaid carers, focusing in the main on quantitative evidence. This covers a broad range of topics and the literature is very extensive. We therefore sought to maximise breadth and depth by beginning with recent key reviews: international meta-reviews of systematic reviews of interventions to support unpaid carers by Parker and colleagues (2010) for the period 2000–2009 and by Thomas and colleagues (2016) for 2009–2016, Victor's (2009) review of 107 UK studies 1990–2009 and the review by Knapp and colleagues (2016) on technology for people with dementia and their carers. We also drew on Pickard's (2004) review of support for unpaid carers for the Audit Commission,

which used mainly UK but also international literature from 1990 to 2003. A search using relevant search terms¹ and key databases (Academic Search Complete, ASSIA, HMIC, Pubmed, Google Scholar, Modern toolkit, SCOPUS, Social Care Online and Web of Science) was supplemented with key, more recent, systematic reviews as needed, except for formal services for care-recipients, work conditions and cash benefits, where we could find no systematic reviews or meta-reviews. For the latter, we utilised reports and key recent academic papers, again retrieved from the key databases listed above.

OECD, World Health Organisation (WHO) and EU synthesis reports also formed part of the evidence base, including the comprehensive OECD report by Colombo and colleagues (2011), the 2016 WHO Report on Ageing and Health and the recent European Social Policy Network (ESPN) 35-country synthesis report on the impact of national policies on carers' employment and wellbeing (Bouquet et al., 2016). In addition, we included evidence from UK government reports, policy documents and impact assessments, as well as reports from key voluntary sector organisations such as Carers UK and Eurocarers. We also reviewed key publications from academic research units working in this field. We focused in the main on quantitative studies to provide data that, where available, could potentially be used for further analysis of policy reforms and interventions.

Findings: interventions and support for carers

Indirect support for carers: services for people with care needs

In a number of countries (e.g. Sweden and England), policy on unpaid carers aims to provide 'replacement' formal care services for the person with care needs in order to also support unpaid carers, especially with their employment and health. Such substitute or complementary formal care may include ongoing services such as home care or personal assistants, or occasional substitute care such as respite (short breaks). Thus in this review we are examining evidence on formal care services and their effectiveness in supporting unpaid carers. In many cases these services also have benefits for the care-recipient; this is however outside of the scope of this review. In some instances it can be difficult to separate whether an intervention is for carers, for service users, or indeed both: respite care is a case in point.

Carers' labour force participation

Although some research finds no relationship (Bullock et al., 2003; US study) or a negative relationship (Covinsky et

¹ Including MeSH terms such as 'care givers'; 'carers'; 'family caregivers'; 'spouse caregivers', supplemented with terms widely used in the literature such as 'informal' or 'unpaid' carer, plus search terms around intervention type (e.g. 'counselling', 'care leave') and outcomes (e.g. 'employment').

al., 2001; US study), the vast majority of research shows a positive relationship between use of formal services by the care-recipient and carers' employment outcomes and thus the potential to reduce individual, employer and societal costs of negative employment outcomes. This is the case using within-country studies (e.g. Scharlach, 2007 in the US; Pickard et al., 2015 in England). These studies find that the provision of formal care support for the person with care needs is associated with a higher probability of being in employment, particularly for women. This is particularly so for those providing unpaid care above the threshold of ten or more hours a week. That a greater effect is seen for people providing care at higher intensity is perhaps unsurprising in the context of the relationship between higher-intensity caring and negative employment outcomes.

Modelling of German data finds that benefits in kind have small positive effects on labour supply. A 1% increase of benefits in kind leads to an increase in labour force participation of 0.02%. The effects are larger for women (0.03%) and at higher care levels (0.07%) (Geyer & Korfhage, 2015). Pickard and colleagues find a positive association between carers' employment and receipt of paid services in England. Specifically, women who provide unpaid care for ten or more hours a week have significantly higher odds (OR 1.57, CI 1.34–1.85) of being in employment if the person they care for receives at least one formal paid service compared with if they receive no services, as do men (1.69, CI 1.34–2.12) (Pickard et al., 2015). On specific services, the odds ratios are: home care (women 1.64; men 1.69); personal assistant (women 1.74; men 2.45); day care (women 1.26; men non-significant); meals-on-wheels or equivalent (women 2.85; men ns) (Pickard et al., 2015).

Quantitative findings on formal care services are backed up by qualitative studies which show that carers feel that provision of services for the care-recipient is important in enabling them to remain in employment and the lack of services is a barrier to being in employment (Milne et al., 2014; Yeandle et al., 2007; Carers UK, 2016; Arksey & Glendinning, 2008). The importance of social care for the care-recipient in supporting carers' employment has been recognised in carers' strategies and legislation, most recently in the 2014 Care Act (Her Majesty's Government, 2014).

