

## Special Issue

# Knowledge generation about care-giving in the UK: a critical review of research paradigms

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### What is known about this topic

- The number of family carers in the UK will rise significantly over the next 30 years; demand for care is predicted to outstrip supply by 2017.
- Despite sustained policy development, carers remain a profoundly disadvantaged group.
- There is an established body of work exploring the conceptual, theoretical and experiential nature of caring.

### What this paper adds

- Knowledge about carers is predominantly generated from two separate research paradigms.
- There is a growing body of evidence relating to enumerating carers, their tasks, the impact of caring and the efficacy of policy and services.
- Conceptual and theoretical work exploring the nature of care extends understanding of care as a normative activity.
- Greater integration between the two dominant fields of enquiry could generate new knowledge about care and caring.

### Abstract

While discourse about care and caring is well developed in the UK, the nature of knowledge generation about care and the research paradigms that underpin it have been subjected to limited critical reflection and analysis. An overarching synthesis of evidence – intended to promote debate and facilitate new understandings – identifies two largely separate bodies of carer-related research. The first body of work – referred to as Gathering and Evaluating – provides evidence of the extent of care-giving, who provides care to whom and with what impact; it also focuses on evaluating policy and service efficacy. This type of research tends to dominate public perception about caring, influences the type and extent of policy and support for carers and attracts funding from policy and health-related sources. However, it also tends to be conceptually and theoretically narrow, has limited engagement with carers' perspectives and adopts an atomistic purview on the care-giving landscape. The second body of work – Conceptualising and Theorising – explores the conceptual and experiential nature of care and aims to extend thinking and theory about caring. It is concerned with promoting understanding of care as an integral part of human relationships, embedded in the life course, and a product of interdependence and reciprocity. This work conceptualises care as both an activity *and* a disposition and foregrounds the development of an 'ethic of care', thereby providing a perspective within which to recognise both the challenges care-giving may present and the significance of care as a normative activity. It tends to be funded from social science sources and, while strong in capturing carers' experiences, has limited policy and service-related purchase. Much could be gained for citizens, carers and families, and the generation of knowledge advanced, if the two bodies of research were integrated to a greater degree.

**Keywords:** care, carer, carer research, caring/care-giving, knowledge generation

## Introduction

Over the last 30 years, social care policies in Western Europe have been underpinned by an assumption that people with dependency needs are best cared for by their relatives in the community (Means *et al.* 2008). A long-term shift towards an ageing population, the continuing trend away from institutional care and improvements in the longevity of those with lifelong disabilities have resulted in a significant rise in the number of people who need support to live at home (Hudson 2005, HM Treasury and Department for Education and Skills 2007). There has been a commensurate increase in the number of family carers. Estimates suggest that 12% (6.4 million) of the UK adult population are carers, a figure that is 10% higher than in 2001. Demographic change coupled with a reduction in public sector support is likely to mean that both the number of carers and the intensity of care will increase (Carers UK 2010). It is predicted that the 'tipping point of care' – when the need for family care for older people outweighs the supply of carers – will be reached by 2017 (Pickard 2008, 2013, Jagger *et al.* 2010).

Although much has been written about caring in the UK, the nature of the evidence base itself has been the focus of limited exploration. This paper offers a critical analysis of the nature of carer-related research and its links to the generation of knowledge about care, carers and care-giving. It is timely; not only are carers growing in number but they are also the subject of a range of policy initiatives across the UK (HM Government 2008, 2013, DH 2010a). Carers are also situated on the cusp of the universal shift away from the provision of welfare services to those with dependency needs, and they experience the direct consequences of public sector 'austerity measures' (Humphries 2011).

The paper aims to explore how knowledge about carers has been generated and developed; synthesise key dimensions of the carer's research paradigm; and critique the relationship of research and/or theory to understanding of carers and care-giving in contemporary Britain. It draws on literature – primarily peer-reviewed papers – written in English dating from 1995. While the authors acknowledge the significance of theoretical and empirical work pre-dating 1995, for example Parker (1985) and Graham (1991), this year was chosen as it marks the introduction of the Carers (Recognition and Services) Act 1995, which heralded a new policy era for carers (HM Government 1995). Such critical engagement with research-related literature has the potential to enhance understanding of the process of knowledge generation, promote new insights and facilitate debate.

