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Knowledge generation and former carers: reflections and ways forward

Introduction

The fact that the number of family carers is increasing both internationally and nationally is now well-recognised (OECD, 2011). In the United Kingdom (UK) it is estimated that 8.8 million people are adult carers, a figure predicted to rise to 9 million by 2037 (Carers UK, 2015, 2019; Carers Trust, 2019). As in many other developed countries, this reflects a long-term shift towards an ageing population, lower use of institutional care, improved longevity of those with lifelong disabilities and reduced expenditure on public services (Office National Statistics, 2013; Humphries et al, 2016). It is much less recognised that those factors that lead to the growth in the number of carers also leads to a growth in the number of those who 'were' carers - a population known as former carers (Larkin and Milne, 2017, 2017a; Carers UK, 2014a; NHS England, 2014). This population is the focus of our paper.

There have been some attempts to quantify how many people become former carers. For instance, in the UK, around a third of carers cease 'caring' each year (Carers UK, 2014a). In 2018, in Ireland it is estimated there are at least 62,000 former carers (Care Alliance, 2018). Recent work has also shown that about a third of the former carer population is older, i.e. aged 65+, and that this includes a growing subgroup aged 85+. Many are spouses (Carers UK, 2014a). This profile mirrors that of the carer population overall (Age UK, 2016; Henwood et al, 2017; Larkin et al, 2018).

Carers become former carers for different reasons; there is more than one 'route' into acquiring this status. Cavaye and Watts (2016a) highlight two of the most common routes - when the cared-for person is admitted to a long-term care setting or dies. Other routes include: when the cared-for person is admitted to a hospital or hospice, s/he goes into remission (e.g. for cancer patients) and s/he recovers from their health problem (e.g. those who have undergone major surgery) (Larkin and Milne, 2017). Furthermore, being a former carer may not be a static state; carers may transition in and out of caring roles across their life course (Larkin, 2009; Department of Health,

2014) being a carer or a former carer more than once. An example is a midlife woman who cares for her parent(s), upon whose death she becomes a former carer. She may then care for her husband and become a former carer once again when he is admitted to a care home or dies.

Although former carers are marginal to carer-related discourse and services (Orzeck and Silverman, 2008; Larkin, 2009; Scrutton and Creighton, 2015) there are signs - in the UK at least - that they are beginning to have a more visible public and policy profile (Department of Health, 2014; NHS England, 2014; Hirst, 2014). In 2014 NHS England made clear it would “include support for bereaved carers” in its ambitions for End of Life Care (NHS England, 2014:13) and in the same year Carers UK identified former carers as being “.... in need of support and advice, as they find themselves in a new and often difficult situation” (Carers UK, 2014a: 6). Carers UK now have a forum focused specifically on meeting the needs of former carers and include them in their annual State of Caring Survey (Carers UK, 2019). In addition, a small but growing, international body of research is developing. Whilst the number of academic papers on former carers is very small in comparison to the many thousands about carers more generally (Thomas et al, 2016, Kelleher and O’Riordan, 2017), their distinctive status and experiences are beginning to be recognised (Larkin, 2009; Cronin et al, 2015; Cavaye and Watts 2016b; Henwood et al, 2017; Larkin and Milne, 2017).

Using this small, but developing, body of work as a starting point, this paper offers a critical reflection on existing knowledge about former carers. It then offers a timely exploration of ways in which the evidence base can be further developed and new knowledge generated. In particular, the authors suggest that the application of key theoretical perspectives and constructs drawn from carer-related research could be extended into the former carers terrain. Our aim is to stimulate debate as opposed to proposing a definitive way forward. Whilst every effort has been made to include international literature, for reasons of brevity and consistency, examples of policy, services and practice are UK based. The term ‘former carer’ is used throughout; ‘caring’ and ‘caregiving’ are used interchangeably as are ‘carer’ and ‘caregiver’¹.

