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Measures to support unpaid carers

Joanna Marczak, Blanche Le Bihan, Giovanni Lamura,
Lennarth Johansson, Agnieszka Sowa, Jose-Luis Fernandez

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Authors

Joanna Marczak, London School of Economics and Political Science, UK
Blanche Le Bihan, School of Public Health, France
Giovanni Lamura, Italian National Institute of Health and Science on Aging, Italy
Lennarth Johansson, The Stockholm Gerontology Research Center, Sweden
Agnieszka Sowa, Centre for Social and Economic Research, Poland
Jose-Luis Fernandez, Joanna London School of Economics and Political Science, UK

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Introduction

Informal and family care has attracted significant policy attention within national and supranational forums, partly driven by concerns over the quality of long-term care services and fiscal sustainability and by a recognition of the critical role of carers in ensuring the sustainability of the care system (Courtin et al., 2014). Carers provide the lion's share of long-term care support: as much as 80% of all care across the European Union (Eurocarers, 2017). The objective of this report is to synthesize recent policy developments in relation to unpaid care across Europe, and to review international evidence about the impact of interventions to support unpaid carers on costs and outcomes.

Main findings

Existing scholarship on interventions to support unpaid carers identified through the study's rapid international literature review point to mixed and limited results, particularly where questions of (cost-) effectiveness are concerned. Research tends to be characterized by methodological shortcomings often involving poor quality of primary research based on small samples, and outcome measures which not always reflect outcomes valued by carers, which overall means conclusions have to be tentative. Research also tends to be geographically biased to the cases of the United States, England and Canada, with a pronounced lack of studies from central and eastern Europe making generalizability problematic. Of the existing evidence, the strongest positive findings relate to effectiveness of education, training and information for carers. Beyond this, research evidence is often mixed. It is however important to note that few studies illustrated negative intervention effects. Although evidence in relation to respite show mostly no effects and some negative effects, in qualitative studies carers seem to value respite care: this apparent conflict between empirical evidence and views of carers calls for research triangulating qualitative and quantitative evidence. Furthermore, the literature review indicated that to obtain a robust picture of outcomes and costs it is vital to examine costs per dyad of carer and cared-for person. Reviews often conclude that it may be that a combination of interventions, or a multi-dimensional intervention, are most effective in supporting carers.

Policy measures with regard to informal carers examined in the report correspond to interventions directly addressed to carers. They can be classified into three main types: compensation measures (aiming at rewarding carers' time financially or via social security), supportive measures (aiming at assisting carers in performing their role) and reconciliation measures (aiming at facilitating work/life balance).

Concerning the first type, the report shows that what is available in almost all countries is the possibility for carers to be directly compensated via the cash benefits granted to the care recipient.

The second category of measures include a wide range of interventions such as information, counselling, training, official recognition, support groups, assessment of carers' needs or respite measures. A continuum can be identified from countries where this type of measure is largely absent (Bulgaria, Poland and Latvia) to countries where the variety of these supportive measures have been introduced (France or Finland). In eight out of the 12 countries studied in the report, there has been a move forward in further recognizing the role of informal carers through legislation.

Finally, reconciliation measures are developing in all countries. Working flexibility opportunities exist (legally) in seven out of the 12 countries studied. In addition, care leaves were introduced in nine of the 12 investigated countries, but with different characteristics. They can be long (lasting three or more months) or short, they can concern only the end of life of the older person (which is the case for most of the long care leaves in the countries studied) and can be paid or unpaid. The financial benefit related to the care leave can vary greatly. In some countries, recipients receive a full compensation (Italy or Austria), in others it is more limited (from 80% in Sweden to 55-60% in Germany or the Czech Republic), while in other countries the care leave is unpaid or virtually so (Finland, France and England).

Links between care regimes and the approach to family care remain tentative. Supported familialism – when family care is recognized as a solution to care for elderly people and public measures are developed to help families to face their caring activities – is expanding in most sampled European countries. This is the case even in some central and eastern European countries which have hitherto been characterized by unsupported familialism (except in Poland and Latvia which where care by the family is dominant by default) or in Nordic countries operating a social democratic model where the availability of publicly subsidized services is important. And it is clearly seen in England, where measures designed to help carers have been introduced from as early as the 1960s. Even so, different forms of supported familialism can be identified in relation to the type of measures (compensation, supportive or reconciliation) addressed to informal carers. These forms include a strong policy choice towards supportive types of measures – information, training and respite – (France and more recently in Spain), as well the introduction (Finland) or further development (Austria, England, Germany, Italy) of compensation measures. Though there is a trend to develop measures to improve work/life balance in all countries, the impact of these varies considerably, due for instance to the characteristics of the care leave offered.

Conclusions

Aging populations mean increasing demand for service and care worldwide. This, together with predictions of the decreasing availability of informal carers, has led to increased focus on and the rediscovery of the potential role of families.

Informal carers are clearly not a homogenous group. They vary not only in their socioeconomic characteristics such as age or employment status but also regarding the intensity of care they provide. The type of intervention(s) needed to support informal carers will depend on the level and type of care need of the care-recipient and the carer's broader circumstances.

A trend towards the form of 'supported' familialism seems to characterize developments in most countries. However, the components and intensity of this evolution vary greatly from one country to another, according to the initial national configuration (care regime) and the characteristics of the schemes implemented. The complex (and often contradictory) context of institutional, social and economic factors as well as the specific care culture in a given national context will need to be considered when framing support for informal carers in that country.

Section 1: Introduction

The multifaceted roles of carers: resource, providers and persons with their own needs

Definitions of (informal or unpaid) carers vary. Eurocarers, a European network representing informal carers and their organisations, defines a carer as "as a person who provides – usually – unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework". Other definitions emphasise the nature of the support provided. Hence, the Organisation for Economic Co-operation and Development (OECD) defines carers as individuals providing help with personal care or basic activities of daily living (ADL) to people with functional limitations. Regardless of the precise definition used, and in spite of some differences in patterns of unpaid care provision across countries, unpaid carers are systematically found to provide the lion's share of long-term care support in Europe. In fact, some estimates suggest that unpaid carers provide as much as 80% of all care across the EU (Eurocarers, 2017). Women provide approximately two thirds of unpaid care, although the gender differential in unpaid care provision reduces significantly with age, and in the older age groups men provide as much informal care as women (to their elderly spouse).

Informal and family care has attracted significant policy attention within national and supranational (EU) forums, partly driven by concerns over the fiscal sustainability and quality of long-term care services and by a clear recognition of the critical role of unpaid carers in ensuring the sustainability of the care system (Courtin et al., 2014). Looking to the future, factors such as changes in the willingness to provide support to relatives and friends, increases in the physical distance between family members, greater female labour force participation, growing divorce rates and reduction in the numbers of children might all lead to future reductions in the supply of unpaid care. Reductions in the life expectancy gap between males and females might counteract to some extent these effects by increasing the availability of informal care provided by men spouses (Hoffmann and Rodrigues, 2010).

The variability between countries in terms of the volume and type of unpaid care provided is partly related to differences in cultural expectations about the division of caring responsibilities between the family and the state (Triantafillou, 2010). In some settings, care provision is viewed as primarily the responsibility of individuals and their families, and formal services are only assumed to be required only if informal care is unavailable (Twigg and Atkin, 1994). Such expectations are particularly prevalent in familialistic welfare states[1], in which state policies typically aim to simultaneously encourage and enable family members to meet the care needs of their dependent relatives through for example cash for care and/or care leave schemes. Such policies however can lead to the overreliance of individuals with long-term care needs on their families. In contrast, de-familialistic states aim to minimise expectations about the role of family on the provision of care either through providing publicly-funded formal long-term care services and/or through stimulating market-based solutions in the long-term care sector. Market-driven solutions may however lead to class-biases because they tend to privilege more affluent individuals who can afford to purchase (better quality) care. As is often the case in the long-term care area, the unpaid care policy picture is mixed, and many countries combine familialistic and de-familialising policies, and even welfare states emphasising the de-familialisation of care system (e.g. Scandinavian countries) rely on unpaid care as their main source of care (Leitner, 2003). Section two of this report provides a detailed discussion of types of policy measures to support informal carers which exist in different European care systems.

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[1] Esping Andersen (1990; Esping-Andersen, 1999) identified familialistic and de-familialising welfare regimes with regard to the extent to which families are held responsible for their members' welfare. Feminist scholars expanded the debates by exposing the gender arrangements that underpin (de)familialism in welfare regimes (Leitner, 2003; Saraceno, 2016).

Carers as resources and co-workers

The formal care system can interact with unpaid carers in different ways. The nature of this interaction has been exemplified by (Twigg and Atkin, 1994) in terms of whether carers are viewed (and treated) by the formal system as resources (freely available and to be used when possible as the primary source of support), as co-workers (complementing the activities of formal services), as co-clients with needs of their own to be supported, and as superseded carers whose caring activity ought to be substituted by inputs from the formal system. The multifaceted nature of carers' roles in the long-term care sector underpins difficulties in evaluative work in this field (Hoffmann and Rodrigues, 2010).

In the internationally widespread context of declining public social care resources, unpaid carers are often perceived as a relatively inexpensive (and therefore cost-effective) resource. The costs of policies for supporting informal carers, if not free, are relatively low, and small amounts of formal support for carers are hoped to ensure the provision of significant levels of care inputs from family members. Care systems which view carers as resources therefore focus their policy objectives on the cared-for person. In these systems, interventions to support carers aim at ensuring that they retain the ability to provide unpaid care. Carers are not viewed as primary subjects for policy intervention and potential conflicts of interest between the carer and person cared for tend to be ignored. In systems dealing with carers as co-workers, formal services aim to work alongside informal carers, and to coordinate and complement each other's caring activity. Although in these systems the primary focus is still on the person in need of care, it is recognised that supporting carers is important not only to ensure the continuity of care but also in terms of the quality of care provided (Twigg and Atkin, 1994).

As indicated above, there are concerns about the future availability of unpaid care due to demographic, social and policy trends, and about the associated increases in demand for formal long-term care services (Glendinning et al., 2009; Triantafillou, 2010). However, the influence of social and cultural factors (e.g. kinship relationship, or women's expectations) makes it difficult to evaluate likely future gaps in informal care supply and to develop policies to encourage unpaid care giving. Mostly, the decision to take up caregiving remains with the individual (Twigg and Atkin, 1994).

Carers' as individuals with their own rights

Carers may be viewed as clients, people who need care and support in their own right. In care systems underpinned by such an approach, carers' needs and their wellbeing are important outcomes per se, even if they conflict occasionally with the needs of persons cared for (e.g. respite care is an example of support for carers which may conflict with the wishes of people cared for) (Twigg 2006). The provision of informal care can have profound consequences for carers. Caring responsibilities may constrain social participation and often necessitate withdrawal from the work force and lead to financial losses (Pickard et al., 2015; Pickard et al., 2012); caring may have adverse effects on the psychological and physical health of carers (Gilhooly et al., 2016) who may thus need support to maintain their own health and well-being.