Two distinctive research paradigms emerged from the analytic process. These can be viewed as overarching ordering frameworks for exploring key themes: they also serve as organising platforms upon which to present the review findings.

## Caring in the UK: 'gathering and evaluating'

This research paradigm is closely aligned to the dominant discourse about caring in the UK and primarily focuses on profiling the nature and extent of care-giving, assessing its impact and evaluating the effectiveness of carer-related policy and services.

### Profiling carers

As noted above, the demand for input from carers is increasing. There is predicted to be nine million carers by 2037; three in five adults in the UK will become a carer at some point in their lives (Carers UK 2010). Over a quarter (26%) of all carers care for a spouse or a partner, more than half (52%) care for their parents/in law and 13% care for a disabled son or daughter (Niblett 2011). A significant proportion (70%) of the cared-for population are aged over 65 and many have an age-related disability or chronic health condition(s) (Health and Social Care Information Centre 2010a,b). Key tasks that carers perform include preparing meals, shopping, cleaning, administering medication, personal care and providing social and emotional support (Larkin 2012).

While carers are predominately mid-life women, a quarter are aged over 65 years and around 2% are young people. Most young carers start caring before the age of 12 and continue caring throughout their childhood. Just under half of all carers provide care for 20+ hours per week and a fifth care for 50+ hours; 14% care for two people (Becker & Becker 2008, Clewett *et al.* 2010).

### The impact of caring

There is substantial evidence of the negative impact of caring on carers' health. One survey identified that 40% of carers experience 'significant levels' of distress and depression (Royal College of General Practitioners 2011). Other work suggests that carers providing 20+ hours of care per week over extended periods have twice the risk of experiencing psychological distress than non-carers; more intensive levels of care are also associated with a 23% higher risk of stroke (Hirst 2005). The physical effects of caring are worst among older carers who may have health problems

of their own (Pinquart & Sorensen 2003, Carers UK 2008, Capistrant *et al.* 2012). Many young carers experience physical, emotional and/or social problems and routinely encounter difficulties in sustaining education (Dearden & Becker 2004, Hamilton & Adamson 2013).

Caring has also been found to impact significantly carers' capacity to remain in work; nearly three-fifths of carers are obliged to give up paid work to care (Milne *et al.* 2013). Estimated loss of earnings is £11,000+ per year per carer and an annual loss of £5.3 million to the UK economy (King & Pickard 2013). Additionally, caring impacts profoundly on carers' quality of life; a recent survey identified that many carers experience 'restrictedness' – feeling isolated and unable to leave the dependent relative. Indeed, four in ten carers had not had a day off for over 18 months (Buckner & Yeandle 2011).

In terms of the financial impact of caring, lowered income, coupled with higher costs arising from care-related expenses (e.g. additional laundry), means that long-term carers are at considerable risk of poverty. Recent research identifies that 74% of carers 'struggle to cope with paying for essential items' (including food) and around 66% use their savings to pay for care for the person they support (Buckner & Yeandle 2011).

The benefits of caring have also been explored, albeit on a smaller scale. Key benefits include a sense of giving back and higher levels of subjective well-being (Nolan *et al.* 1996). Positive aspects of caring tend to be correlated with lower levels of burden, better health and fewer negative reactions to the problems of the care receiver. There is also evidence that stresses and satisfactions coexist. For example, although young carers experience significant disadvantage, they often value their role because it engenders 'feelings of pride and worth, a sense of accomplishment, greater resilience and a positive outlook on life' (Smyth *et al.* 2011, p. 157, Aldridge & Becker 1994, Hunt *et al.* 2005).