Several cross-country comparisons have shown that countries with extensive provision of formal home care services tend to have higher levels of employment among those 'at risk' of caring compared to those with less extensive provision of formal home care services (e.g. Lundsgaard, 2005). Using European Community Household Panel data, Viitanen (2007) found that raising government expenditure on formal services for older people to the EU average (or the EU average excluding Denmark as an outlier) in countries below that average would increase labour force participation rates among women aged 45–59 by between 9 and 13 percentage points. Comparing the cost of doing so to the average tax revenue per person, Viitanen concluded that

such a policy would be potentially cost-effective.

Two other studies – one by Heger (2014) using data from the Survey for Health, Aging and Retirement in Europe (SHARE), and one by Lamura et al. (2008) as part of the European Commission's 2006 EUROFAMCARE multi-country study – found increased labour force participation to be associated with formal care services. Haberkern (2015), also using SHARE data, found similar results looking at filial carers but much more so for daughters, concluding that 'in general, care-giving by sons is hardly influenced by social care policies' (Haberkern, 2015). A recent synthesis of reports from country experts on the impact of policies from 35 European countries found that a model of generous in-kind benefits to dependent people was particularly effective in improving the work-life balance of women providing unpaid care (Bouget et al., 2016).

Although most studies look at services for the care-recipient and labour force participation *rates*, a similar effect is found for working hours in EU countries (e.g. Rodriguez, 2013; Viitanen, 2010) and OECD countries (e.g. Colombo et al., 2011). Geyer and Korfhage (2015) found that a 1% increase of benefits in kind leads to an increase in average working hours of 0.06%. Again, this effect was greater for women (0.10%) and at higher caring intensity (0.21%).

Much of the literature on services and employment does not differentiate type of service. However, the type of services that appear to be most effective in supporting carers' employment are home care, personal assistants, day care and meals-on-wheels or their equivalent (Pickard et al., 2015). These types of services are provided during the working day and so can enable carers to be in paid employment. They are also services which provide ADL (activities of daily living) related or personal care. This type of care is most 'time-bound' (Hassink & van den Berg, 2011), i.e. it has to be done at a particular time, unlike many IADL (instrumental activities of daily living) tasks such as shopping, cleaning or paperwork, and is thus least compatible with employment. Personal care is also most strongly associated with higher care hours and therefore these types of services are likely to be of most benefit to higher intensity carers, the group who are most at risk of leaving employment. Pickard and colleagues (2015) further found that 'short breaks' (respite) are effective in supporting carers' employment only if in combination with other services.

Carers' health and wellbeing

There is much less research on the effect of services in supporting carers' health and wellbeing, with the exception of short breaks (respite). There is some evidence from Davies and Fernandez (2000) that day care and home care can be effective in reducing the negative psychological effects of caring, particularly for higher-intensity carers, but little more recent research. The research on short breaks and carer health is extensive and includes many high-quality studies and systematic reviews. In the main, these studies

focus on carer mental health and wellbeing outcomes rather than physical health. Victor's (2009) review of 107 UK studies is typical in concluding that although carers generally showed satisfaction with breaks, and perceive benefits to their emotional wellbeing, there is little robust quantitative evidence of improvements to emotional wellbeing, and in fact several studies show negative effects on carers' emotional wellbeing. The meta-reviews by Parker and colleagues (2010) and Thomas and colleagues (2016) similarly concluded that there is no evidence for the impact of respite care on physical or mental health, with a suggestion from some reviews that it has negative impact on measures of carers' wellbeing or quality of life (e.g. Shaw, 2009; Schoenmakers, 2010).

A Cochrane review of four studies concluded again that current evidence does not demonstrate any benefits or adverse effects from the use of respite care for people with dementia or their carers (Maayan et al., 2014). Thomas and colleagues (2016) are not alone in highlighting the paradox of respite care: the value placed on it by carers, contrasting with research showing no or adverse effects. Colombo and colleagues further add that both duration and frequency of respite breaks are relevant when assessing the importance for the carer and the care-recipient but again conclude that although carers highly value such services, this does not systematically translate into better mental health outcomes for carers. Both reviews of cost-effectiveness identified in the Parker et al. (2010) meta-review find no evidence of cost-effectiveness for respite care (Mason, 2007; Shaw, 2009), both covering the same studies.

Yeandle and Wigfield (2011) conducted an evaluation of the Department of Health's (DH) National Carers' Strategy Demonstrator Sites programme which included twelve 'breaks' sites which ran over 18 months. Total expenditure was £9,527,613, with 5,655 carers supported: a cost of on average £1,685 per carer, although there was wide local variation. Almost half of the carers felt that accessing the service had enabled them to have more time for themselves. Carers' perceptions of how their health and wellbeing were affected showed positive outcomes. Analysis comparing carers who said they had not received a break with all other respondents completing the four-month follow-up questionnaire showed that carers who had not received a break were more likely than those who had done so to show a significant deterioration in their wellbeing scores. However, the proportion of carers who showed 'poor wellbeing', as measured by these questions, was higher after than before the service was received.