Informal carers are not a homogenous group, and vary in their socioeconomic characteristics (age, employment status, gender) and in the intensity and nature of the care they provide. Working age cares are often confronted with a wide range of competing responsibilities at professional and personal levels, raising questions about how to achieve the right balance between work, caring and other personal objectives and responsibilities (Colombo et al., 2011; Le Bihan and Martin, 2012). Although at present informal carers are most likely to be of working age, it is likely that population ageing will mean that a greater proportion of caring duties will be fulfilled by older people (Hoffmann and Rodrigues, 2010). Older carers often present the additional challenge of acting as carers at the same time as presenting care needs themselves. On average, the carers providing the highest levels of care are those that share a household with the cared-for person. These carers are those most likely to need support (Pickard, 2004).

An important question is therefore how best to address informal carers' complex needs. European governments have gradually implemented policies to support carers' health and wellbeing, to support them in their caring role, to assist them to combine work with care and to compensate them for income (including pension) loss incurred as a result of their caring activity (Colombo et al., 2011; Courtin et al., 2014). Section three of this report gives an overview of available evidence of effectiveness of different technologies to support carers.

The fluidity of the separation between formal and informal care

The traditional distinction between formal (professional) and informal (unpaid, family) care, is becoming increasingly blurred following recent changes in the LTC regulatory systems. For instance, the introduction of cash for care schemes linked to the personalisation agenda has enabled individuals in need of care to pay previously 'unpaid' carers, or to employ live-in migrants as carers (Le Bihan, 2012). The term 'semi-formal' care has been introduced to describe these new types of relationships between carers, users, and the care system. Pfau-Effinger et al., (2009) provide a useful description of semi-formal care, which they define as care "provided by family members or within social networks in the context of Welfare state programmes, such that it is no longer informal, but has some formal features in that it is registered and may also be connected with some kind of pay and social security" (Pfau-Effinger et al., 2009: 212).

Semi-formal care is however an ambiguous and complex term. Whilst payment for an unpaid carer through an employment contract constitutes a step towards formalisation of the relationship between the carer and the cared-for person, care activities often constitute structured, organised work regardless of the presence of a payment. In addition, the quality of care, whether formal or informal, is often closely associated with individual wishes and preferences which might vary through time, and is significantly affected by the personal relationship between carers and cared-for person (Le Bihan, 2012; Twigg and Atkin, 1994).

Policy objectives

The main policy objectives when unpaid care is considered are related to assuring sufficient quality of life of carers, particularly when care demand and intensity is high, enabling reconciliation of care and work and assuring adequate balance between formal and informal care structures, based on partnership and support. Dilemma related to reaching these goals at the point of designing a policy involve a potential conflict of interest between supporting carers and cared for when financial and organizational constraints are faced. Given the predominant role of unpaid carers in each welfare regime supporting them in a most efficient way is a necessity.

Improving quality of carers' life outcomes

Provision of family care is related to high psychological (stress, burn-out syndrome, anxiety, risk of depression), physical (owns' health and functional abilities deterioration), social (social isolation, deconstruction of friends and family networks) and economic (high risk of labour market exit, loss of career opportunities) burden and costs (Argimon et al., 2004; Frederick, 2018). Psychological distress in caregiver's lives arises from permanent stress and anxiety related either to owns' situation or the state of health of the cared for and might lead to burn-out syndrome and depression. Physically, informal care provision might results in deprivation of own health needs and deterioration in physical abilities, the risk of which increases as carers' age and the intensity of care rises. Supporting dependent persons is often also at the cost of owns' social relations, what might again negatively impact emotional stability.

Another interrelated factor is anxiety and distress related to financial instability and poor economic standing if career opportunities of care giver are under pressure.

There are various methods of informal carers' support: direct (supporting carers) and indirect (supporting dependent persons), financial and non-financial (trainings, counselling), regulatory, improving access to specific services, including formal care services. While improving quality of life of carers is perceived as an imperative and policy necessity, with supportive intervention reducing distress and improving quality of life of carers, there is insufficient evidence on the kind of support that is the most effective (Candy et al., 2011).

Some of the dilemmas policy makers face is whether it is more effective to directly support carers or to support dependent people. And if carers are supported, which measures then are the most beneficial for improving life outcomes of the carers and cared for: financial or non-financial? Shall the support be targeted to specific groups of people depending on the type of care, it's intensity, life-stage of a dependent person, or types of diseases, in which care provision is particularly burdensome (i.e. in care for people with dementia)?

Tensions at policy level are also related to the proper balancing of long-term care objectives of reaching outcomes best fitted to the needs of dependent people and at the same time supporting their carers. Section three of the report provides an overview of policy measures adopted to support unpaid care across European countries and the section four points to evidence of effectiveness of some interventions, also emphasising impact on the quality of life of carers.

Improving employment outcomes for carers

Given the importance of informal care, assuring balance between care obligations, employment opportunities and other life goals becomes an important policy objective. Ability to engage in employment depends on a number of factors, such the intensity of care provided, human capital levels, socio-demographic characteristics and employment opportunities as well as the choice of care that is available and can substitute or complement family care (Colombo et al., 2011). Providing personal care might be (and typically is) incompatible with employment, reducing employment capabilities which results in labour market exit, inability to undertake employment, for working carers it impacts intensity of work, wages and career opportunities (Colombo et al., 2011; Kroger and Yeandle, 2013).

Employability of care providers is an outcome of individual level factors, labour market structures and welfare policies, specifically in the field of long-term care provision, respite care and support for cared for and the carer. Thus, support for informal carers involves complex, direct and indirect measures (Triantafillou, 2010) and strongly varies between countries.

Concerns have been raised that in most European countries, there are no systematic policies in place to assess and map the needs of informal carers in a way that adequately supports their participation in the labour market (Courtin et al., 2014). The extent to which carers can balance employment and care responsibilities varies across welfare regimes. Nordic and Anglo-Saxon countries tend to offer more developed support measures. In these systems, carers' labour market participation is typically supported through a combination of cash benefits, alongside funding for formal care, respite care options, and flexible employment arrangements (Bouget et al., 2016; Colombo et al., 2011).

In Continental and Southern Europe, the care burden of family is strongly lessened thanks to generous cash benefits that can be used for obtaining formal care, but still a substantial decrease in employment – labour market exit or reducing working hours – of carers is observed.

In Central and Eastern Europe, where long-term care remains underdeveloped and benefits related to care often cannot be combined with employment, provision of care most frequently leads to labour market deactivation.

There is a gender bias related to employment and care as in most countries employment rates of females, who typically become the main care providers, are lower.

With the variety of policy instruments, supporting reconciliation of care and work is coming to forefront of long-term care policies, but still there is little evidence of the actual impact of specific measures. Whilst up-to-date the most common type of carers' support have been cash benefits, enabling personalisation of care and buying care services, other policy instruments are growing in importance.

Responsibility for creating carers' friendly work environment is shared by the governments, shaping long-term care policies and employment regulations, and the entrepreneurs who create carers' friendly work environment via adapting working conditions to the needs of informal carers through flexible working arrangements, care leaves, secure work contracts and assurance of equal right of carers and non-carers to develop their professional carers (Eurocarers, 2017). Innovative solutions in this field include corporate schemes supporting carers in their work environment by a system of transfers on the top of wages as it is done in Italy (Barbabella et al., 2018).

Contain costs of formal care services

A certain amount of informal care is essential in filling the gaps of formal care provisions, supplementing them or ensuring that care is provided in critical times, thus unpaid carers constitute a vital element of the care market releasing the burden on formal services. As population ageing is forecasted to intensify, placing further pressures on formal care services, supporting informal carers to enable them to continue caring for as long as they wish to do so is an important policy objective as a demand management strategy. Moreover, in the context of raising concerns over fiscal sustainability of formal care sectors, many countries have turned towards reducing reliance on institutional care to replace it by apparently less costly community services (Marczak and Wistow, 2015). Although the emphasis on community care in providing long-term care can bring more recognition to the care given by unpaid carers which are recognised as one of the building blocks of community care, it may intensify unpaid carers' burden (Pickard, 2004; Pickard et al., 2016). Moreover, for individuals with high level needs (e.g. those requiring around the clock care), institutional care may be more appropriate relative to care provided by unpaid carers (Colombo et al., 2011).

Balancing formal and informal care systems

Unpaid family care is typically the main source of care when demands related to health status of a fragile elderly are not high and needs are relatively easy to be met (Bonsang, 2009). A spouse or children become then a primary source of care, which can effectively substitute other types of care, especially if costs of care provision, such as loss of employment or decrease in incomes, are non-existent or are relatively low thanks to the welfare systems supporting unpaid carers.

However, when health condition of a dependent person worsens and the needs are growing, the substitution effect of unpaid care disappears and the need for formal, professional care is rising. There is a significant evidence of complementarity or supplementation of unpaid, family care with formal care when the needs for care are high (Geerts and Van den Bosch, 2011; Litwin and Attias-Donfut, 2009). The mix of care and preferences for different types of care might be related on the one hand to the supply of care, and on the other to individual choice and family relations. Litwin and Attias-Donfut (2009) point that formal care is more prevalent when unpaid care is provided by children or other family member, rather than by spouses, whose engagement tends to be more intense.

When the choice of care is considered, there is little relation with the type of the welfare regime and the generosity of the long-term care system. The selection of the type of care – formal, informal or the mix of these two forms – is related rather to the health status and needs of the dependent person than to provision of services (Geerts and Van den Bosch, 2011; Jiménez-Martin et al., 2011; Litwin and Attias-Donfut, 2009). Whilst the rates of formal care utilization strongly differ between European countries, the care choice patterns are found to be quite similar across different welfare regimes pointing to little tension between formal and informal care and preferences of formal care utilization by solitary older people and people with greater care needs.

Given the cost-containment element of policies on the one hand and ability of family carers to provide care when adequate and sufficient, the policy objective is to optimize the relation between formal and informal care structures, potentially incorporating family care into formal care structures by recognizing their role in legal regulation, supporting them financially or provide them with respite.

Section 2. The implementation of unpaid care policies across European countries

Conceptual framework

Three types of policy measures addressing informal carers

In the light of the multifaceted role played by unpaid carers and of the objectives characterizing policies addressing them described in the previous section, it is preliminarily appropriate to define more precisely what such policies include, to better understand how they are implemented in the different countries.

To this purpose, it should be underlined – following Courtin and colleagues (2014) – that carers are often not the main, core focus of the services or measures proposed; therefore, a distinction can be made between "direct" measures targeting informal carers, and "indirect" measures targeting the cared for persons, which have however also an impact on their carers.