### Support for carers

Policy recognition of carers' contributions has increased over the last 20 years (Glendinning *et al.* 2009). This is indicative of the promotion of carers from 'the wings of welfare' to legitimate recipients of support in their own right (Larkin & Milne 2014). A number of intersecting policies explicitly focus on carers' rights to have their needs assessed, protect their health and well-being, access support, training and employment, and 'live a life outside caring' (HM Government 2008, 2013, Moran *et al.* 2012). Among the most significant policies in the UK are the Carers

Recognition and Services Act (1995) and the cross-government 'Carers Strategies' (HM Government 1999, 2008, DH 2010a).

Nonetheless, the fact that many carers are still profoundly disadvantaged by caring raises the question of how effective such policies are (Molyneaux *et al.* 2011, Carers UK 2012a,b). Relevant evidence suggests that carers are routinely overlooked and feel unsupported, powerless and marginalised; increased choice and control do not feature in the majority of carers' daily lives (Glasby *et al.* 2010, Ridley *et al.* 2010). That the economic value of family care has been estimated to be £119 billion – a rise of 37% since 2007 – additionally suggests that carers lack recognition and/or support (Anderson *et al.* 2009).

More specifically, in terms of access to services, available data suggest that only 6% of *all* carers in England receive a needs assessment (Health & Social Care Information Centre 2010a). In 2012, nearly a third (31%) of carers providing 35 hours+ per week reported receiving 'no practical support' (Carers UK 2013, p. 3). In 2013, only 1 in 10 carers received Carers Allowance – the main benefit for carers in England (National Audit Office 2014). Evidence relating to service effectiveness is mixed. Counselling appears to impact positively on self-rated health (Mittleman *et al.* 2007) and integrated programmes of support are effective in terms of alleviating stress and delaying care home admission (Droes *et al.* 2006). Despite the enormous popularity of carer support groups, evidence of their effectiveness relates primarily to psycho-educational groups for carers of people with dementia (Milne *et al.* 2013a). Information (e.g. about services, and advice about managing challenging behaviours) is rated highly (Marriot *et al.* 2000). Carers value practical help with the physical aspects of care (e.g. incontinence) and those carers providing intensive care appreciate good-quality respite care (Arksey & Weatherly 2004). While there is some evidence that personal budgets do allow carers greater flexibility, there are concerns that their management increases carers' workloads (DH 2010b, Mitchell *et al.* 2013). Research also shows that insufficient information is available about managing direct payments and/or what to do when things go wrong (Glasby & Littlechild 2010, Manthorpe & Samsi 2013).

### Caring in the UK: 'conceptualising and theorising'

In contrast, the second substantive field of carer-related research explores the conceptual and experiential nature of care; it aims to extend thinking and

theory about caring as a multidimensional activity and as an integral part of human relationships.

### Conceptualising carers

Although the term 'carer' is now widely understood to be (usually) a family member who provides unpaid care to a relative with dependency needs, it is a contested term (Chamberlayne & King 2000). In part, this is because 'carer' is not recognised as a label by many of those who 'do care-giving'; indeed, as many as half of all carers do not own the term (Lloyd 2006). Some commentators even argue that it is a bureaucratically generated notion, turning 'what is a normal human experience into an unnecessarily complex phenomenon' (Molyneaux *et al.* 2011, p. 422). That carers do not belong under one definitional umbrella and are a widely diverse population also contributes to inconsistency in the term's usage and its confused meaning. Furthermore, some carers, especially older carers, may simultaneously be service users (Warren 2007, Rapaport & Manthorpe 2008).

Carers' experiences are shaped not only by their personal responses to caring but also by a myriad of situational and structural factors. These include the number of hours spent caring, length of care-giving, type of care, relationship, nature of the cared-for person's needs and access to formal services. Key structural dimensions include gender, age, race and sexuality (Ridley *et al.* 2010). For instance, female carers feel more obliged to give up paid work to care and are more reluctant to ask for support from services than their male counterparts (Milne & Hatzidimitriadou 2003). Many older spousal carers care alone and unsupported because their beliefs about the 'care contract' underpinning long-term marriage lead them to resist the 'intrusion' of 'outsiders', including services (Arksey & Glendinning 2007). Similarly, many black and ethnic minority carers consider 'carer' to be a 'culturally inappropriate' (Lloyd 2006, p. 954) term and antithetical to 'normal' family relations (O'Connor 2007).