¹ The terms ‘caregiving and ‘caregiver’ tend to be favoured more in USA based research

Existing knowledge about former carers

Research that has been done on former carers consistently shows that they are exposed to a range of disadvantages arising from their caring experiences. These are particularly profound for those who have cared over the long-term and intensively². Specific problems include: loneliness and social isolation, physical ill health such as back pain and high blood pressure, and mental health problems primarily depression. These problems not only persist but can deepen post-caring. Lower levels of social activity, smaller social networks, dissatisfaction with support received and/or a strained relationship with the cared for person are all correlated with higher levels of post-caring depression. Other disadvantages include financial hardship; care-related expenses (e.g. additional laundry linked to incontinence) deplete savings and contribute to debt. Time out of the workforce as a consequence of caring also adversely affects retirement income. Withdrawal of carer-related benefits (e.g. Carers Allowance in the UK)³, post caring compounds financial difficulties. Work related skills lost during caring can damage prospects of returning to a pre-caring job or embarking on a new career post-caring. Not only does this mean that opportunities to address financial losses are jeopardised but non-financial benefits linked to work, such as status, identity, and membership social networks, are also lost (Bass and Bowman, 1990; McLaughlin and Ritchie, 1994; Boerner, 2004; Hirst, 2005; Li, 2005; Larkin , 2009; Larkin and Milne, 2017; Burton et al., 2008; Carers UK, 2014a, b; Cronin et al, 2015; Purkis and Ceci, 2015; Carmichael and Ercoloni, 2016; Cavaye and Watts 2016a, b).

Whatever challenges former carers face, apart from former carer support groups sometimes offered by third sector carer organisations, there is little support from formal services. In the UK this is mainly because once carers are no longer 'actively' caring, they are not regarded by statutory agencies as justifying assessments of need or access to support (Larkin, 2007; Carers UK, 2014a; Cavaye and Watts 2016b).

² Intensive caring is defined as caring for at least 20 hours per week

³ Carer's Allowance is a benefit for people who regularly spend at least 35 hours a week caring for someone with substantial needs

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Most evidence about former carers has been generated from its 'parent field' of caring (Larkin 2009; Larkin and Milne, 2017; McCarron et al, 2011; Cavaye and Watts, 2016b; Kelleher and O'Riordan, 2017). In this literature post-caring is primarily understood as a final stage, or end phase, of the caregiving trajectory. Established theoretical models conceptualise caring as a continuum from pre-caring through to post-caring; post-caring is seen as integral to the 'overall caregiving career' (Orzeck and Silverman, 2008: 212; Schulz et al.1997; Aneshensel et al, 2004). Brown and Stetz's (1999) study of caregivers of people with life-threatening illnesses illustrates this approach well. They used the concept of 'labor of caregiving' and suggest that this comprises four phases - becoming a caregiver, taking care, midwifing the death, and taking the next step. Essentially caring 'begins' at diagnosis, or when the care recipient first becomes unwell, and continues for several months after the person dies.

During the 1990s, research focused on dementia care developed a similar model, identifying caring as taking place in temporal stages (Nolan et al, 1996; Dellasega, and Nolan 1997). Caring was seen as beginning pre-diagnosis and ending when the person with dementia is admitted to long-term care. The 'final' stage was referred to as 'a new beginning' and denotes when instrumental care ends and adjustment to the status of former carer begins (Nolan et al, 1996). Three additional phases have been identified in more recent work on carers of older people who are admitted to long-term care (many of whom have dementia). The first two - the 'decision making process' and making arrangements for 'moving into the care home' - occur pre-admission. The third phase - 'making it better' - occurs post-admission and involves the carer establishing a new 'carer role' (Davies and Nolan, 2004, 2006).

Very few theoretical models focus on the post-caring stage itself. Larkin's (2009) work about bereaved carers, developed the concept of a distinctive post-caring trajectory comprising three phases. The first two are the 'post-caring void' and 'closing down the caring time' whilst the third - 'constructing life post-caring' - involves getting 'life together' again, during which former carers reconnect with their families, pursue their interests, and take up new activities. Although Cronin et al (2015) do not use the term 'trajectory', they conceptualise the post-caring period as a time of being 'between worlds' during which former carers experience three iterative interrelated transitions.

These transitions have congruence with Larkin's (2009) findings and are referred to as 'loss of the caring world', 'living in loss', and 'moving on'.