In this regard, Naiditch and colleagues (2013) have proposed an even more complex distinction between direct/indirect and specific/unspecific interventions. Despite these and other rigorous attempts, however, in reality the boundary between "carer-specific" measures and those supporting older people in need of care remains often blurred.

As indeed, recalled by Kröger and Yeandle (2013), if services addressed to older people can be partly considered also as a way to meet the informal carers' needs, they must be distinguished from direct carer supports, which cover payments, services and rights accorded directly to carers.

Following Saraceno's analysis (Saraceno, 2016), the first type of measures correspond to policies that liberate families from (at least a share of) the caring activities, while the second type reflects policies aiming at helping families in performing such activities.

In this report, differently from the approach followed by Courtin and colleagues (2014), the focus is on direct measures to informal carers, a great variety of which have been developed in the last decades. As highlighted by Saraceno (Saraceno, 2016) in order to allow families to care for their older relatives, they provide time and/or money as well as a third resource, i.e. "competencies". The latter include knowledge on the elder care system and on the different solutions available to care for an older relative, knowledge on the technical dimensions of the caring activities, and on strategies and tools to promote the empowerment of the carer.

Colombo et al. (2011) suggested a more detailed classification, considering following categories: caregiver allowance; allowance for the person being cared for, tax credit; additional benefits (country-specific specific special support policies such as tax deductions, pension credits, nursing fees etc.); paid and/or unpaid leave; flexible work arrangements; training/education; and respite care.

By integrating these different resources, we have developed a typology of the forms of direct support provided to informal carers, distinguishing them into three main types (defined as indicated in Table 1):

- Compensation measures;
- Supportive measures; and
- Reconciliation measures.

For the purposes of this analysis, cash for care benefits addressed to the older people, but which are in practice used as a financial reward or compensation for informal carers, will be also considered, and classified under the category "compensation measures" (unless restrictions are in force that prevent them to be used in such a way).

Table 1. Core typologies of policies and measures directly addressing unpaid carers

TYPE OF MEASURES	DEFINITION / AIMS	MEASURES
Compensation measures	Means to reward carers' time financially or via social security rights	• Carers' allowance • Insurance right • Tax reliefs • Elder care benefit (if usable by the carer)
Supportive measures	Help to enable carers to carry out their caring activities	• Information (on the different services, allowances, support solutions available to meet the needs of an older person) • Counselling (on decision to make and services to use) • Training (competencies needed to care for an older person in terms of nutrition, transfers, mobility and activities of daily living) • Support groups (carers organization, carers' group subsidized by public authorities) • Formalized assessment of carer's needs (existence of specific assessment procedures for informal carers, psychological support and counselling by professionals) • Formalized definition of informal carer • Respite (measures which facilitate in-home or day care or institutional short time respite i.e. existence of this type of service and/or of financial support to pay for these services)
Conciliation measures	Interventions to facilitate carers who have a job to combine work and care	• Care leaves: short/long; paid/unpaid • Legal possibility of working flexibility

Different national LTC regime configurations and forms of familialism

In this report, the development over time of the LTC service sector is considered as a necessary element for a better understanding of the scope of the three types of direct policy interventions considered. The countries involved in our analysis cover a wide range of the care regimes, as identified in the literature (Anttonen et al., 2003; Anttonen and Sipilä, 1996; Daly and Lewis, 1998)[2]: the Nordic social democratic model (Sweden and Finland), the liberal model (England), the corporatist model (Germany) and the familialist model (Italy and Spain). While still maintaining a traditionally strong familialist orientation in the sector of LTC, France and Austria[3] have also developed LTC policies since the 1990s, and can therefore be considered as mixed models. Finally, our analysis includes transition countries (Bulgaria, Czech Republic, Latvia, and Poland), too.

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[2] Other approaches – e.g. those proposed by Kaschowitz and Brandt (2017) or by Pfeiferova et al.(2013) – classify countries according to a simpler criterion, based on the dichotomy family-services, thus distinguishing for instance only "service based" vs. "family-based" regimes.

[3] The Austria model has been considered "mixed" since it is characterised by strong familialist values, but at the same time by a stronger supply of care services than that usually reported by traditional familialist care regimes. Furthermore, the Austrian regime has several similarities with the German one (in terms of emphasis on cash, family, and migrant care work), but, unlike Germany, its long-term care system is not organized under a corporatist approach (as Pflegegeld is tax-funded, and not based on social contributions nor long-term care funds).

The care regime concept is an important element, as it characterizes and helps to understand the type of LTC policies which have been developing in the different countries and, particularly, the level of service provision, which constitutes an indirect support to families caring for older care recipients. No matter what starting LTC model characterizes a country, however, the concept of Welfare mix has to be adapted to the analysis of social care sector, which involves a combination of different providers, public, private and informal. Considering the growing importance of the family in all current national welfare configurations – in continuity or not with those prevailing in the past – Saraceno (2016) suggests focusing on the different forms of familialism taking place by means of positive, direct or indirect policy interventions, or even through the lack of public support. According to her conceptualization, three main models can be distinguished:

- familialism "by default" (or unsupported familialism): occurring when there are no or very scarce public alternatives to informal family care;
- "prescribed" familialism: taking place when familialism is actively enforced by laws;
- "supported" familialism: occurring when family care is recognized as (one of the) a solution to care for elderly people and various public measures are developed to help families to face their caring activities (direct or indirect financial transfers – e.g. via cash benefits or taxation – training, care leaves etc.)

In the following, after an analysis of the main policy interventions characterizing the investigated countries (based on the evidence gathered by means of country reports)[4], we will come back to this conceptualization in the attempt to outline the emerging trends currently taking place across Europe.

The range of policy interventions across European countries

This section proposes a mapping of the different policy measures (services or allowances) directly addressed to informal carers in the 12 investigated countries. In the following, we will refer to what is provided for by the current national legislation (i.e. excluding isolated local initiatives), without further analyzing whether and to which extent interventions are taken up by potential recipients. In this regard, it should be considered also that the provision of support services, payments or rights, is often complex and can take place at national, regional and/or local levels, depending upon the governance organization prevailing in each country.

As anticipated in the previous section, we distinguished the different forms of direct support provided to informal carers into three main types (defined as indicated in Table 1): compensation measures; supportive measures; and reconciliation measures.

Compensation measures

Under "compensation measures", we consider all interventions aiming at directly reward unpaid carers for their informal activity, by granting them financial or economic rights. These include in the first place carers' allowances, insurance or pension benefits for carers, as well as tax reliefs whose beneficiary is the carer his-/herself. However, since in many countries measures addressing older care recipients are often used to indirectly compensate their carers, these will be also considered in our analysis (unless this indirect form of use is explicitly excluded by the national legislation in force).

As shown in Table 2, in the majority of countries according to the current legislation no cash benefits are provided directly to the carer. When this occurs, it has often more a symbolic value, given the low amount it consists of. Exceptions are represented by England, Finland and Sweden. However, while in the former two countries these benefits take the form of cash compensations for the care provided, in Sweden it is represented by an employment contract between the carer and the municipality (so

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[4] Country reports are available at: http://www.cequa.org/copy-of-all-publications. A more detailed overview of the interventions available country by country is reported in the Appendix at the end of this section.

Table 2. Direct or indirect compensation measures available to unpaid carers, by country

	DIRECT COMPENSATION			INDIRECT COMPENSATION
	Carer's allowance	Insurance/pension rights	Tax reliefs for carers	Benefits to care recipients used to compensate carers for their informal support
Austria		●	●	+++
Bulgaria	+			+
Czech Republic				+
England	++	●	●	++
Finland	+++	●		++
France		●	●	+
Germany			●	+++
Italy	+°	●	●	+++
Latvia				
Poland	+	●		+
Spain		●^		++
Sweden	+++*			+

+ low level / ++ medium level / +++ high level

° legislated, but not yet implemented

* takes the form of a contractual employment of the carer to provide assistance to the care recipient

^ acquired by carers through contributions paid on a voluntary basis

that the latter becomes the employer of the carer – who is eligible only if no older than 65 – who receives salary and social protection like the staff of formal care services).

What is available in almost all countries is the possibility for the carer to be indirectly compensated via the cash benefits granted to the care recipient, who can use them to reward the carer for the informal assistance provided by him/her. However, also in this case it should be underlined that the amount of the benefits granted by current legislations reaches usually a relatively low or medium level, exceptions being represented by the more generous Austrian and German cash-for-care schemes. Less frequent seems to be other forms of compensation, such as insurance/pension rights or tax reliefs for expenses incurred for the care of dependent family members, that carers can claim directly as main beneficiary.

Supportive measures

Supportive measures correspond to interventions directly addressed to carers and aiming at assisting them in performing their assistive role. They include a wide range of possible interventions – information, counselling, training, support groups, formalized assessment of carers' needs, formalized recognition of carers, respite solutions – which are diversely present in the countries studied (Table 3).

Table 3. Supportive measures available to unpaid carers, by country

	Information/ counselling	Medical check ups	Training	Support groups	Formal recognition of carers	Formalized assessment of carers' needs	Respite
Austria	●		●	●	●	●	●
Bulgaria	●						●
Czech Republic	●		●	●	●		●
England	●	●	●	●	●	●	●
Finland	●	●	●	●	●	●	●
France	●		●	●	●	●	●
Germany	●		●	?	●	●	●
Italy	◗	◗	●	●	●		●
Latvia							
Poland							
Spain	●		●		●		●
Sweden	●		●	●	●		●

◗ Only in some regions

According to the availability of the different forms of supportive measures, we propose to distinguish between three types of situations: countries in which these measures are largely absent; countries in which some measures exist; and countries in which the wide range of measures exist (Table 4). In fact, a continuum can be identified, from countries where this type of measures is largely absent (Bulgaria, Poland and Latvia), to countries were the variety of possible supportive measures have been introduced (France or Finland). In an intermediate group of countries (Italy, Spain and the Czech Republic), a limited number of measures have been created and is available to carers.

An additional, potentially useful distinction can be made between measures related to the legal or formal recognition of the role of unpaid carers, and interventions intended to practically support carers in their caring activities, thus enabling the development of the competencies needed. In 8 out of the 12 countries studied, there has been an official recognition of the role of carers. This represents a step forward compared to the snapshot taken by Courtin and colleagues in 2014,

Table 4. Countries by level of availability of supportive measures for unpaid carers

Measures are largely absent	Some measures exist	Wide range of supportive measures	
Bulgaria Latvia Poland	Czech Republic Italy Spain	Austria Finland Germany	England France Sweden

which underlined that the (lack of) identification of informal carers as strategic component of the LTC system was a crucial weakness of existing policies in this sector. Our current mapping shows that countries have moved forward in further recognizing the role of informal carers through legislation, as shown for instance in Finland by the 2016 reform of the law on informal care support, in Germany with the 2015 Care leave Act, in France with the 2015 Act on adapting society to an ageing population, and in Austria with the introduction of a care leave in 2014. In Sweden, the 2009 Social services Act has been reviewed in 2014, confirming the obligation for social services to support informal carers, while in Italy different legislative proposals have underlined the recognition and support of family carers in 2016, leading in December 2017 to the adoption of a yearly fund of €20 million to support carers for the 2018–2020 period. It should be underlined, however, that while this process of a growing recognition through legislation of the role of unpaid carers can be considered as a common trend in Europe, no commonly agreed definition of informal carers still exists across countries.