The conceptual models employed by services and policy makers have also been analysed. In the 1990s, Twigg *et al.* (1990) examined the ways in which agencies responded to carers. They identified that professionals tend to adopt one of four models: carers as resources; co-workers; co-clients; or as superseded carers, i.e. carers who can do everything. This work exposed the employment of a conceptual framework – albeit one operating opaquely – that directly influenced decision-making and resource allocation.

Linked work reviewing recent policies intended to promote choice and control for service users suggests

ongoing conceptual confusion. Although co-production aims to re-sculpt the relationship between users and services, it could be criticised for failing to take account of carers' needs (Carr 2010). Carers' exclusion from decisions about the form and content of their relative's care package suggests that they are primarily conceptualised as a 'resource' (Larkin & Milne 2014). This view is reinforced by evidence that assessments of service user need are expected to take account of the family carer's contribution *before* eligibility for local authority support is calculated (DH 2010a).

With reference to self-directed care, not only is there evidence that some carers do not benefit from personal budgets but that they are expected to take on additional roles. The almost simultaneous introduction of austerity measures and the roll out of personal budgets have amplified this expectation (Humphries 2011, Mitchell *et al.* 2013). The provision of formal carer training by professionals is also relevant and indicative of a recent shift towards conceptualising carers as members of the 'care workforce' and as having an obligation to learn a set of formal skills (Brown *et al.* 2001, Larkin 2012, Sadler & McKeivitt 2013).

### Theorising caring

As caring is integral to many relationships, the distinction between caring as a normative activity and an activity beyond the normative is problematic. Driven, in part, by a need to expose this bifurcation, caring has been the focus of a number of theoretical analyses; these have separately *and* collectively extended understanding of caring as an activity (Bowlby *et al.* 2010).

Work in the 1980s argued that care was a:

Homogenous activity focused around the provision of instrumental support ... as one person 'doing care to' another. (Ray *et al.* 2009, p. 116)

Feminist perspectives emphasised the way care was gendered and viewed as a 'natural' female activity distinguishing between 'caring about' and 'caring for' (Hockey & James 2003, Barnes 2006). The former involves *feelings* of concern, while the latter is about the *tasks* of tending (Ungerson 1983, Dalley 1996).

The carer/cared-for dichotomy was challenged in the 1990s and analyses extended to relational aspects of care. Caring relationships were (re)characterised by 'interdependence and reciprocity' (Walmsley 1993, p. 137) and as (often) being embedded in a shared life course (Nolan *et al.* 2004). The interdependence of caring is a core dimension of Kittay's (1999) notion of

'nested dependencies'. She argues that nobody is truly autonomous for long and that 'independence' as a pure state is neither realistic nor desirable; we are inter-dependent because we all depend on someone else in our lives and they on us (Ray *et al.* 2009).

The inherent mutuality and attachment that characterise care relationships have also been emphasised in the growing body of literature on an 'ethic of care'. Fisher and Tronto (1990) define an ethic of care as having four core elements: attentiveness (noticing the needs of others – caring about); responsibility (caring for); competence; and responsiveness (awareness of one's own vulnerabilities). Sevenhuijsen (1998) adds a fifth element – trust – and Engster (2007) suggests a sixth – respect. Although they adopt differing viewpoints, these authors argue that care is central to the social fabric of society; it binds together families and communities, and is embedded in personal and social relations (Daly & Lewis 2000). These notions are in turn embodied in the principles underpinning care-giving: obligation, duty, love and loyalty (Sims-Gould & Martin-Matthews 2008). An ethic of care provides a perspective within which to recognise both the challenges that care-giving may sometimes present and the significance of care as a dimension of human relationships. Tronto (1993) defines care as both an activity *and* a disposition.