This lack of theorisation around post-caring per se, and the tendency towards the 'default' addition of a former carer stage to the end of the caring trajectory is problematic. It results in the creation of a bifurcatory model of carer/former carer i.e. that there is a definitive point at which a person *stops* being a carer and *becomes* a 'former carer'. It also implies that carers *are* providing care and former carers *are not*. Furthermore, this frame of reference conceptualises the status of former carer as static. Dementia caring illustrates the limitations imposed by this approach well. Evidence suggests that the journey from 'carer' to 'former carer' for those caring for someone with dementia who requires long-term care may involve at least two overlapping stages. When the cared-for person enters a care home the carer's status becomes that of former carer. However, when the person with dementia dies the carer's status shifts into a 'new' type of former carer - that of bereaved former carer. This experience of status-shift involves a series of transitions, rather than a single move from one status to another, as suggested by the existing bifurcatory model (Moore and Dow, 2015; Roland and Chappell, 2015).

Other groups of carers also challenge this unidirectional linear approach to theorising former caring. These include carers of relatives with chronic conditions who are regularly admitted to, and discharged from, hospital, may move in, and out, of being a carer *and* a former carer. Carers who support a spouse at home *and* a parent in long-term care do not 'fit' this model either as they simultaneously occupy both statuses. Whilst work is beginning on carers who concurrently support two relatives in the community, there is not, as yet, recognition that a carer can be a carer *and* a former carer at the same time.

In addition to its under-developed theorisation there is an absence of conceptual granularity and analytical depth in existing knowledge about former carers. For instance, the concept of diversity is absent in former carer research. This is an interesting deficit as research on ethnicity and care (Katbamna et al, 2004, Carers UK, 2011, Greenwood, et al, 2015) and lesbian, gay, bisexual, and transgender (LGBT)

carers - to name but two areas - is growing. With reference to the former body of work, there is evidence that whilst carers from Black and Minority Ethnic (BAME) groups and majority groups face similar challenges, BAME carers “face additional barriers, for instance cultural barriers, stereotypes and language which can increase the chances of poorer health, poverty and social exclusion” (Carers UK, 2011:3). It is likely, given the legacies of caring discussed above, that these carers are at increased risk of disadvantage post-caring too. Non-familial dyads are more common in LGBTB caring relationships. ‘Families of choice’, including friends, lovers and ex-partners are now recognised as significant providers of care for LGBT adults with dependency needs (Newman, 2005, Willis et al, 2011). This suggests that there is a need to explore post-caring experiences, trajectories and models of support which do not privilege familial relationships.

The changing contours of family life additionally means that there is an emerging literature about care across different households; this has relevance to work on former carers too. Households can be linked by dissolved marriages, reconstituted families, non-resident partners and close friends (Williams, 2012).

Another challenge of existing research is its methodological limitations. Most studies focused on former carers are small-scale, short term and focus on a single group e.g. bereaved former carers, dementia former carers. The evidence base is also fragmented and atomised (Larkin and Milne, 2017, Cavaye and Watts, 2016a, b; Kelleher and McGrath, 2016).

In sum, not only do former carers experience a range of disadvantages but knowledge about them and their experiences is limited and is constrained by theoretical, conceptual and methodological weaknesses. Given that a range of theoretical and conceptual analyses have been used to add considerable depth, breadth and granularity to research and understanding in the carers’ field more widely (Ray et al, 2009; Bowlby et al, 2010; Milne and Larkin, 2015), the authors suggest that the time is ripe to develop the conceptual and theoretical dimensions within former carer research. We suggest that this could represent a first step in facilitating the generation of new knowledge about former carers.

Former carers: theoretical and conceptual directions

In the following section we explore some of the ways in which selected theories and constructs, usefully employed in existing carer-related research, could enrich and expand understanding of former carers as a group and former caring as a concept, process and lived experience.

Theory and former carer knowledge generation

Theoretical models developed in the 1980s and 1990s explored the ways in which social care agencies conceptualise carers and how service allocation was underpinned by, a largely hidden, construction of the carer as either a 'resource', a 'co-worker', a 'co-client' or a 'superceded carer' (Twigg, 1989; Twigg et al, 1990). This work not only exposed the nature of the relationship between agencies, professionals and carers but highlighted the 'lack of fit' between policy aims to 'support carers' and practice 'on the ground' (Manthorpe et al, 2003; Phillips, 2007; Milne and Larkin, 2015). This lens of analysis could be employed in work with former carers in different ways; it could explore how they are viewed by those agencies with whom they have contact (for example, care home staff, or the in the case of bereaved former carers, statutory services). In addition, it could explore the extent to which their 'construction' as a carer extends into their construction as a former carer.