Conciliation measures

Increasing employment rates and generating economic growth have become core objectives in European Union's Member States. As part of the global "supportive measure" category, reconciliation measures represent one of the main dimensions of public intervention towards unpaid carers. Carers' – and more particularly women's – participation to the labour market has indeed begun to require EU member states to introduce or extend their reconciliation policy measures, in both child and elder care (Saraceno 2010, 2016).

Different types of interventions can be identified as relevant to the reconciliation objective (Table 5). They aim at giving carers more time to combine their different care and work responsibilities, and to allow the flexibility needed to provide support to older parents without giving up jobs. Providing time to

Table 5. Availability of conciliation measures for unpaid carers, by country

	Long unpaid care leave	Short unpaid care leave	Long paid care leave	Short paid care leave	Working flexibility
Austria			●	●	●
Bulgaria	●		●		
Czech Republic			●		●
England		●			●
Finland		●			●
France	●	●		◗	●
Germany	●			●	●
Italy	●		●	●	
Latvia					
Poland				●	
Spain					
Sweden			●		●

◗ Possibility to receive a small financial compensation for a maximum of 3 weeks.

both professional and caring activities is therefore the key objective of these measures. Among the measures that are most frequently available are the possibility to work flexibly and to benefit from a longer period of paid leave (although the level of payment and conditions for taking up these measures vary across countries).

A first possible criterion to classify countries in this regard refers to the level of availability of the different conciliation measures (Table 6). According to this criterion, we can distinguish: countries in which these measures are absent; countries where two types of conciliation measure exist; and countries where a variety of conciliation measures exist. Except from Latvia, Poland and Spain, all countries have introduced explicit reconciliation measures. Despite the many differences between the LTC policy in Germany and Italy, both countries have developed a variety of reconciliation measures. This evolution is recent in Germany, whereas it has existed since the 1990s' in Italy. The Finnish case should be more precisely clarified, since the main existing "care leaves" correspond actually to "carers' breaks" for the so called "compensated informal carers", i.e. those who have a contract with the municipalities to take care of their older relative. A leave of absence from work to care for a sick relative has also been introduced in this country in 2011, but, just as in France, it is unpaid and marginal (Kroger and Yeandle, 2013).

A second result concerns the characteristics of the care leaves introduced in 9 of the 12 investigated countries (Table 7). Though there is a common orientation to facilitate reconciliation in these countries, the contents of the measures developed are different, for two reasons. First, because the existing care leaves, which are all limited in time, can either be long, i.e. lasting three or more months (this being the case in 7 out of the 9 countries) or short (this applying to (5 out of the 9 countries). In most countries, the long care leaves often concern the end of life of the cared for. Short leaves aim instead at giving carers the possibility to claim time off work to deal with care-related sudden, unexpected emergencies or difficulties, and to facilitate the organization of care activities.

Table 6. Countries by level of availability of conciliation measures for unpaid carers

Measures are absent	Two types of measures		Variety of measures
Latvia Poland Spain	Bulgaria Sweden England	France Czech Rep Finland	Austria Germany Italy

Table 7. Countries by duration of the care leaves available to unpaid carers

	Paid		Unpaid
Short (days off)	Austria Germany France	Bulgaria Italy Poland	Finland
Long (3 months or more)	Austria Czech Rep	Sweden Italy	France Germany England

Secondly, the financial benefit related to the care leave can vary greatly. In some countries, beneficiaries continue to receive a full salary, up to a rather high income level (e.g. €41,000 per year in Italy, or full compensation of salary for short care leave in Austria), in others they receive more limited financial compensation (from 80% in Sweden, to 55–60% in Germany or the Czech Republic), while in some the care leave is fully unpaid (Finland, France and England). In France, a financial compensation exists for one of the two possible short care leave forms existing – which concerns end of life of the older person – but only to a very limited extent (i.e. €50 per day for a maximum of three weeks).

Finally, it should be mentioned that working flexibility exists in 7 out of the 12 countries studied. However, considering measures specific to elder care (we will not analyze here the general legal right to flexible working hours, which exists for example in England or Italy), working flexibility is mainly possible through the use of care leaves which give the possibility to work part time.

Evolution of familialism across the different LTC regimes

In this section, we adopt a national configuration perspective to analyze the direction of current developments in the different countries. Core questions of this analysis are: what does the mapping of the measures addressed to informal carers suggest about the different national LTC configurations studied? Is it possible to draw a comparative analysis of the policy interventions that have been developing throughout Europe to support informal carers? Table 8 summarizes the types of measures addressed to informal carers existing in the investigated countries and, based on their evolution, suggests how recent developments might have affected (or not) the forms of familialism in each country, according to Saraceno's typology.

Table 8. Overview of countries by available measures and forms of familialism

	Compensation measures*		Supportive measures	Reconciliation measures	Forms of familialism
	Formalized	Financial			
Sweden	Strong		Developing	Developing	"Supported"
Finland	Strong		Strong	Weak but developing	"Supported"
England		Middle	Developing	Developing	"Supported"
Germany		Strong	Developing	Developing	"Supported"
Austria		Strong	Weak	Developing	From "by default" to "supported"
Czech Republic		Weak	Developing	Developing	From "by default" to "supported"
Italy		Strong	Weak	Strong	From "prescribed" to "supported"
Spain		Weak	Developing	Weak	From "prescribed" to "supported"
France		Weak	Strong	Weak but developing	From "prescribed" to "supported"
Bulgaria		Weak	Weak	Developing	From "by default" to "partly supported"
Poland		Weak		weak	"By default"
Latvia					"By default"

* We distinguish here between financial compensation (i.e. cash allowance) and formalized compensation (i.e. formalization of the role of informal carers through a contract).

On the whole, a common trend towards the form of "supported" familialism seems to characterize developments in several countries. However, the components and intensity of such an evolution vary from one country to another.

In Sweden and Finland, for instance, support for carers was traditionally indirect, through the development of publicly subsidized services addressed to older people at home and in institutions. In more recent times, however, with the increase in the need for informal care, explicit measures addressed directly to carers have been promoted. This concerns both compensation measures –following a particularly intensive approach in Finland with the status of "compensated informal carer", that gives access to contractual financial compensations and a right to respite – and supportive measures, also in Sweden, where however reconciliation measures seem to be a currently more strongly pursued objective.

Another country that seems to fit into the "supported" familism group is England. The English government has been among the first to adopt measures designed to support carers, as early as in the 1960s, and these interventions cover today a wide range of areas. However, only recently a stronger emphasis has been put on reconciliation measures, with the creation of a specific leave that, even if it is unpaid, meets the need of an increasing number of carers juggling between work and care responsibilities in everyday life.

Italy and Spain, two traditionally familialist countries, seem to have both evolved from a "prescribed" familialism to a "supported" form of it, but following different paths. This concerns, on the one hand, the type of implemented interventions, as emphasis has been put in Italy more on reconciliation and (traditionally strong) financial compensations, while in Spain the focus has been more on developing supportive measures. On the other hand, it should be underlined that Spain's policy efforts in the area of informal care – albeit partly weakened by the impact of the international economic crisis - have been undertaken within the framework of a major reform involving the whole LTC sector, of which there is no sign in the Italian context (Casanova et al., 2017).

As for France - a country characterized by strong familialist values, albeit partly mitigated by the development of substantial, nation-wide LTC policy measures - it can be stated that it has been moving towards a "supported" form of familialism, too. This is mainly the result of the fact that public authorities stressed supportive measures as the main answer to help informal carers, while reconciliation measures, remain comparatively weak, and compensation measures are deliberately out of the traditional French policy focus.

Germany, which is part of the corporatist model with its LTC insurance, has also a strong tradition of familialism as far as social care is concerned. Through the introduction of the LTC insurance scheme, a form of supported familialism has been established, which has been recently further strengthened via additional supportive and reconciliation measures.

Last, but not least, different speeds and directions seem to characterize the developments taking place in the so-called transition LTC regimes in Central and Eastern Europe. Among the four included in the current study, the Czech Republic seems to be undoubtedly the most dynamic and structured in pursuing a policy towards a "supported" form of familism, by means of a series of interventions addressing carers especially via supportive and reconciliation measures. Less evident, if not even absent, are the steps undertaken by the other three countries, with Bulgaria reporting some progress in the promotion of carers' work-life balance and Poland offering some form of very weak financial compensation.

Limitations

It should be underlined that the country reports (on which the analysis carried out in this section is based) had the purpose of providing only a general overview of recent developments in the broad field of LTC. Therefore, while they included a specific section dedicated to report policy innovations taking place in the field of informal/unpaid care, they could not deliver any in-depth, detailed examination of all components making up the policy framework characterizing each country. As a consequence, our analysis can provide only a glimpse of current general trends, without any systematic historical perspective.

Notwithstanding, we believe the analysis offered in this section allows to usefully integrate the information provided by Courtin et al. (2014), as well as the most recent comparative studies of national reconciliation policies carried out at EU level (Bouget et al., 2016; Ghailani, 2018), for two reasons. First, it focuses on unpaid carers of older people only, thus providing more specific information than that, more generic, delivered by the above-mentioned studies (which illustrate, more unspecifically, policies and measures concerning carers in general, including those caring for children or dependent adults, who might by characterised by different needs and conditions). And, secondly, it adopts a more comprehensive approach, aimed at understanding all different kinds of policies, and not limited to some dimensions only (such as for instance those in the area of work-life balance).

Since this research led in 2018, the reflection proposed on forms of familialism has been continued with a recent publication investigating in depth the evolution of familialism in European countries (Le Bihan et al., 2019).

Section 3. Does it work? Evidence about the consequences of policies and interventions for supporting unpaid carers

The sections below summarise evidence related to effectiveness and costs of a number of interventions to support unpaid carers, in areas related to psychological and physical health, impact on institutionalisation of the person cared for, employment consequences and we also review evidence on costs and cost-effectiveness. We present a summary table of key evidence in Appendix 3.

Methodology

This section is based on a rapid literature review which aimed to summarise international evidence regarding the (cost) effectiveness of interventions to support unpaid carers. Narrative, systematic reviews and meta-analyses in English were searched for in the Cochrane Library of Systematic Reviews, google scholar, web of science, PubMed and other relevant websites; academic and research reviews were included (see Appendix 2 for full details of data sources and key phrases used for rapid literature review). The searches were not restricted by age, or country and included documents published between 2006 and 2016. International evidence in English was completed by evidence from selected European countries in their respective national languages based on individual studies not included in international evidence. Although there was an overlap of primary studies in the reviews, it was not formally investigated in our review and warrants future evaluation. The effect of this overlap is difficult to judge without substantial additional analysis, but it could run the risk of exaggerating effects from the undue influence of individual studies, and present difficulties arising from contradictory assessments of the same study.