Williams (2004) extends this analytical lens by proposing a 'political ethic of care'. This incorporates paid and unpaid care and reframes care activities as being embedded in one's personal and work life, and in space and time. This not only challenges the 'work ethic', which, Williams considers, has dominated our thinking about care, but also 'normalises responsibilities for (both) giving and ... receiving care' (2001, p. 489). A related shift defines care as a shared activity and a dimension of citizenship. This perspective emphasises a collectivist approach to care, accommodates a number of different contexts and care groupings, and allows for the supporting and valuing of difference (Barnes 2012). It also reflects a re-engagement with the feminist ethics of equity, justice and autonomy (Lloyd 2010).

Another strand of the care discourse to emerge in the 1990s can be found in postmodernist interpretations of power. These emphasise the way that 'power in caring relationships is constantly (re)created and (re)negotiated through interaction' and is therefore 'fluid, complex, and constantly shifting' (Dominelli & Gollins 1997, p. 412). Not only did this perspective challenge the notion of care-giving as fixed but simultaneously highlighted *both* relationality and power within caring relationships. Caring and care also 'evolve over time' (Bowlby *et al.* 2010, p. 46) as a

result of changes in the caring relationship and in response to wider contextual factors, including policy changes. One example is the 'shift in the locus of care' for people with long-term conditions, from care in hospitals to care by families in the community (McGarry 2008, p. 83).

Recent work specifically exploring the spatially situated nature of care adds another theoretical dimension. Carers' decisions are not only shaped by their moral orientation, social context, personal and relationship biography but also by the 'sites and spaces' where care occurs (Milligan & Wiles 2010, p. 740). In 'framing the home as the preferred site of long-term care, community care policies have framed the home as a therapeutic landscape' (Egdell 2013, p. 890). The carer is obliged to negotiate a balance between protecting the home as a private space and engaging with the institutionalised infrastructure of formal care. Often, it is only when the cared-for person enters a care home that the full extent of the carer's role prior to admission becomes clear.

### **Generating knowledge about carers and caring: is research fit for purpose?**

The growth in research about family care since the 1980s can be credited, in part, for raising carers' public profile (Parker 1995, Glendinning *et al.* 2009). In addition to exploring the extent of care-giving in the UK it has 'helped to ensure that caring is prioritised as a significant issue for social policy and practice' (Barnes 2006, p. 1). Furthermore, it has underpinned the development of a highly organised and politically active carers' movement and has extended understanding of care and caring. More recently, the very nature of what care is and how it is embedded in human relationships across, and within, the life course has been the subject of illuminating analyses.

The authors have suggested that the majority of carer-related research can be characterised as belonging to one of two distinctive paradigms. Not only is this an issue for its epistemological basis but, as there is a reinforcing link between the type of research and the nature of knowledge generated, it is important to explore the implications of this relationship for understandings of care and caring.

### **Gathering and evaluating – reflecting on the evidence base**

The primary foci of the majority of studies in the 'Gathering and Evaluating' camp are twofold: enumerating carers, what they do and with what effect, and assessment of the impact and effectiveness of

policy and services. There can be little doubt that this work has not only successfully maintained carers inside the purview of government but has also foregrounded caring as an issue of national significance. The inclusion of questions about caring in the Census is a key example (White 2013). Much of the work is positivistic, quantitative and regarded as methodologically rigorous (Stalker 2003). It is noteworthy, however, that projects are increasingly incorporating a qualitative arm; this is especially the case for evaluations of services (Ellins *et al.* 2012).

Many of the research findings generated by the 'gatherers and evaluators' are (relatively) accessible. Survey-related work on 'carers' health' by Carers UK and national projects on 'carers' quality of life' conducted by well-established research units are distinctive examples. This research not only provides an audit – a temporal 'stocktake' – of the extent, types and impact of family caring in the UK but it also has the capacity, at least theoretically, to improve support for carers. Many of the larger studies also have a cost-effectiveness dimension, which directly addresses the economic concerns of policy makers and can offer cost/benefit analyses of interventions or initiatives. This work strongly influences the direction of travel of carer policy and service investment; it is routinely funded by government departments or sources concerned with care service 'inputs' and user and carer-related 'outcomes', e.g. the National Institute for Health Research.