Feminist perspectives - also developed in the 1980s - emphasised the way that care is gendered. This work highlighted, for the first time, that the majority of family carers are women and that care is regarded as a 'natural' female activity comprising the separate, but often intersecting, dimensions of 'caring about' and 'caring for'. The former involves *feelings* of concern whilst the latter is about the *tasks* of tending (Ungerson, 1983; Dalley, 1996). Other feminist writers took this a step further arguing that it is the fusion of task and feeling – namely labour *and* love - that characterises family care according it a distinctive status (Graham, 1983; Lewis and Meredith 1988). For some former carers the balance of labour and love is likely to shift. By way of illustration, post admission to long term care the majority of carers would do far fewer instrumental care tasks, but may undertake new tasks such as interacting with other residents, taking part in social events, and monitoring the quality of care (Dellasega and Nolan, 1997; Davies and Nolan, 2006; Moore and Dow 2015). How these new

tasks influence the nature and lived experience of being a (former) carer and how emotions, some of which are also new (such as guilt and concerns regarding care quality), affect both the care relationship and the carer's own wellbeing are under-researched. Gendered distinctions would be additionally interesting to explore.

Another theoretical approach which is relevant is lifecourse analysis. This seeks to identify how the effects - individually and in combination - of our - individual and shared - lifecourse experiences interact, intersect and accumulate and how they impact on later life patterns and outcomes (Bruhn and Rebach, 2014; Carmichael and Ercolani, 2016; Milne, 2020). The focus is on how each life stage is both embedded in the circumstances and experiences of previous life stages *and* has consequences for subsequent life stages (Green, 2010; Marmot, 2010; Ray et al, 2015). In carer-related research the lifecourse lens has foregrounded relational aspects of care, emphasising the interdependence and reciprocity of many care relationships and the fact that they are (often) embedded in a shared lifecourse (Walmsley, 1993; Kittay, 1999; Nolan et al, 2004). It has helped to illuminate the commitment of many long-term carers to caring and to the care dyad (Rand et al, 2017). The lifecourse lens could be employed to further explore the connectivity between active caring and former carers' 'legacies' (see above) and help 'attach' former caring as a life stage *and* experience to the earlier lifecourse. It is also credited with making visible the role played by social and structural inequalities. Therefore, it could help to extend understanding of difference and diversity amongst former carers, for example by exploring the influence of culture, low socio-economic status or belonging to a black or minority ethnic group has on former carers' lives, health, experiences and roles.

The 'ethic of care' builds on the relational dimension highlighted by lifecourse analysis (Barnes, 2012). It emphasises the inherent mutuality and attachment that is integral to most human relationships, including those characterised by care tasks and activities, and identifies care as an intrinsic dimension of personal relationships, families and communities (Fisher and Tronto, 1990; Tronto, 1993; Sevenhuijsen, 1998; Engster, 2007). The ethic of care perspective offers an alternative to 'traditional' conceptualisations of care and caring by constructing care as part of 'everyday life' and ordinary social relations and as relevant to the many not just the few (Daly and Lewis, 2000; Lloyd, 2006, 2012; Barnes, 2012). As most former carers would have

become active 'carers' over a period of time - often years - and their caring roles and tasks are an extension of 'what has gone before' the ethic of care may have particular resonance for them. The fact that many older former carers will have resisted defining themselves as a carer speaks to the values and integrative principles of this approach. This optic could help to foreground the relationship challenges that being a former carer brings and/or help to explore how former carers - and their relatives - develop new forms of mutuality and reciprocity and (re)define the process and role of caring (Lloyd, 2006; Barnes et al, 2015). As an ethic of care has been used to strengthen arguments about links between caring and social justice, this perspective may also provide an opportunity to raise the political profile of former carers and engage with a rights-based discourse.