Quantity and quality of available evidence

Despite increasing policy emphasis to support unpaid carers, literature review highlighted that evidence of interventions for carers in the areas of indirect support, direct support, work conditions and combinations of these, is scarce. Literature often highlighted gaps in the evidence base regarding groups of carers as studies often focus on carers of people with dementia. For example, out of 52 high and medium quality systematic reviews included in a recent meta-review, 24 reviews concerned carers of people with dementia, 10 carers of cancer patients, 6 carers of people with stroke, 4 were of carers of people with mental health problems and remaining 8 of carers of people with various conditions (Thomas et al., 2017). There are also gaps regarding types of interventions studies (evidence on multicomponent interventions composed of psychosocial or psychoeducational content, education and training were more commonly studied than e.g. respite care), and outcomes studied (e.g. aspects of psychological/mental health/wellbeing and QoL are studied more often than physical health), and studies on cost-effectiveness are limited.

Several reviews concluded that in many cases it may be that a combination of interventions, or a multi-dimensional intervention, that 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 (Dickinson et al., 2017; Gilhooly et al., 2016; Thinnes and Padilla, 2011; Thomas et al., 2017; Vandepitte et al., 2016). The lack of evidence of effectiveness does not mean that these interventions had no positive impact; rather it may reflect poor quality primary research, which was highlighted by many reviews, heterogeneity of interventions and of instruments used for outcome measures, poorly defined outcome measures, short follow-up periods as well as small sample sizes in primary research which made it often difficult to compare results and to conduct meta-analyses (Greenwood et al., 2016; Jones et al., 2012; Lopez-Hartmann et al., 2012; Maayan et al., 2014; McKechnie et al., 2014; Shaw et al., 2009; Thinnes and Padilla, 2011; Thomas et al., 2016; Vandepitte et al., 2016). Available evidence is often drawn from UK, USA and Canada, reviews also include evidence from a number of European countries including Germany, Austria, France, Italy, Spain, Sweden, Finland, Norway, the Netherlands, Ireland, Russia with a pronounced lack of studies from Central and Eastern Europe. Because primary studies were conducted in a range of countries, there is a question as to how transferrable the findings are, given the diverse nature of health and social care provision across different settings.

Furthermore, as Thomas et al. (2017) noted, outcome measures might have little relevance to the recipients of the interventions. The authors asked carers to give their views on the overall findings of their meta review to examine whether the interventions reviewed were ones that carers might find helpful. They found that carers of people with different conditions may find different types of interventions useful and effective different. Similarly, what might be useful and effective at one stage in the caring trajectory might not be useful or effective at another stage. Such differences, as Thomas et al. (2017) noted underlined the difficulty of selecting an appropriate 'control' group of carers or conditions in a controlled research design. Carers also felt that variations in caring situations and across carers made it difficult to see that a single intervention could be the 'answer' in supporting carers. Rather, as they put it, 'because of the complexities of the situations there is unlikely to be a one size fits all that will be right at any one time'. All interventions assessed as effective in the meta review were seen as acceptable by consulted carers, but they pointed out that what was actually available was limited and incomplete, and that although education and training for the carer might have a part to play, this was no substitute for 'direct intervention on the carer's own behalf'. They also raised the issue of the value to carers of standard services, including respite, provided to the person they cared for (Thomas, et al., 2017).

This was also the conclusion reached by the European Social Policy Network (ESPN). Overall, ESPN experts considered that the best way to reach the objective of a good work life balance for carers is to design and to implement a broad-based, comprehensive and coordinated policy of services to those receiving care (European Commission, 2016).

Evidence on specific interventions outcome and type of intervention

Existing evidence illustrates a negative association between caring and carers' psychological health, such as depression, anxiety and overall poorer wellbeing, including stress and burden (Gilhooly et al., 2016; Thinnes and Padilla, 2011). There is less evidence on the impact of caring on physical health, however available review data show that carers have worse physical health than non-carers (Bauer and Sousa-Poza, 2015; Brimblecombe et al., 2018; Legg et al., 2011). Intensity of caring and co-residence are significantly associated with poorer health, duration of care provision was also found to have a significant effect on carers' physical health (Brimblecombe et al., 2018). The research findings also differ strongly among subgroups, although there is some evidence that female, spousal, and intense caregivers tend to be the most affected by caregiving (Bauer and Sousa-Poza, 2015).

Outcome: Psychological health: stress, burden, depression, coping

Respite care The evidence on the impact of respite care on carers psychological health are mixed. For example, there is some evidence from three high quality systematic reviews that although caregivers were highly satisfied with respite care for frail elderly people, they experienced small or none improvements in burden, physical or mental health (Lopez-Hartmann et al., 2012; Maayan et al., 2014; Mason et al., 2007; Shaw et al., 2009).

Respite care was related to improvements in anger and burden after 3 and 6 months follow up, however it had negative impact on caregiver's quality of life after 6 to 12 months (Shaw et al., 2009). No intervention effects of respite care on caregiver stress, burden, anxiety and other measures of psychological health were reported in Maayan et al. (2014)[5], however there is tentative evidence that some caregivers benefit more than others. For example, vulnerable caregivers, with a severe mismatch between care giving demand and help received in the preceding six months, who receive respite care, showed significantly reductions in stress biomarkers, however non-vulnerable caregivers did not (Maayan et al., 2014).

Masons et al. (2007) review suggested that respite for caregivers of frail elderly people generally has a small positive effect on caregiver burden, caregiver mental or physical health; it had positive effect on burden and depression but negative on quality of life. The review found no evidence that respite affects care recipients (positively or negatively). Caregiver satisfaction levels for all types of respite were generally high and caregivers appeared to be more satisfied with respite than with usual care (Mason et al., 2007).

Two meta reviews found none or negative effects of respite care[6] (Parker et al., 2010; Thomas et al., 2016), for example an adverse intervention effect was noted for respite care and stress and burden with a statistically significant increase in carer burden (based on two studies were included; quality was not reported) (Thomas et al, 2017). As Thomas et al (2017) meta review noted the effectiveness of respite care remains a paradox, given the apparent conflict between empirical [7]evidence and views of carers, calling for research triangulating qualitative and quantitative evidence on respite care. The lack of evidenced benefits of respite care may however reflect the lack of high-quality research rather than actual lack of positive results (Brimblecombe et al., 2018; Maayan et al., 2014).

Technology-based interventions Existing international evidence illustrates a mixed, but generally positive impact of various technology-based solutions for carers (and people they care for) on carers' wellbeing and psychological health.

For example, a systematic review evidenced that computer interventions containing educational or professional therapy material reduced dementia caregivers' anxiety levels, increased self-efficacy and reduced stress and depression levels, although results were mixed in relation to social support (McKechnie et al., 2014).

Another literature review concluded that carers of people with moderate to severe dementia who had access to therapists, professional carers or support groups via videoconferencing, email, text messaging or web-based platforms could experience enhanced social interaction and enjoyment, improved quality of life, or enhanced ability to recognize their needs. There was also some evidence in the review that commercially available sensors for people with moderate to severe dementia could improve outcomes of their carers, providing them with enhanced feelings of safety and improved quality of sleep (Knapp et al., 2015),

Similarly, a Cochrane review concluded that telephone counselling without any additional intervention can reduce depressive symptoms and also meets the important needs of carers, the conclusion on depressive symptoms was supported in the analysis of three moderate quality studies (Lins et al., 2014).

Web-based carer support interventions, and Caregiver's Friend schemes involving delivery of positive caregiving strategies via text and video revealed positive intervention effects (overall four studies of different quality) (Thomas et al., 2016). No adverse effects were found in any of the above studies. The findings could support the provision of computer-mediated interventions for carers.

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[5] The authors' conclusion of this Cochrane review was based on four randomised controlled trials comparing respite care with a control intervention for people with dementia, all rated as of very low quality.

[6] The latter meta-review (Thomas, 2017) was an update of the earlier one (Parker 2010).

[7] Thomas' meta review included 61 systematic reviews (27 high quality; 25 medium quality; and 9 low quality).

However, reported interventions in the above reviews were for carers of people with dementia and studies on the impact of technological interventions on other groups of carers are limited. Studies on the technological solutions for people in need of care show mixed results: for example, technologically provided 'therapeutic' entertainment, for persons with dementia decreased psychological distress and had a respite' effect for the carers.

Although telecare was reported to have potential to improve carers' wellbeing, technological devices were reported to create additional work for carers to ensure that devices worked effectively sometimes leading to additional stress and anxiety, which indicates the need to include carers' needs in the assessment process and ensure appropriate training for carers (Knapp et al., 2015). The reviews however noted that the effectiveness evaluations in technology-based interventions are complicated by the speed of technological development and because technologies are used alongside other services, making it hard to identify their separate effects (Knapp et al. 2015).

Psychosocial, psychoeducation, therapy, support groups and other interventions Overall, a number of reviews, including two meta-reviews (based on narrative and statistical syntheses) revealed positive effects of various educational, psychosocial interventions and support groups on carers' outcomes.

Thomas et al. (2017) meta-review found that the strongest evidence of effectiveness was in relation to education, training and information for carers. These types of interventions – particularly when active and targeted rather than passive and generic – appeared to increase carers' knowledge and abilities as carers. There was some suggestion that this might also improve carers' mental health or their coping. The review concluded that this latter possibility remained to be tested rigorously in research specifically designed to do so and that explored both effectiveness and costs. Positive effects were found on depression following a homecare education intervention with professional support; and for anxiety and depression after a befriending intervention. Quantitative syntheses showed statistically significant positive intervention effects on depression following educational interventions and on anxiety and depression following cognitive reframing interventions and for carer support groups (Thomas et al., 2016).

Another meta-review[8] found psychosocial and psychoeducational interventions, support groups, multicomponent interventions as beneficial in improving mental health and reducing depression for caregivers of people with dementia (Gilhooly et al., 2016). Similar findings were presented by Dickinson et al. (2017) systematic review of systematic reviews[9] and the authors concluded that the greatest effectiveness of psychosocial interventions for carers is achieved when the interventions include both an educational and a therapeutic component; the effectiveness is increased when the intervention is delivered via a support group.

A Cochrane review reported a statistically significant reduction in caregivers' stress and strain, general distress, depression, improved health related QALY following an intervention focusing on 'teaching procedural knowledge' (formal multidisciplinary training of caregiver in the prevention and management of common problems related to stroke) when compared to usual care carers of stroke survivors. The review however found no significant effect on carers' outcomes for psychoeducational or information and support interventions (findings presented here based on one study, high quality) (Legg et al., 2011).