The absence of an observable relationship may of course mean there is not one to observe. It may also be – as several reviews suggest – that results may reflect the lack of high-quality research in this area rather than an actual lack of benefit (e.g. Maayan et al., 2015; Parker et al., 2010). Equally, as short breaks are by definition services provided for a short length of time they may only be sufficient to provide

temporary relief rather than any substantive improvements before returning to an often very demanding caring situation and the same intensity of care hours, a key factor in poorer mental health. This is particularly the case in situations where the care-recipient's health is worsening over time and care hours are increasing (e.g. Yeandle et al., 2012).

Services directly for carers

There is a very extensive international literature on interventions aimed directly at carers. The research covers a range of interventions for people in a range of caring situations and caring for people with differing needs. Evaluations of these interventions, and indeed the interventions themselves, focus almost exclusively on health as an outcome, in the main mental health and wellbeing. Despite the extensiveness of the literature, reviews comment on the need for more methodologically robust, rigorous research in this area, particularly for some types of interventions and for research on cost-effectiveness, the lack of which was highlighted as a particular weakness, (e.g. Parker et al., 2010; Thomas et al., 2016).

Nevertheless, there is evidence of some effective and potentially effective interventions to support carers. In summary, reviews and reports conclude that different carers need different interventions, dependent on level and type of care need and other circumstances of carer and care-recipient. Within this, interventions that appear to be most effective and, where there is evidence, also cost-effective are psychological therapy, training and education interventions, and support groups (e.g. Pickard, 2004; Victor, 2009; Parker et al., 2010; Chien, 2011; Colombo et al., 2011; Nai-Ching et al., 2015; WHO, 2015; Heslin et al., 2016; Thomas et al., 2016).

Specific examples of effective interventions are shown in table 1. Interventions are aimed at carers of people with different care needs. Within the scope of our review (carers of older people) the majority of studies evaluate interventions aimed at carers of people with dementia; the next largest group is carers of people who have had a stroke and carers of people with cancer/at end-of-life. Some of the interventions combine more than one type, for example training and psychological support. In addition, there is some qualitative evidence of interventions to support carers. For example, Yeandle and Wigfield (2011), in their evaluation of the *Caring with Confidence* training programme for carers, found improved self-reported health or wellbeing immediately after the programme and six months later. There are other types of interventions that appear to be effective. For example, there is 'tentative' evidence from a recent review of the effectiveness of meditation-based techniques for carers of people with dementia (Hurley, 2014.)

Work conditions

Our review looked at two types of work conditions indicated in the literature as being potentially effective: (i) flexible

Table 1. Examples of effective services directly aimed at unpaid carers

Intervention	Outcomes	Carer's circumstances (if specified)
<i>Psychological/psychosocial/psychoeducational</i>		
START programme (STrategies for RelaTives; psychological therapy)	Effective and cost-effective at reducing depression and anxiety (Livingston et al., 2014)	Carers of people with dementia
Computer-mediated psychosocial intervention	Reduced depression, anxiety, burden and stress (McKechnie review, 2014)	Carers of people with dementia
Telephone counselling	Reduced depression (Lins review, 2014)	Carers of people with dementia
Cognitive behavioural therapy (CBT)	Reduces depression, anxiety, burden and stress (Vernooij-Dassen review, 2011)	Carers of people with dementia
Couples-based psychosocial interventions	Reduces psychological and physical distress (Regan review, 2012)	Carers of people with cancer
Psychosocial intervention based on problem solving and communication skills	Improves quality of life (Waldron review, 2013)	Carers of people with cancer
Group interventions; Care-recipient/carer dyad interventions; one-to-one interventions	Positive effects on carer quality of life, burden of patient's symptoms and carer burden (Harding review, 2011)	Carers of people with cancer and palliative care
CBT and psycho-educational interventions	Improved psychological health (including anxiety), quality of life (Nai Ching review, 2015)	Carers of people with cancer and palliative care
Interventions comprising psychoeducation, skills training, and/or counselling	Positive effect on quality of life and burden but not depression (Northouse, 2010)	Carers of people with cancer
<i>Education/training (often with support)</i>		
Training in nursing and personal care techniques and providing 'problem-solving partnerships' and support	Positive effects on carers' quality of life and well-being. (Brereton, 2007)	Carers of people who had had a stroke
Education interventions	Improved mental health (using 36-Item Short Form Survey: SF-36) (Lee meta-analysis, 2007) E.g. Grant et al. (2002): intervention consisted of problem-solving; increasing knowledge about stroke and care for a stroke patient. Follow up at 13 weeks post-intervention	Carers of people who had had a stroke
Training in management of stroke patients	Reduced anxiety and depression; improved quality of life, reduced burden (Kalra et al., 2004); evidence of cost-effectiveness	Carers of people who had had a stroke
Educational interventions aimed at teaching skills	Reduces burden (Jensen et al., 2015)	Carers of people with dementia
<i>Support groups</i>		
Support groups	Reduces depression and burden (Chien review, 2011)	Carers of people with dementia
Videoconferencing	Improved carers wellbeing (Dam et al. review, 2016)	Carers of people with dementia
<i>Other</i>		
Meditation-based interventions	Reduced depression (Hurley review, 2014) e.g. Franco et al., 2010: 10 weekly sessions, 90 minutes each with additional at home practice, 40 minutes daily reduces depression and burden post-treatment and at four months' follow-up	Carers of people with dementia