However, the work generated within the 'Gathering and Evaluating' field can be criticised on a number of levels. While many individual projects are robust, its overall evidence base is fragmented and uneven. Studies tend to take place in silos with minimal sustained cross-fertilisation between research groups or between funders. Additionally, the foci, specific methodology, nature and size of projects vary considerably. Key foci include a specific group of carers (e.g. working carers, young carers); the type of carer and cared-for relationship (e.g. spouse carer, parent carer); carers of people with a particular condition (e.g. dementia carers); a particular issue (e.g. the health of long-term carers); and a service or type of support (e.g. support groups, respite care) (Baikie 2002, Milne *et al.* 2013a). The nature of care-giving itself (i.e. personal care, physical care, emotional support, etc.) and the level of care (i.e. mild/moderate/intensive) are also common lenses of analysis (Arksey & Weatherly 2004).

Studies range in size from the local small scale, e.g. questionnaires with 12 young carers, to national surveys and evaluations (Becker & Becker 2008, Jones *et al.* 2012). Meta and secondary analyses of datasets

and systematic literature reviews have also contributed to the evidence base (Victor 2009); these have usually focused on a specific group of carers and/or a service (e.g. Arksey *et al.* 2004).

These differences weaken the additive capacity of studies, especially the smaller ones, and duplication of effort is not uncommon (Greene *et al.* 2008, NBCCWN 2008). Competition, rather than collaboration, characterises this landscape. Furthermore, research in this field tends to capture evidence of carers who are visible, struggling to include those who do not self-identify, e.g. carers of people with mental health problems. Also, despite claims to the contrary, project findings do not necessarily influence care practice. Research has consistently identified that 'carers' needs assessments' fail to be conducted in a personalised way, produce little in the way of additional support and rarely explore the willingness of carers to continue caring. However, practice remains weak, inconsistent and vulnerable to local authority vicissitudes (Mitchell *et al.* 2013).

In addition to the dimensions of the studies themselves, work in this field has long been criticised for being conceptually narrow and under-theorised. Carers tend to be uncritically defined as a close relative offering instrumental care to another family member with dependency needs. There is a dichotomy between 'carer' and 'care receiver' and the 'snapshot' nature that characterises much of the research tends to present care as a static process – fixed in time and space. Although implicit rather than explicit, much of the work is underpinned by a stress/burden model of care-giving; an assumption that the role of services is to relieve carers and extend their capacity to care is a related issue (Milne & Chryssanthopoulou 2005, Mittelman 2005).

### Conceptualising and theorising – reflecting on the evidence base

Research, which seeks to conceptualise and/theorise care-related issues, tends to adopt a wide lens of analysis. Care and caring are viewed as embedded in ordinary relationships rather than exclusively being 'an activity' that one person does to another in circumstances characterised by ill-health. Its strengths are its inclusivity and an understanding that care is multidimensional: a way of conceptualising personal and social relations including those traditionally thought of as 'care relationships'; a set of ethical and moral values; *and* a practice (Barnes 2012). The work challenges the narrow definition of carer adopted by policy makers and services, instead highlighting the interdependencies that we all have across the life

course and within our relationships. An ethic of care – the framework that underpins much of the work in this field – prompts us to give attention to the ways in which social connectivity can be supported to improve the well-being of all, rather than limiting ‘care’ to a peripheral position of relevance only in extremis (Tronto 2010). One of the risks of marginalising carers in this way, Bowden (1997) argues, is that we lose sight of its significance ‘in the everyday’ encouraging a tendency to ignore it, devalue it and disregard it.

The work is critical of the language commonly used in policy and practice discourse. Terms such as ‘substantial care’ and ‘dependency’ not only emphasise a distinction between those who ‘need care’ from those who do not, but reinforce a uni-directionality of support that does not reflect the mutuality that characterises many family relationships. It is additionally critical of the stress/burden paradigm. From the perspective of the ethic of care, Lloyd argues...

...The discourse about burdensomeness is a way of marginalising older people and also disassociating the young, fit and able bodied from their own vulnerability and their future old age. (Lloyd 2010, p. 135)

It also marginalises carers (Milne 2010).