Conceptual analysis and former carer knowledge generation

There are a number of concepts drawn from carer-related research that have particular potential to generate new knowledge about former carers. These are the emotiospatial hermeneutic, emotional labour, social liminality, hybridity, biographical disruption, and social identity.

Work using the emotiospatial hermeneutic has explored carers' experiences in relation to 'the place of care,' including a care home. The admission of their relative to long-term care has been described by Milligan as an 'embodied emotional experience' highlighting it as a felt and relational experience as well as a physical one (Milligan, 2005: 2010). This work has also identified the role played by affective aspects of a care home – such as whether it engenders feelings of warmth and inclusion - in shaping the extent to which family carers manage the transition well and are able to create a new carer identity (Milligan, 2005). Further employment of the emotiospatial hermeneutic could deepen our understanding about *how* carers make the transition process, what influences the experience, how they negotiate the new environment including the care home staff, and the complex role played by emotions in reframing and/or retaining a carer identity in a long-term care setting (Victor, 2010; Tanner et al, 2015).

The concept of emotional labour - the regulation of emotions required in dealing with others' feelings in order to fulfil a caring role - has been used in both the paid, and

more recently, the unpaid care domain (Hochschild, 1979; James, 1989;). It has illuminated discourse about how family carers manage their emotions, particularly when these are conflictual and/or complex, and has related potential to add depth and perspective to our understanding of former carers emotional challenges too (James, 1989; Twigg, 2006). For instance, the extent to which family carers of those in long-term care continue to regulate their emotions to produce particular feeling states and whether such regulation is at the expense of their own well-being. A carer may be upset that they are not 'allowed' into the care home as often as they would like or are stopped from doing some care tasks. However, in order to ensure that their relative is not upset and is able to remain in the home, they do not raise their concerns and strive to appear contented when visiting. Insights may similarly be gained in relationship to carers of those in hospital or hospices.

A third construct - that of social liminality - refers to transitional periods in an individual's life during which they are 'betwixt and between' socially ascribed roles (Szokolczai, 2009; Wetherell, 2012). It is often used in the context of dislocation, particularly in relation to migrants who have neither adopted the norms and/or culture of their new country nor relinquished those associated with their old one (Turner, 1969; Whalley-Hammell, 2006; Trusson, 2016). That the post-caring period has been conceptualised as a time of being 'between worlds' (Cronin et al, 2015) suggests that it could usefully be explored through the lens of social liminality. Specifically, it may help develop a more nuanced understanding of the process of transition from carer to former carer, and the nature of the conceptual shift(s) in caring roles through time.

The associated notion of 'hybrid identities', drawn from post-structural cultural theory, also acknowledges that integrating into a new country or society involves being 'between two cultures' (Anthias, 2001:621). It differs from social liminality as a construct in that it emphasises how identity, during this transition, is not only shaped by elements of the cultural heritage of origin but also by structural inequalities created by the meta social categories of age, gender, ethnicity and class (Werbner and Modood, 1997; Anthias, 2001; Pluss, 2013; Pulla and Woods, 2014). Use of the concept of hybridity could help to explore these structural influences and illuminate the nature and diversity of identity amongst former carers (Pluss, 2013). We know, for example, that an elderly wife's experiences of caring and identity as a 'carer' are very different

from those of an older husband as a consequence, primarily, of structurally determined gendered differences embedded in the lifecourse and in marriage (Milne and Hatzidimitriadou, 2003). We also know that those with caring responsibilities in BAME communities are often reluctant to adopt a carer identity because of cultural norms about familial expectations (Greenwood, et al, 2015). The extent to which these differences extend into, and shape, former carers' lives, experiences and identities is unexplored.