working practices, such as flexible work hours, option to work from home and flexible leave including unpaid leave; (ii) statutory paid care leave.

Flexible working

There is evidence that flexible work conditions enable better reconciliation of work and care and lead to a lower chance of not being in employment. For example, EU experts conclude that the work-life balance of working carers is better in countries with various part-time work arrangements and flexible working time (Bouget et al., 2016). Flexible working helps accommodate caring responsibilities and limits the consequences of providing care on employment (Da Roit & Naldini, 2010; Colombo et al., 2011). Arksey and Glendinning (2008) found that flexible working hours were critical to the successful combination of work and caregiving. Similar findings were reported in a small-scale study by Arksey and colleagues (2005), a report by the Social Protection Committee on long-term care (Social Protection Committee, 2015) and recent evidence reviews for Foresight (Hoff, 2015; Nazroo, 2015). Flexible working increases the chances of remaining in employment or extends the employment trajectory (e.g. Pavalko & Henderson, 2006; Arksey & Moree, 2008; HSISC, 2010; Mooney & Statham, 2002; Age UK, 2012; Ikeda, 2017). Flexible working hours lower the chances of reduced hours of work for carers in Australia and the UK (Bouget et al., 2016). There is also some evidence that flexible working mitigates the mental and physical effects on the health of carers, with the effect larger for women (Earle & Heymann, 2011).

There are also positive outcomes for employers in terms of improved retention, productivity, good employee relations and concomitant lower costs (Schneider et al., 2011; Carers UK, 2014; Hoff, 2015). Hamblin & Hoff (2011) found that working carers employed by a publicly recognised 'best practice employer' are reluctant to leave their jobs there, even at the expense of better earnings or career prospects elsewhere.

However, there is also some evidence that flexible working does not increase probability of remaining in employment. For example, Henz (2006) found that job flexibility has little effect for women leaving the labour market. Working carers, particularly those caring for ten or more hours a week, are more likely to leave employment than to reduce their hours (Colombo et al., 2011; Age UK & Carers UK, 2016). It is likely that flexible working practices are not the only factor. The ability to work flexibly depends on household income, the structure of the labour market with respect to opportunities for part-time or flexible work (Bouget et al., 2016) and type of job (Henz, 2004). It also depends on level of care need (Rodriguez et al., 2013; Milne, 2014). For higher-intensity care hours, or as care hours increase beyond risk thresholds, flexible working may not be sufficient to enable reconciliation of work and care (e.g. Pickard et al., 2015). In part, this is because higher intensity of care hours reflects

greater care needs which tend to be *personal* care needs. These needs are less time-flexible and therefore less compatible with even reduced or flexible work conditions (Hassink & van den Berg, 2011). Flexible working arrangements alone may not be sufficient to enable higher-intensity carers to work and care, and a combination of work conditions and other interventions may be needed (e.g. DWP, 2014a; Colombo et al., 2011; Arksey & Corden, 2009; Hoff, 2015; Mooney & Stratham, 2002).

In England since 2007, carers have had the right to request flexible working; this was extended to all employees with 26 weeks' service or more in 2014. There are still some issues. There are financial consequences for carers of, for example, reduced-hour working, through lower income and lower pension contributions (Arksey et al., 2005; Evandrou & Glaser, 2003). Lack of awareness of rights is also a factor. Recent research evidence suggests that few carers are aware of their right to request flexible working (HSISC, 2010). Data from the 2009/10 Survey of Carers in Households show that only 27% of carers in full-time employment and 24% of those in part-time employment were aware of their rights to request flexible working. There are concerns about requesting flexible working. Some carers are reluctant to reveal their carer status to employers or to take advantage of flexible working arrangements, for fear of being thought of as a 'weak' employee (e.g. Arksey, 2005). Carers have concerns that their employer would disadvantage them if they were to request flexible working. This was particularly true of people working in sectors such as manufacturing, where carers felt they would be perceived as 'difficult' and could risk losing their job (Age UK & Carers UK, 2016).