Van Mierlo et al. (2012) review of psychosocial intervention for family carers of persons with dementia concluded that most positive intervention effects were found in the subgroup of female carers of people with a diagnosis 'dementia not otherwise specified'. The positive effects were most often

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[8] Based on 45 systematic reviews, of which 15 were meta-analyses.

[9] Most of the studies in this meta-review overlap with the meta-reviews by Parker et al. (2010) and Thomas et al. (2016).

related to the outcome categories ‘competence and self-efficacy’ (n=33) and ‘mental health’ (n=24). The fewest positive effects were reported on outcome categories ‘quality of life’ (n=6) and ‘attitude towards person with dementia’ (n=6).

Other reviews found positive effects of psychosocial interventions on carers’ self-efficacy (Tang and Chan, 2016) and of psychosocial education as well as CBT therapy on carers (of older people with physical or psychiatric disability) reduction in depression, perceived stress, caregiver burden, anger and hostility, Improvement in self-efficacy, overall mood, adaptive coping, well-being, psychological and social quality of life (Coon and Evans, 2009).

A review reported no difference in carers’ (of people with dementia) outcomes (GHQ) between a specialist nursing (Admiral Nurse) intervention providing education and psychosocial support and a control group (receiving help from CPNs or memory clinic), although the intervention was valued by carers (Bunn et al., 2016). However, another review found a positive effect of advanced nursing practice intervention offering psycho-social support on caregivers depression (after 2 and 4 weeks) (Lopez-Hartmann et al., 2012).

Vandepitte and colleagues (2016) systematic review concluded that psychoeducational interventions are the most commonly investigated in RCTs and non-RCTs and overall the evidence supports their effectiveness (86% of studies included in the review evidenced benefits) although showing the typical inconsistency in the findings. Of this broad type, the multicomponent interventions were frequently studied, illustrating positive impact on caregivers (83%) especially in self-efficacy, burden, and depressive symptoms. However, they had in general less effect on care-recipient outcomes (39%) except for delay of nursing home placement. The single component psychoeducational interventions solely focusing on one strategy (such as education, social support) were less effective (67%) than multicomponent interventions (90%).

Outcome: Impact on physical health

There is less evidence on the effectiveness of intervention on carers’ physical health. Physical health (where defined) included physical distress, somatic complaints, physical functioning, perceived or subjective health status, and sleep improvement. Some formal outcome measures were reported (e.g. Health Status Questionnaire (HSQ)-12). Seven reviews included in a recent meta-review which reported on carers’ physical health, overall reported some improved physical health outcomes for carers. For example, a narrative synthesis showed reductions in physical distress of carers of people with cancer following couple-based psychosocial support involving disease management, psychoeducation, telephone counselling, and a development of family coping skills (two studies; one strong and one moderate quality). A meta-analysis revealed a small statistically significant effect of multicomponent psychoeducation activities for carers of cancer patients for physical functioning (self-care behaviours and sleep quality) (six studies; quality not reported) (Thomas et al., 2016). Van Mierlo’s et al. 2012 review of evidence (based on four studies reporting on physical health) concluded that interventions successful in improving physical functioning in carers of people with dementia were: an education and support programme; cognitive behavioural therapy; an exercise programme and nutritional education; and a nursing intervention using the Progressively Lowered Stress Threshold Model. The type of dementia, mental health problems and presence of anxiety in the person with dementia were related to positive intervention effects for carers (Van Mierlo et al., 2012).

Outcome: Impact on institutionalisation of the person cared for

Based on three reviews, a meta review found delays to institutionalisation of people with dementia with support programs, psychosocial and multicomponent interventions for carers (Gilhooly et al., 2016). Similarly, there is some evidence that multicomponent strategies (e.g. supportive and educational strategies, family counselling) for caregivers significantly decreased the odds of and increased the time to institutionalization of people with dementia (Thinnes and Padilla, 2011) and reduced the rates of nursing home placement of people with Alzheimer's disease (Mittelman et al., 2006). Another meta-review reported mixed results. While no effects of carers' cognitive reframing were found on institutionalisations in one identified review, another review reported that caregiver psychotherapy delayed institutionalisation, yet another one reported that although psychoeducational interventions had no effect on institutionalisation, multicomponent interventions were significantly related to delayed institutionalisation of persons with dementia, multicomponent interventions were also associated with a delay in the institutionalisation of people with mild to moderately severe Alzheimer's disease in another review (Dickinson et al., 2017). Mason et al. (2007) review found no reliable evidence that respite care delays entry to institutional care.

Outcome: Employment consequences

Very limited evidence exists on the consequences of interventions on carers' employment, and the existing evidence focus on evaluating impact of indirect support for carers (support for the person in need of care). Bauer et al. (2015) review of evidence on the impact of informal caregiving on carers employment noted that despite the prevalence of informal caregiving and its primary association with lower levels of employment, the affected labour force is seemingly small. Quantitative analysis suggests that the relationship between informal care provision and labour market outcome differs between Northern, Central and Southern Europe. Investment in informal caregiving decreases the probability of working for men (not for women) and reduces the number of hours worked for both men and women more in Central Europe than in Southern Europe. The caregiving role reduces the number of hours worked more for men in Northern than in Southern Europe. Bohlin et al. (2008) explain these results by different cultural contexts: "outcomes might be less severe in countries where norms favouring family loyalties and intergenerational support are stronger, since more acceptance will exist among employers and employees, when caring for ones` older parents". Consequently, the authors noted that numerous dimensions that effect outcomes must be considered when transferring evidence from one country to another (Bolin et al., 2008).

Brimblecombe (2018) concluded that there is evidence illustrating a positive relationship between formal services by the care-recipient and carers' employment. For example, two studies in the review (UK and US), demonstrated an association between provision of formal care and a higher probability of employment for carers. The association was particularly strong for women, for people who provided care for more than 10 hours a week and for those providing higher intensity care. Similarly, two studies using the Survey for Health, Aging and Retirement in Europe (SHARE) data, and EUROFAMCARE multi-country study found increased labour force participation to be associated with formal care services, in one study this association was stronger for daughters. Brimblecombe (2018) noted that literature tends not to differentiate between the type of services and impact on employment of unpaid carers.

There is some evidence from England that home care, day care, personal assistants, and meals-on-wheels are most effective in supporting carers employment, while 'short breaks' are effective in supporting carers' employment but only if combined with other services (Pickard et al., 2015).

There is also some evidence that assistive technology for service users can be effective in helping carers achieve a better balance between work and care, however, it has been noted in the literature that such solutions may be helpful if they are part of a broader package of services and support (Brimblecombe et al., 2018).

An overview on the impact of flexible work, care benefits, care leaves, respite care and formal long-term care provisions, on unpaid carers' employment in Poland noted lack of evidence around their effectiveness and also limited uptake. For example, only around 300 companies in Poland signed an agreement to support flexible work for carers with very limited impact (Muszyńska, 2003).

Costs and cost-effectiveness

Evidence on costs and cost-effectiveness is not only limited, but it also illustrates mixed results. Several studies found significant difference in costs between intervention and control groups: a study on carers receiving subsidised day care services found the average daily cost for the control group to be lower than in the intervention group (US$41.15, compared to US$47.10 for the intervention[10]) at 12 months.

Another study found a significant difference for caregiver costs of psychosocial interventions at 12 months (intervention group costs Can$4,545, control group costs Can$2,005), but there was no difference in the costs when these were calculated per caregiver and person they cared for dyad (Jones et al., 2012).

There is some evidence from one study on cost savings based on total annual health and social care costs where carers of stroke patients received an education and training intervention and it was reported that the cost reduction was likely due to differences in length of hospital stay (Thomas et al., 2016).

Knapp et al. (2013) reported on a randomised trial evaluating a multi-component psychosocial intervention for carers and behaviour management for the care recipient where each additional care-free hour for carers cost approximately $5 per day or an extra $893 over a six-month period (Knapp et al., 2013).

Based on one study, a befriender facilitator intervention mean costs per caregiver at 15 months were £122,665 for the intervention group and £120,852 for the control group and the incremental cost-effectiveness ratio (ICER) was calculated at £105,954[11] with a 42.2% probability that the ICER is below £30,000 per QALY (Charlesworth et al. 2008 in Jones et al., 2012).

Another study showed no evidence of cost effectiveness from a volunteer befriending intervention for carers of people with dementia (Smith et al. 2014 in Thomas et al., 2016). In-home/telephone tailored occupational therapy program for a dyad of caregiver and the person the cared for was reported to have mean cost per patient at 12 weeks lower in the intervention group than the control group[12] (Jones et al., 2012).

One review illustrated inconclusive evidence of cost-effectiveness based on six studies looking at the total costs of home palliative care (not defined further) versus usual care for carers of people with various conditions (Thomas et al., 2016).

Two reviews included in the Parker et al (2010) meta-review found no evidence of cost-effectiveness for respite care. The range of costs collected in studies varied, with studies including health service use, social service use, informal caregiving time or a mixture of all three (Jones et al., 2012; Knapp et al., 2013).

In this section we have drawn on international review to highlight key evidence related to (cost) effectiveness of interventions to support unpaid carers. In the concluding section below, we bring together main messages from this study and present some policy implications.

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[10] Loss of employment hours were costed using hourly wage estimates from the Bureau of Labor Statistics (US) Jones et al. (2012).

[11] Base-case analysis was on costs and effects at 15 months. Mean QALY gains per caregiver were calculated using EQ-5D data and were 0.946 for the intervention group and 0.929 for the control group at 15 months, a non-significant difference (p = 0.315).

[12] Outcome measures were collected at baseline, 6 and 12 weeks. Intervention lasted

Section 4. Discussion, policy implications and future research

The global increase in life expectancy and ageing of the population translates into increasing number of people in need of LTC, positing challenges to the sustainability of formal care systems. This has meant that policy and research interest in carers who provide support on an unpaid basis to disabled, ill or older people has grown in importance over the last decade. 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 (Brimblecombe et al., 2018). The key aim of this report was to examine international evidence on interventions to support unpaid carers (cost-) effectively and to analyse policy measures implemented in European countries to support carers.

With regards to policy measures directed at informal carers in Europe our analyses illustrated that compensation measures (aiming at rewarding carers' time financially or via social security) available in most countries include the cash benefits granted to the care recipient. Supportive measures (aiming at assisting carers in performing their role, including a wide range of interventions from support groups to respite care) are largely absent in some countries (Bulgaria, Poland and Latvia) whereas in others (France or Finland). A variety of supportive measures have been introduced. While reconciliation measures are developing in all countries: working flexibility opportunities exist (legally) in 7 out of the 12 countries studied; care leaves were introduced in 9 of the 12 investigated countries, however they vary widely in both length of leave as well as wage replacement.