A fifth construct is that of biographical disruption. This has been widely used to explore people's experiences of, and adjustment to, chronic illness. Chronic illness is seen as a critical event which profoundly disrupts a person's life and can undermine their sense of self, security and social relationships. It prompts a need to redefine self-identity and create a new order in relationships and daily life (Bury, 1982, 2000). Whilst this construct has been used as a conceptual lens in relation to carers of those with a chronic illness (Adamson and Donovan, 2005; Barnes, 2006; Barken, 2014) it has not, to date, been used to explore former carers' experiences. It could make visible the disruptive impact of long-term care - or hospice/hospital - admission and/or expose former carers' development of a strategy to maintain biographical continuity, incorporating changes in their caring role into a pre-existing biographical schema (Whalley-Hammell, 2006). This may offer insights into the relational - often dyadic - nature of family care and add a new perspective to our (rather narrow) understanding of the biographical function of the carer continuing to provide care to a relative post admission to a care setting. Furthermore, the exploration of carers' management of the biographical assault of long-term care admission - on top of having managed the impact of their relative's ill health - would generate new knowledge. Additionally, this construct could be used to develop understanding of the experiences of those who shift in and out of the caring role and, importantly, those who leave caring behind altogether. This latter group are completely outside of the care arena and yet challenge existing, largely positive understanding about care and caring, and disrupt the 'heroic loyal' carer paradigm (Barnes, 2012).

Social identity theory is a sixth concept. This suggests that individuals have a repertoire of social and personal identities, the importance and strength of which vary over time (Tajfel and Turner, 1979; Stryker and Burke, 2000). Whilst the concept of a

role identity repertoire has been used in carer research (Hughes et al, 2013), it has rarely been applied to research with former carer research (Westacott and Ragdale, 2015) despite the fact that former caring is replete with role-related issues. As noted above, existing work on former carers whose relative is in long term care shows that they often adopt a new 'carer identity' post admission. This (often) involves taking on a different set of roles which tend to continue until the cared-for persons' death. Other roles may be variations on their previous caring activities such as helping to provide personal care, offering emotional and practical support, advocating for their relative and managing their money (White, 1994; Seltzer et al, 2001; Davies and Nolan, 2006).

There is evidence that a further set of role identity changes occur upon the cared-for persons' death. One of the most striking features of bereaved carers lives' is the frequency they either seek paid employment within the care sector, engage in voluntary activities related to caring and/or take on another unpaid caring role. Indeed there is growing evidence of the recurrence of family caring across the life course (Bruhn and Rebach, 2014; Hirst, 2014; Carmichael and Ercolani, 2016). Concepts such as 'vocation carer' (Lewis and Meredith, 1988) and 'serial carer' (Larkin, 2009) have been used to describe the sequential nature of caregiving roles. Whilst the reasons for a continued association with caring and care-related roles are complex, a need to retain a carer identity has been suggested as a primary, if subconscious, driver. For many long-term carers this may well be their dominant, or only, role and identity (Cronin et al, 2015; Hirst, 2005; Larkin, 2009; McLaughlin and Ritchie, 1994). Analysis of the conceptual and experiential nature of role identity could make visible previously invisible aspects of the work done by former carers to retain a carer identity, both as a person and for the social/publicly facing world, through and during post-caring transitions.

Opening up the Debate on Former Carer Research

Applying theoretical and conceptual analyses such as those discussed in this paper can expose new and/or previously invisible emotional, psychological, environmental and social dimensions of former carers' lives and experiences *and* former caring as a process. More specifically, they can help identify different phases of the 'transition' *from* carer *to* former carer and the cognitive and emotional mechanisms employed by

carers to manage the shift(s) in status, role and identity. Further exploration of the current bifurcatory lens opens up the possibility of challenging existing thinking in ways that may facilitate the development of new language and more nuanced ways of understanding former carers' lives and experiences. The distinction between 'carer' and 'former carer' and between being a 'former carer' for a relative in a care home and subsequently a 'former carer' of a relative who has died are two key examples.

Whilst developments have been proposed in relationship to specific theories and concepts, we recognise that valuable outcomes are most likely to be produced from their synthesis and intersectionality. The theories and concepts overlap and share terrain. The aim of presenting material as we have is to make clear how their employment in carer-related research has enriched this broader field and suggest ways that they could contribute to research with, and on, former carers. In so doing, the intention is to open up debate about research relating to this liminal, but growing, population of carers.