Care leave

The literature on care leave is less extensive and Glendinning (2016) argues that multiple reasons for work and care decisions mean it is not possible to assess the impact of lack of care leave on caregiving or labour market participation. Carers may, for various reasons, be reluctant to stop paid work altogether; rather, they want to achieve an ongoing balance between caring and employment (e.g. Arksey et al., 2005). However, there is some evidence that care leave may have a positive effect on employment in some circumstances, particularly in combination with flexible working practices (e.g. Pavalko & Henderson, 2006; Colombo et al., 2011; Skira, 2015; Bouget et al., 2016; Social Protection Committee, 2015; Ikeda, 2017). In the US, Pavalko and Henderson found that carers who had access to unpaid family leave were more likely to remain employed than carers who did not have this benefit (odds ratio 3.74). Also using US data, Skira (2015) found that unpaid care leave was associated with a 44% increase in the proportion of women in full-time employment in the years subsequent to the take-up of the unpaid leave. For part-time employment, this was 27%. Skira (2015) found similar increases in women's full- and part-time employment rates for paid care

leave as unpaid care leave, although take-up was higher for the former.

However, there are substantial differences in work conditions between the US and other countries. The US is the only advanced economy in the world that does not guarantee its workers any paid annual leave, with the result that paid average annual leave is among the lowest in the world with some employers offering no paid leave at all (World Bank, 2017). Many carers use annual leave, when available, for caring responsibilities (Colombo et al., 2011; Ikeda, 2017). Working hours in the US are also among the longest in the world's advanced economies (World Bank, 2017). Ikeda suggests that the system of Family Care Leave in Japan² helps unpaid carers stay in employment, particularly in conjunction with the other provisions for carers in Japan since 2016, including rights to flexibility at work. However, when caring responsibilities were prolonged, care leave was less effective (Ikeda, 2017). Other research also shows that care leave alone may be insufficient where care demands are intense and sustained over a long period of time (Arksey, 2003; Hill et al., 2008) and at higher levels of need, unpaid care may be insufficient on its own to meet care needs (Colombo et al., 2011).

Paid leave may have a more significant effect (Earle & Heymann, 2011) and when unpaid, or paid at the employer's discretion, may act as a major disincentive, as in many cases carers are unable to afford a period of unpaid leave (Mooney et al., 2002; Arksey et al., 2005; Colombo et al., 2011). In the absence of statutory rights to care leave there is significant variation between employment sectors, with care leave most often used in the public sector and/or in larger companies (Colombo et al., 2011). However, carers may be reluctant to request even statutory paid leave for similar reasons to those suggested above for the reluctance to request flexible working. For example, there is evidence of concerns about impact on career (Colombo et al., 2011). An additional issue can be that care leave is not flexible enough to support carers in their caring situations nor to meet the care needs of the person they support. Different care leave arrangements in, for example, Australia, Canada, Denmark, Japan and Sweden address the issues of lack of statutory provision, lack of statutory payment and lack of flexibility.

Cash benefits

There are two main policy approaches to cash benefits: (i) carer's allowance, which is provided directly to the carer if she or he applies for it, subject to eligibility criteria (as with the current system in England); (ii) a care allowance to a person with care needs who may buy in the services of carers from the labour market, or use it to pay a relative to provide care.

Higher levels of cash benefits can alleviate poverty for families, particularly in combination with part-time employment or part-time care leave, as they provide some compensation for reduced income (Bouget, 2016). However, they can also increase or maintain gender inequality and low income, as even in the most generous countries payment for care involves fairly low wages (e.g. Bouget, 2016; Colombo et al., 2011). Higher levels also act as a disincentive to work, again particularly for women, and so have negative effects on female labour force participation (e.g. Haberkern, 2015; Skira, 2015). Skira (2015) found that rates of women's non-employment increased from 59.5% at baseline to 62.2% under the carer allowance model, with corresponding decreases in full-time employment, and to a lesser extent part-time employment. There is thus a trade-off. If the level of cash benefits is high enough to reduce risk of poverty, it tends to act as a disincentive to work, particularly for those with relatively low (household) income relative to allowance level and/or low earning power, who may be those with most difficulties entering the labour market. By increasing non-labour income through cash benefits, the marginal utility of an extra hour of working decreases, thus acting as a negative labour supply incentive (Geyer & Korfhage, 2015). When allowances are low or very low, EU experts consider that they do not have any impact on carer's employment, except for poor families where even low allowances could have a disincentive effect on the employment of carers (Bouget et al., 2016). Looking at German data, Geyer and Korfhage (2015) found that a 1% increase in benefits in cash decreases working hours by 0.46% and labour force participation by 0.17%. For women, this is a decrease of 0.60% and 0.19% respectively. For women caring at higher intensity there is a decrease of 0.71% and 0.25% respectively.