Link between care regimes and the type of familialism remains tentative. Supported familialism, i.e. when family care is considered to be a solution to care for people with care needs and public measures developed to help families to face their caring activities, is expanding in most sampled European countries, including CEE. Yet, different forms of supported familialism can be identified in relation with the type of measures (compensation type, supportive type or reconciliation type) addressed to informal carers. These forms include a strong policy choice towards supportive measures type – information, training and respite – (France and more recently in Spain), as well the introduction (Finland) or further development (Italy, Germany, Austria, England) of the traditional compensation measures. Though there is a common trend to facilitate work/life balance in all countries, the impact of the measures developed varies considerably, due to the characteristics of the care leaves.

Current international research evidence on interventions to support carers points to mixed and limited results, particularly where questions of (cost-) effectiveness are concerned. The most robust evidence illustrating positive effects relates to provision of education, training and information for carers. The evidence suggests that such interventions improve carers' knowledge and abilities and may also improve their mental health, coping and carers' burden. Beyond this, research evidence is often mixed. It should be however pointed out that few studies included in the examined reviews demonstrated negative interventions' effects.

Although evidence relating to respite care often illustrated no effects and, in some cases negative effects, in qualitative studies carers appeared to value respite care in helping them to continue in their caring role: this stark conflict between statistical evidence and views of carers calls for research triangulating qualitative and quantitative methods. Careful distinction between different types of respite is needed in primary research as well as assessment of quality of respite to improve the current evidence-base. Furthermore, the literature review indicated that examining costs per carer and person they care for dyad is vital to obtain a robust picture of outcomes and costs involved. Importantly, reviews often conclude that it may be that a combination of interventions, or a multimodal intervention, are most effective in supporting carers. As carers are a diverse group, there is also an urgent need for studies to examine impact of interventions for different types of carers, for example, there is a distinct gap in the evidence relating to carers from minority groups.

Overall, the evidence on the (cost-)effectiveness of schemes to support carers tends to involve poor quality primary research based on small samples, and outcome measures which not always reflect outcomes valued by carers. The evidence-base also tends to be geographically biased to the cases of the United States, England and Canada, with a pronounced lack of studies from Central and Eastern Europe. This brings to light the crucial need for better data that allows us to draw robust and comparative conclusions. This requires inter-disciplinary cooperation between researchers to carry out experimental and mixed-method research. The reality of mixed findings necessitates trade-offs and imperfect solutions when translating research evidence into policy measures.

Knowledge of the local care systems and the needs of different population groups is vital to design measures to support a wide range of carers. Still, it is also important to remember that generic services for the people with care needs may be critical to carers' health and well-being (Bouget et al., 2016; Vandepitte et al., 2016). For example, if people with care needs receive good quality and prompt health care services both they and their carers may benefit. Similarly, if people with disabilities are provided with opportunities to meet other people, carers may benefit from the potential positive effect this activity may have on the mood of the person they care for (Thomas et al., 2017). This places the onus on policy makers to proactively combine support specifically designed to support carers with other solutions which are likely to improve support for people they care for.

Appendices

Appendix 1A: Overview of support policies for informal carers in Austria, Bulgaria, France and Germany

	Austria	Bulgaria	France	Germany
LONG-TERM CARE				
Elder care benefit	Cash-for-care (Pflegegeld) to compensate care-related expenses, often used as symbolic payment to informal carers	Yes, means tested, dependent on degree of loss of dependency Can be used for heating, transport etc, but not for LTC services (these are provided in kind) (Mincheva & Kanazireva 2010; Office of Retirement and Disability Policy 2010)	Yes Cash-for-care to finance a specific care package	Yes LTCI gives the choice between cash or in-kind services
COMPENSATION MEASURES				
Carer's allowance	No, but cash-for-care (Pflegegeld)	Yes Financial social assistance for carers of severely ill family members. Initially meant for unemployed family members. Temporarily suspended due to lack of funds	No However, cash-for-care scheme can be used to pay a wage to a relative (except spouse) Low numbers of claimants	Yes Cash-for-care can be used for informal carers
Insurance/ pension rights	Cost-free health and retirement insurance for informal carers who would otherwise be able to participate in the labour market. Old age pension paid by federal government since 2009	No	Yes Entitlement to social security when caring for an older person 75+	Yes (Courtin et al. 2014)
Tax reliefs for care recipients	Care-related expenditure is tax-deductible for people in need of care (Costa-i-Font & Courbage (2011)		Yes (OECD 2011a)	Yes (Theobald 2011)
Tax reliefs for carers	Yes Relief for care-related expenditure by informal carers of family members (excess on extraordinary expenses / Selbstbehalt)		Yes	Yes Disability and Carer's Allowance in Germany (2012).

Appendix 1A: Overview of support policies for informal carers in Austria, Bulgaria, France and Germany (continued)

	Austria	Bulgaria	France	Germany
SUPPORTIVE MEASURES				
Information Counselling	Yes Information services at national level (Courtin et al. 2014) Information and support services at various levels (NGOs, regional/local authorities, counselling centres etc.)	Yes But very limited	Yes Local information centres and national web platform)	Yes Information centers for beneficiaries and their relations (Pflegestützpunkt)
Medical check ups	No	No	No	No
Training	No	No	Yes	Yes Informal carers can choose to participate in training in first aid and basic care
Support groups	Yes National level: “Interessensvertretung pflegende Angehörige” umbrella organisation for support and advocacy of informal carers Local level: support groups by NGOs and/or local authorities	No	No	No
Formal recognition of carers	Yes, informal carers of close relatives are eligible for benefits such as cost-free insurance, respite care, etc.	No	Specific definition of carer in 2015 Act on Adapting society to an ageing population	Broadening of the definition of “close family” in the 2015 Care leave act
Formalized assessement of carers’ needs	Free counselling by psychologists, social workers or other experts (aim: prevention of health-related strain due to informal care)	No	Taken into account in assessment procedure of the situation of the cared for (to receive cash for care)	Six module assessment used to define need for care, irrespective of type of benefits chosen (i.e. cash versus in-kind
Respite	Financial contribution to substitutionary care costs in case of illness, holiday or other important reason. Limit of four weeks/ year	Yes Day care centers, very unequal geographic coverage	Specific respite policy measures (respite platforms and financial support to pay for respite)	Provided for beneficiaries belonging to Care Level Grade 2 and above. (Cash benefits for care provided for up to 6 weeks)

Appendix 1A: Overview of support policies for informal carers in Austria, Bulgaria, France and Germany (continued)

	Austria	Bulgaria	France	Germany
CONCILIATION MEASURES				
Care leave	Yes Full- or part-time leave to organize care for family members can be taken from one to three months (without interruptions). No legal entitlement, but depends on employer. Family hospice leave (full- or part-time) is only available for end-of-life care of relatives (up to six months). The benefit amounts to 55% of net income (plus extra for dependent children). "Pflegefreistellung" – leave to care for sick children or other close family members who live in the same household for up to one working week (pro rata for part-time employment), full compensation of salary	Yes Leave to care for a sick relative (child or parent) issued with a sick leave certificate. Ten days/year at 80% salary Unpaid leave of up to 30 days/year, subject to employer approval	Yes Unpaid short-term care leave, low up-take Paid end-of-life care leave for a maximum of three weeks with limited financial compensation of around €50 per day, low take up	Yes Different care leaves (2015 Care Leave Act): 10 days with financial compensation but complex system Up to 3 months for end-of-life care
Working flexibility	Care leave, part-time care leave	No	Care leave can be used to facilitate part time work	Care leave used for part time

Appendix 1B: Overview of support policies for informal carers in Italy, Latvia, Poland and Spain

	Italy	Latvia	Poland	Spain
LONG-TERM CARE				
Elder care benefit	Yes Long-Term Care Insurance (LTCI) gives a choice between cash or in kind services	No explicit policy measure available	Yes Cash allowance for older people but very low and insufficient to cover informal and formal care needs	Yes (Peña-Longobardo et al. 2016)
COMPENSATION MEASURES				
Carer's allowance	Introduced by the Budget Law for 2018, but no clear indications yet on amount and how to access it	No	Yes, but only in case of legal (certified) disability of an older person	No, but existing LTC benefit can exceptionally be used to pay for informal carers
Insurance/ pension rights	Pension rights are recognized for the duration of caregiving (only for those who are on leave from their paid work).	No	Yes	Subscription to social security is possible (special voluntary agreement). Includes retirement, permanent disability, death, illness. Paid by carers
Tax reliefs for care recipients		No		No
Tax reliefs for carers	Possible for expenses incurred by carers for dependent family members, up to a of maximum of €399/year.	No		No

Appendix 1B: Overview of support policies for informal carers in Italy, Latvia, Poland and Spain (continued)

	Italy	Latvia	Poland	Spain
SUPPORTIVE MEASURES				
Information Counselling	No specific information centres/programme (except for Emilia-Romagna)	No	No	Yes
Medical check ups	No	No	No	No
Training	No (except for Emilia-Romagna)	No	No	Yes
Support groups	Carers' groupa exist, but unequally distributed	No	No	No
Formal recognition of carers	Carers were formally recognized for the first time at national level by the Budget Law for 2018	No	No	Recognition of the role of carer in 2006 Law
Formalized assessement of carers' needs	No	No	No	No
Respite	These services are rare but present in the most developed regions, especially in Northern Italy (see also cell below)	No	No	Yes
CONCILIATION MEASURES				
Care leave	Paid leave is available in two main forms: • Three daily permits per month • Two years of extraordinary leave (can be split into single days)	No	No	No
Working flexibility	Carers have the right to request to reduce their working time by up to 50%, for up to two years	No	No	No

Appendix 1C: Overview of support policies for informal carers in Sweden, Czech Republic, England and Finland

	Sweden	Czech Republic	England	Finland
LONG-TERM CARE				
Elder care benefit	Yes	Yes, Care allowance (for those who care for/after people who have level of need assessed as I to IV). Is considered very useful even if it remains insufficient to cover formal home care (especially for those with level IV of care needs)	Yes	Yes Carers receive cash allowances (minimum €300/month Care recipients receive vouchers that can be used to purchase services during respite
COMPENSATION MEASURES				
Carer's allowance	Yes Municipality employs a family carer	No However, there is a possibility for carers to be paid with care allowance	Yes For carers providing at least 35hr per week The uptake of the allowance doubled between 2003 and 2017, however, there are still questions whether all those entitled to the allowance are claiming it	Yes Minimum €300/month) Contract with municipality, Municipal-level variation in allowances
Insurance/ pension rights	No	Unemployment and sickness benefits while receiving care allowance as carers	Yes Carers' credit (national insurance credits to build towards state pensions)	Universal health and social care. Municipalities insure compensated carers for occupational accidents. Care allowances are taxable income and contribute to state pension
Tax reliefs for care recipients				(OECD 2011b)
Tax reliefs for carers				