One of the strongest messages of the ‘conceptualisers and theorists’ is that care is a much more complex issue than is presented in policy and delivered in practice, and that policy makers ignore the importance people attach to experiencing care *inside* a relationship (Williams 2004, Kittay 2010). Fine (2013) suggests that market principles have reduced care to an impersonal product and that, because it is linked to notions of dependency, it has become a devalued term in policy and social care literature. A discourse of care has been replaced by consumer-related terms such as choice and control and users and carers are constructed as rational, autonomous and well-informed (Barnes 2012). That this image is profoundly at odds with the situations of most people who need to make use of social care services, for example, an older person with dementia and their frail spouse carer, is a perverse and largely unacknowledged paradox (Tronto 2010).

Rooting research in the experiences of families and service users is a key strength of this body of work. Barnes’s (2012) recent study of service providers and older service users shows us not only that the relational and emotional dimensions of care matter as much, if not more, to older people than the functional aspects, but that by adopting an ethic of care approach, better quality care can be delivered. A care

practice defined by tasks and time rather than active listening, attentiveness and meaningful communication is not meeting need; nor is it acknowledging the intersection of the moral and ethical with the practical (Tronto 1993). Linking these findings to the world of family care-giving offers the opportunity to move beyond the current situation whereby ‘carers’ are the identified subjects of substantial empirical research to a shared understanding of the nature of care and an expectation that the role of policy is to deliver improved well-being to all rather than to support the relatively few (Barnes 2012). Incorporating both informal and formal care inside the care discourse also provides for a shared understanding of the dimensions and practice of an ethic of care in lay *and* professional contexts (Williams 2001, 2004). Funding for this sort of work typically comes from social science-related sources, e.g. the Economic and Social Research Council or public and third sector agencies (ESRC 2008).

More critically, the ‘conceptualisers and theorists’ are barely visible inside the carer-related discourse that dominates policy thinking and informs public perception about carers. However persuasive the debate about universal care may be, it is a challenge to define who precisely is the focus of analysis. As the development of public policy depends – to some degree – on how it defines its reach, pinning down the reach of an ethic of care is a considerable challenge. How one measures an improvement in the well-being of an entire population and links that improvement to a change in approach and language is a related issue and one that evades definitive deliberation. Its lack of capacity to speak to an economic agenda is also a weakness. These issues explain, in part, why this research has a limited foothold in applied work and a weak link to service and policy development in health and social care.

The work is strongly grounded in sociological analysis and although much of it is linked to the ‘real world’ of paid and unpaid carers, its association with broader political issues hinders its absorption into mainstream thinking about caring. What this field is asking for in the way of change is substantial and includes an infusion of ‘care thinking into political thinking’ (Tronto 2010, p. 164). This is profoundly at odds with the way carers are constructed inside policy and is an uncomfortable bedfellow for a welfare discourse that defines fewer and fewer carers as ‘eligible’ for support from the public purse, rigidly separates informal from formal care and makes increasing demands on families to provide care.

## Conclusion

Given the centrality of research to extending understanding and generating knowledge about care and caring and to improving support for carers, it is pivotal that it builds on its strengths and tackles its deficits. In this position paper, we have argued that, currently, two separate research paradigms with very different perspectives and approaches dominate the terrain. The authors' aim to encourage debate about the best way forward for carer-related research lies at its core; a goal constrained to some extent by space and a need to balance breadth, depth and coherence. While the two fields share an overarching goal – to improve the lives of those who give and receive care – their capacity to pool intellectual and methodological resources and develop synergies is very limited. Despite a considerable investment in carer-related research, many key questions remain, at best, partially answered. It is our contention that drawing on the strengths of existing research and encouraging cross-fertilisation has considerable potential to meet the needs of citizens, families and carers, generate new knowledge and develop new paradigms to address one of the most challenging and complex issues of the 21st century. Although much work needs to be done to work towards this aim, a critical reflection on 'the state of the art' provides a catalyst for future debate, further analysis and innovative research.

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