In some instances, the policy as well as the level act as disincentives to work because the eligibility criteria limit combination with formal paid employment, or more than minimal formal employment, as is the case in the UK (Glendinning, 2016). In addition to creating disincentives to take up formal employment, cash benefits or allowances discourage carers from working additional hours. Some carers may forgo opportunities to increase their working hours and earnings to stay within the Carers Allowance earnings limit. Others report being unable to do overtime because of the risk of exceeding the earnings limit (Arksey et al., 2005; Fry et al., 2011; DWP, 2014b). Earnings-limited allowances such as those in England generate incentives for carers to reduce hours of work (Colombo et al., 2011). The employment effect of cash benefits depends not only on level and eligibility criteria but also on the structure of the labour market, especially the availability of part-time and flexible working hours and, as noted before, the carer's (family) income (Bouget et al., 2016). There will clearly be a difference in effect of cash benefits for carers of working age and non-working age. Furthermore, providing financial incentives for carers might be a helpful strategy especially for low-intensity, low-skilled

² Ninety-three days long-term leave to be taken in up to three blocks, plus five days per year short-term leave to be taken in half or whole days.

care, but it might be more problematic as care needs increase (Colombo et al., 2011; Bonsang, 2009).

In England under the current system, the relatively low weekly earnings limit and the eligibility conditions result in disincentives to work, while the level of payment does not protect against poverty (e.g. Arksey, 2005; Glendinning, 2016). The care allowance system in England also results in significant uncompensated earnings lost by those who reduce from full- to part-time work (Glendinning, 2016). Carers Allowance in England also has a very steep income taper, discounts other benefits and pension³, and is taxed. Perhaps because of this it has very low take up (Fry et al., 2011). One of the benefits of the English Carers Allowance is that it protects carers' state pension and national insurance rights.

Assistive technology (AT)

Our review looked at two broad types of assistive technology. The first is directed at the care-recipient and thus can be seen in the same category as 'replacement' services for care-recipients which have potential to also support carers. We looked at the evidence on technology that acts as memory aids; provides safety or security; and/or enables more independent living. The second type is technology that is aimed directly at the carer such as technology-assisted or delivered training or support. Examples of interventions that appear to be potentially effective for either carers' employment or their health and wellbeing are summarised in table 2.

For AT aimed at care-recipients, there is some evidence for self-reported better balance of work and care for carers (e.g. Mahoney et al., 2008; Beale et al., 2009; Chiatti et al., 2011), but no difference in carer productivity or morale (Mahoney et al., 2008). Several reports conclude that assistive technologies may contribute to a better reconciliation of paid work and family care provided such technologies are part of a broader package of services and support for the care-recipient and/or are integrated in care networks (e.g. Yeandle, 2014; Hoff, 2015). The DH is currently funding two-year pilots looking at the use of telecare in supporting carers' employment (Her Majesty's Government, 2015).

There are rather more studies on the potential effect of AT on the health and wellbeing of carers. Overall there is some evidence for improved health and wellbeing of carers, again particularly if part of a broader package of services and support. However, negative aspects of telecare for carers' wellbeing are also identified. The systematic review by Davies and colleagues (2013) concluded that many evaluations are of weak methodological quality. However, the evidence tentatively indicated that telecare exerts a positive effect on carer stress and strain. They found no evidence to indicate benefits on burden or quality of life. Carretero and colleagues (2015), in their review of evaluations of technology interventions, found qualitative and quantitative

evidence for improved psychological health for carers. They concluded that there may be associated cost savings for health and social care systems, although there are few studies that consider this.

A review by Knapp and colleagues (2016) on technology to manage the global costs of dementia identified both positive and negative aspects of assistive technology for carers for people with dementia. Several studies have reported better, mainly qualitative, health and wellbeing outcomes, in particular less stress, for technology aimed directly at the care-recipient (e.g. Beale et al., 2009; Chiatti et al., 2011; Holthe, 2004; Mahoney et al., 2008; Pleace, 2011; Jarrod & Yeandle, 2009), although some of these are very small-scale studies. Effective interventions may vary by care need but include various memory, safety and security and independent living technology aids. There is also evidence for a reduction in carer stress and depression for telecare aimed directly at carers (e.g. reviews by Bensink et al. (2006), Powell et al. (2008); studies by Marziali & Garcia (2011) and Finkel et al. (2007)) (table 1). Again, the type of AT intervention that is most effective may vary by care need but includes technology-assisted or delivered psychological support, training and education. It may be the type of support is as, or more, important as the method.

The evidence is inconclusive on the effect of telecare on provision of unpaid care, in terms of the amount of time carers spend on caring. In one evaluation, the majority of carers reported that the telecare intervention (monitoring) had improved how they spent their time, freeing up time for themselves (Kinney et al., 2004). Other research found that telecare had decreased time spent caring for a minority (14%), however, an equal proportion (13%) said that it had increased the time that they spent caring, and 73% of participants said that the amount of time spent caring remained 'about the same' (Beale et al., 2009; Jarrod & Yeandle, 2009). A further evaluation that examined change in time spent caring did not find a statistically significant reduction (Mahoney et al., 2008).