Appendix 1C: Overview of support policies for informal carers in Sweden, Czech Republic, England and Finland (continued)

	Sweden	Czech Republic	England	Finland
SUPPORTIVE MEASURES				
Information Counselling	Yes Carers' counsellors in each municipality Website	Yes Various websites available	Yes Legal obligation Information and advice are considered central components of the universal offer provided by local authorities	Yes
Medical check ups	No	No	Pilot	yes
Training	Yes	Yes Training courses organized by many NGOs (subsidies from Europe, regional authorities)	Yes	Yes (since 2016)
Support groups	Yes	Several NGOs at national and regional levels	Yes	
Formal recognition of carers	Yes	Necessity to support informal carers recently highlighted in several policy documents	Yes	Distinction between compensated informal carer (contract signed with municipality) and informal carer
Formalized assessement of carers' needs	No	No	Yes Legal obligation (some indication that number of carers receiving assessments decreased between 2011/12 and 2016/17)	Yes
Respite	Yes Domiciliary (home-based) respite care Institutional respite care	Respite care announced in Social Services Act. Progressively becoming more available (in terms of offer and cost)	Yes Insufficient provision (Carers UK 2017a)	Yes Carers' breaks: 2 days/month for people caring for an older parent 3 days/month for demanding caring situations

Appendix 1C: Overview of support policies for informal carers in Sweden, Czech Republic, England and Finland (continued)

	Sweden	Czech Republic	England	Finland
CONCILIATION MEASURES				
Care leave	Yes For terminally ill relatives: up to 100 days for each patient, amount just below 80% of sickness benefit	Yes Recent introduction of a carer's leave: up to 60% of salary for up to three months	Yes Unpaid care leave: although considered as an achievement by Carers UK, charities are advocating for paid leave (Carers UK 2017b). In a 2015 survey of working carers, 37% of respondents stated that more flexible, special leave arrangements were needed to support carers' work (Carers UK 2015)	
Working flexibility	Yes	Legal right for flexible working arrangements, but in practice great variety of situations (depends on regions, employers, sector of activity, etc.)	Yes	Not clear Working time legislation stipulates that employers should enable part-time employment to care for sick relatives (not clear how obligating the law is and how 'sick relatives' are defined). Final discretion is with the employer. The same applies for sabbatical leave in that the employer decides whether the leave is justified.

Appendix 2: Data sources and key phrases used for rapid literature review

DATA SOURCES

Cochrane Library (Cochrane Database of Systematic Reviews, NHS Economic Evaluation Database, Health Technology Assessment Database)	www.cochranelibrary.com
PubMed	www.ncbi.nlm.nih.gov/pubmed
Medline	http://ovidsp.ovid.com (or via LSE library)
Google scholar	https://scholar.google.co.uk
Web of science	http://wok.mimas.ac.uk
PsycINFO	www.apa.org/pubs/databases/psycinfo
Cumulative Index to Nursing and Allied Health Literature	https://health.ebsco.com/products/the-cinahl-database
Health Management Information Consortium	www.ovid.com/site/catalog/databases/99.jsp
Database of the National Institute for Health and Clinical Excellence (NICE)	www.nice.org.uk/about/what-we-do/evidence-services/journals-and-databases
Social Care Institute of Excellence	www.scie.org.uk
Belgian Health Care Knowledge Centre	https://kce.fgov.be
Alzheimer's' Disease International	www.alz.co.uk
Alzheimer's Europe	www.alzheimer-europe.org
Department of Health UK	www.gov.uk/government/organisations/department-of-health
The King's Fund	www.kingsfund.org.uk
Euro carers	www.eurocarers.org
European Innovation Partnership on Active and Healthy Aging	https://ec.europa.eu/eip/ageing/home_en
Social Care Online	www.scie-socialcareonline.org.uk
Interlinks	http://interlinks.euro.centre.org
Assessing Needs of Care in European Nations	www.ancien-longtermcare.eu
OECD	www.oecd.org/els/health-systems
Australian Institute of Health and Welfare	www.aihw.gov.au/ageing-disability-carers-publications
The Swedish Family Care Competence Centre	www.anhoriga.se/information-in-english
Centre for Policy on Aging	www.cpa.org.uk
Age UK	www.ageuk.org.uk

KEY SEARCH TERMS COMBINED THREE SETS OF KEYWORDS FROM THE AREAS BELOW:

Keywords about the policy area, for example:
- long-term care; social care; dependency; disability; aged care, familisation/defamilisation

Keywords about the nature of the interventions, for example:
- informal care; carers; unpaid care; family; care manager
- flexible working; care and support; respite care; care leave; peer-support; free choice

Keywords about the consequences of interventions, for example:
- costs; resources; cost-effectiveness; efficiency; savings
- effects; effectiveness; outcomes; outputs; wellbeing; satisfaction; stress reductions; carer burden; quality of life…

Appendix 3. Unpaid Carers: rapid literature review summary table

TYPE OF INTERVENTION	POSITIVE EFFECTS	NO EFFECTS	NEGATIVE EFFECTS	OTHER REPORTED	COST-EFFECTIVENESS
Thomas et al. 2017 Including 61 systematic reviews (27 high quality; 25 medium quality; and 9 low quality studies)					
Respite care		Burden (1 systematic review including 4 studies)	Burden (1 review including 2 studies)		
Cognitive behavioural therapy/behavioural therapy/cognitive reframing	Depression (6 studies)	Burden (1 study)		Burden – mixed or inconsistent findings (5 studies)	
Education interventions/family education	Burden (5 studies) Depression (1 study) Carers stress (1 study) Engagement in social activities (2 studies) Carers' perceived health status (4 studies)	Somatic symptoms, anxiety, insomnia, social dysfunction, depression (1 study)		Burden-mixed or inconsistent findings (11 studies)	Total annual health and social care costs were significantly lower for carers who received an education and training intervention (1 study)
Psychosocial interventions/psychosocial education	Marital-family relationships (10 studies) Distress and anxiety (16 studies) Improved self-efficacy (8 studies) Small, non-significant effect on depression (18 studies)	Psychological distress (3 studies)			
Computer-mediated psychosocial interventions	Stress and burden (5 studies)			Social isolation-mixed results reported (1 review including 3 studies)	

Appendix 3. Unpaid Carers: rapid literature review summary table (continued)

TYPE OF INTERVENTION	POSITIVE EFFECTS	NO EFFECTS	NEGATIVE EFFECTS	OTHER REPORTED	COST-EFFECTIVENESS
Counselling/telephone counselling	HRQoL (2 studies) Burden (1 study)				
Befriending	Depression (1 study)				No evidence of cost-effectiveness (1 study)
Support groups	Burden (2 studies) Outcome related to burden but not explicitly defined (24 studies) Coping (2 studies)				
Vandepitte and colleagues (2016)					
Psychoeducational interventions		Depression, burden, and personal gains, but subgroup of carers older than 65 reported improvement in depression (1 study)		Mixed results: no improvement in depression and quality of life but improvement in emotional role functions (1 study)	
Multicomponent intervention individual and group (education, training, emotional support, newsletters, music therapu)	Self-efficacy, depression and burden – individual (11 studies) Various outcomes – strain, disappointment, depression, stress (7 group-based studies) Self-efficacy and depressive symptoms of caregivers – combination of individual and group) (10 studies)	Burden and depressive symptoms – individual intervention (1 study Burden – individual and group focused intervention (1 study)			

Appendix 3. Unpaid Carers: rapid literature review summary table (continued)

TYPE OF INTERVENTION	POSITIVE EFFECTS	NO EFFECTS	NEGATIVE EFFECTS	OTHER REPORTED	COST-EFFECTIVENESS
Respite care	In-home respite care programme indicated some beneficial effects for caregivers which can reduce morbidity and mortality but no benefits in psychological symptoms (1 study)			Reported benefits rather small and mixed – 33% were effective (4 studies)	
Brimblecombe et al (2018)					
Flexible working	Increases the chances of remaining in employment (6 studies) Decrease chances of reduced working hours (1 study) Health (1 study) Improves work-life balance (7 studies)	Little effect on remaining in employment (1 study), particularly for higher intensity carers (3 studies)			
Care leave (paid and unpaid)	Some positive effect on employment in some circumstances, particularly in combination with flexible working (6 studies). Paid leave may have more significant effect (1 study)	Insuficient with long-term and/or high intensity care demands (2 studies) and at higher levels of need (1 study)	Unpaid leave if carers cannot afford it (3 studies)		

Appendix 3. Unpaid Carers: rapid literature review summary table (continued)

TYPE OF INTERVENTION	POSITIVE EFFECTS	NO EFFECTS	NEGATIVE EFFECTS	OTHER REPORTED	COST-EFFECTIVENESS
Formal services for care recipient (e.g. short breaks, homecare, personal assistant, meals on wheels)	Employment participation (7 studies: 3 quantitative and 4 qualitative)	Employment participation (1 study) Little evidence for respite care impact on emotional wellbeing (1 review) No evidence for respite care impact on physical or mental health (2 reviews) No overall benefits (1 review)	Employment participation (1 study)		No evidence of cost-effectiveness for respite care (2 reviews)
Knapp et al. (2015)					
Technological interventions for carers to deliver psychotherapeutic support groups, telecoaching, cognitive behavioural therapy or stress management, telephone-based carer education and training programme	Competence, self-efficacy, (7 studies) Burden and depression (8 studies) Less worry (1study) Wellbeing – early results broadly positive (1 review), but overall limited evidence (3 reviews)	No effect on feeling of role-overload (1 study)			Short-term reduction in outpatient services costs (1 study) Reduction in costs (1 review)
Assistive technologies supporting the person with dementia (e.g. smoke detectors, fall detectors, locator systems, night-time monitoring, memory support devices)	Carers felt safer (1 study) Carers had etter quality of sleep (1 study) Positive feedback from carers (1 study)				

Appendix 3. Unpaid Carers: rapid literature review summary table (continued)

TYPE OF INTERVENTION	POSITIVE EFFECTS	NO EFFECTS	NEGATIVE EFFECTS	OTHER REPORTED	COST-EFFECTIVENESS
Technological interventions to support carers and the delivery and management of care (e.g. videoconferencing, email, text messages, web-based information, interactive voice response programme aiming to disrupt challenging behaviour, MP3 players for people with dementia)	Better awarness of available services and positive impact on loneliness (1 study) Improved carers QoL (1 study) Carers reported greater needs in the intervention group (1 study) Social interactcion (2 studies) Better access to these services, available out of normal working hours (1 study) Decreased psychological distress and respite effect for carers – assessing MP3 players (1 study) Care burden and anxiety for participants with low-to-mid mastery at baseline, and for wives – telephone support system (1 study)	Voice response intervention for challenging behaviour had no effect on carers' outcomes (1 study) Carer burden and anxiety (telephone support system 1 study)			

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