Multi-dimensional support

Different carers may need different interventions, multi-dimensional interventions or combinations of interventions depending on the level and type of care need of the care-recipient and carers' broader circumstances, such as age or economic status. Furthermore, the nature of support needed is likely to change as care needs and carers' personal circumstances change over time. Many studies, reviews and reports conclude that a combination or 'multiple choice' of interventions may be most effective in supporting carers and helping to meet the diverse needs of carers and people with care needs. UK and EU 35-country synthesis reports on reconciling work and care conclude that improving work-life balance for carers requires coordinated measures across multiple policy domains and for both people with care needs and carers. Good work-life balance (and wellbeing) cannot

3 <https://www.gov.uk/carers-allowance/effect-on-other-benefits>

Table 2. Assistive technology (AT)

Intervention	Effect	Carer's circumstances (if specified)
<i>AT for care-recipient (e.g. memory aids; safety/ monitoring; independent living)</i>		
Telecare Scotland (various different projects)	Enabled some carers to participate in paid employment (self-reported) and reduce self-reported stress (Beale et al., 2009; Jarrow & Yeandle, 2009)	Predominantly carers of people with dementia
Information and communications technologies (ICT) for independent living	Self-reported better ability to balance care and employment, fewer health problems (Chiatti et al., 2011).	
Selection of night and day calendar, automatic lamp, item locator, medicine reminder, picture phone and remote day planner	Trend towards a significant reduction in self-reported stress seen between baseline and three-week follow-up, and baseline and 3-month follow-up (Holthe, 2004)	Carers of people with dementia
Motion sensors (two schemes)	Perceived better balance of work and care but no significant quantitative difference in carer productivity or morale (Mahoney et al., 2008). Less stress as measured by a significant increase in carers' self-reported ability to make activities pleasant for the care-recipient and themselves in the intervention groups compared with the control (Mahoney et al., 2008)	Workers who were family carers of an adult who resided alone at home during the workday, with one care-recipient health or safety concern
Services that enable older people to remain at home (included telecare, alarm and mobile warden services).	Improved wellbeing of carers (Pleace, 2011)	
Two or three pieces of equipment from a selection of memory, safety/ monitoring, independent living devices	Self-report recall before and after introduction of the telecare; statistically significant reduction in stress for 8 of the 13 items relating to stress measured (Woolham, 2005).	
Sensors, with bed monitor, gait monitor, impact fall detector and stove sensor	In a before-and-after evaluation that assessed strain using the carer strain index, there was a significant reduction in carer strain between baseline and four months (Alwan et al., 2006).	
MP3 players loaded with individualised musical content for care-recipient	Before & after study, no control, outcome: decreased psychological distress for family carers, offered some 'respite' (Lewis et al., 2015)	Carers of people with dementia
<i>AT for carer (e.g. technology-assisted or delivered training; education; psychosocial support)</i>		
Stress reduction interventions delivered through technology	Appears to reduce improve mental health related outcomes for carers compared to text based chat. Text based chat group (comparison) showed significant improvement in self-efficacy. (Marziali & Garcia, 2011).	Carers of people with dementia+
E-care technology-based psychoeducational intervention for carers	Decreased carer burden and depression (Finkel et al., 2007)	Carers of people with dementia

be achieved by carers' benefits alone; formal care services, flexible working and poverty alleviation measures are also needed (Glendinning, 2016; Bouget et al., 2016). Similarly, Eurocarers (2009), citing Himmelweit (2008), argue that carers need support to combine paid employment and care in terms of cash, time and services.

The Department for Work and Pensions (DWP) *Fuller Working Lives* report (2014a) suggests a range of actions is needed to help more carers stay in employment: support services; income protection; flexible working practices; and innovation in areas such as assistive technology. An EU

report on the indirect costs of LTC argues that the three factors most important to the reconciliation of care and employment are availability of formal care for the person with care needs, policies supporting unpaid carers in combining work and care such as flexible working, and care intensity (Rodriguez et al., 2013). Yeandle and Buckner (2007) report that three key elements have been identified as important in facilitating continued employment: workplace support for carers, effective provision of health and social care, and 'other local infrastructure' such as access to information. An OECD report on providing and paying for long-term

care concludes that both financial support and services are needed to support carers (Colombo et al., 2011). Finally, in his evidence review on volunteering, providing unpaid care and paid employment in later life, Nazroo argues that ‘without sufficient flexible sources of formal care, flexible work places and the support of other informal carers, those taking on informal caring responsibilities are likely to face some degree of withdrawal from paid work’ (Nazroo, 2015, p. 15).

Conclusions

In this paper we have reported on an overview of the evidence on support for unpaid carers. The scope of the review, extent of the body of literature from a range of sources and the rapidly changing policy, practice and funding environments have inevitably resulted in gaps in our coverage. Furthermore, there are significant gaps in the evidence base with regards to some interventions, outcomes and types of caring situation, with a dearth of evidence on cost-effectiveness and few evaluations of key recent policy initiatives. Our review looked at outcomes for carers only. Some of the interventions will have positive (or perhaps negative) outcomes and associated costs for care-recipients as well, but this was beyond the scope of our review. Additionally, there is other effective support for carers such as informal care and support networks that does not fall under the remit of ‘interventions’ in this review.

Nevertheless, our review highlights both the range of interventions and support, and some of the potentially most effective interventions for carers in the areas of indirect support, direct support, work conditions and combinations of these. Evidence is strongest and most consistent for formal care services for people with care needs (so-called ‘replacement’ or ‘substitution’ care); flexible working conditions; psychological therapy, training and education interventions; and support groups. The review also highlights that in many cases it may be that a combination of interventions, or a multi-dimensional intervention, is most effective and that the type of intervention(s) needed will depend on the level and type of care need of the care-recipient and the carer’s broader circumstances. These may change over time. Our findings have implications for social care policy and practice which aim to support carers, and for other public policy areas (such as employment, pensions and welfare benefits). This is particularly pertinent in the context of the changing landscape of global macro-level processes and recent policy, legislative and funding changes affecting local authority and voluntary sector providers of support and services for carers in the UK.

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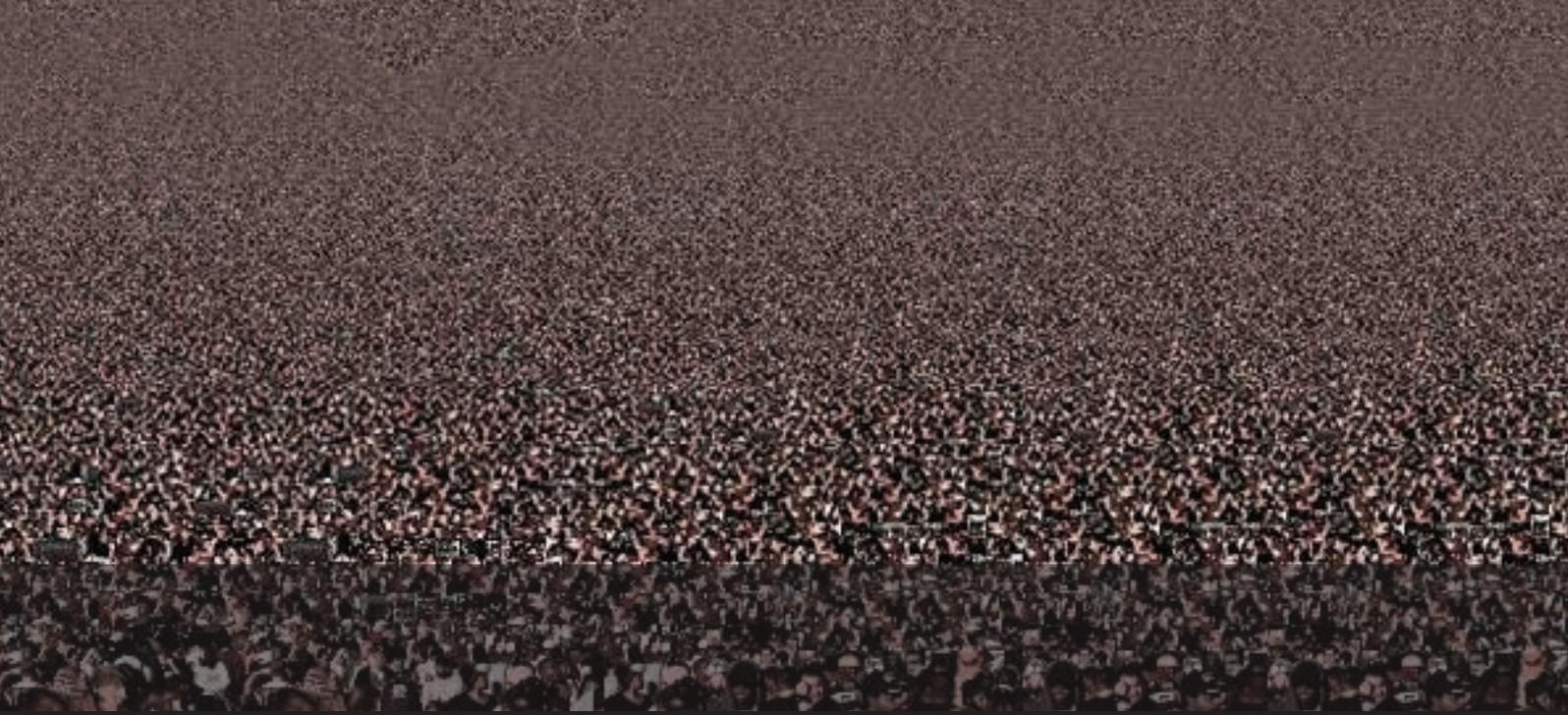
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