This work could also be of practical value; there is emerging evidence that professional engagement and support with carers' experiences during the process of admission of their relative to a care home may help to facilitate more effective adjustment to the change (Moore, and Dow, 2015; Tanner et al, 2015; Ray and Sullivan, 2016). Further research focusing on the lived experience and well-being of users and carers before, during and after admission into a care home could facilitate investment in support for this important and life altering emotional and physical transition by health and social care agencies and professionals. Enhancing the range and quality of support for residents and their relatives is also a possible outcome, for example the home offering a support group for relatives (Sandberg et al, 2001; Tanner et al, 2015; Westacott, and Ragdale, 2015). Importantly too, greater acknowledgement of the damaging role played by the 'legacies of caring' could be used to develop targeted support for former carers, engaging both statutory services (including primary care and hospitals) and third sector carer agencies. Improving the lives of former carers is also a matter of social justice; they are a marginalised group whose caring experiences (often) undermine their health, wellbeing and quality of life yet their need for support gets limited recognition or investment.

Whilst the focus of this paper has been on the potential of selected approaches to extend the boundaries and nature of knowledge in the former carer field, models and approaches drawn from other fields may also offer valuable insights. Social geography, anthropology, social psychology and migration studies are arenas which may be of particular benefit (Milligan and Wiles, 2010). Additional work on the role of 'place' - care home, hospice, hospital - in influencing former carers experiences and wellbeing is one such example. The meaning of 'home' is another.

Integral to opening up the debate about developments in research on former carer is consideration of methodological issues. Research needs to move beyond small scale local projects – the majority 'type' – and think bigger as well as broader. Having existing research evidence in one place would be a positive first step . This is being addressed, in part at least, by the establishment of the Carer Research and Knowledge Exchange Network (CAREN) (<http://wels.open.ac.uk/research-project/caren/>). CAREN is a freely accessible, independent database which acts as both a source of national and international carer-related information and evidence about carers - including former carers - and a network facilitating knowledge exchange between its diverse range of visitors⁴ from all over the world. It also offers an opportunity to build a virtual former carer 'community of interest' inclusive of former carers, which could explore ways of that research could engage with the models and approaches explored in this paper. There is a particular need to infuse former carers research with new theoretical lenses of analysis, engage with different methods (such as ethnography) and develop work that encourages interest and contributions from those hitherto not involved in the former carers field e.g. sociologists with expertise in emotional labour, role identity, and lifecourse studies.

Conclusion

Whilst researchers, policy makers and services are now paying some attention to the emerging population of former carers, this paper suggests that there is significant room for improvement. In particular, there is a need to address theoretical and conceptual deficits and invest in new and different types of research. There is a great deal to be

⁴ CAREN has 18,000+ visitors each year

learned and explored about the process of becoming a former carer *and* about former carers' lives and experiences. Given the proven capacity of the key constructs and theories outlined in this paper to deepen understanding and generate new knowledge in the carers field, the authors contend that their extension into the former carers field has much to offer. This paper is intended to serve as a catalyst for opening up debate and as a platform for taking forward developments in research on, and with, a group of carers whose needs and situations, and unique status, demand academic attention and analysis.

REFERENCES

Adamson, J, Donovan, J, 2005, "Normal disruption': South Asian and African/Caribbean relatives caring for an older family member in the UK', *Social Science & Medicine*, 60, 1, 37-48

Age UK, 2016, *Invisible army of oldest carers saving state billions*, Available at: <http://www.ageuk.org.uk/latest-news/invisible-army-of-oldest-carers-saving-state-billions/>

Aneshensel, C S, Botticello. A L, Yamamoto-Mitani, N, 2004 'When caregiving ends: the course of depressive symptoms after bereavement', *Journal of Health & Social Behavior*, 45, 422–440

Anthias, F, 2001, 'New hybridities, old concepts: the limits of culture', *Ethnic & Racial Studies*, 24, 40, 619-641

Barken, R, 2014, 'Caregivers' Interpretations of Time and Biography: The Experiences of Caring for a Spouse with Parkinson's Disease', *Journal of Contemporary Ethnography*, 43, 6, 695-719

Barnes, M, 2006, *Caring and Social Justice*, London: Palgrave, Macmillan

Barnes M, 2012, *Care in Everyday Life. An Ethic of Care in Practice*, Bristol: Policy: Press

Barnes, M, Brannelly, T, Ward, L, Ward, N, (eds) 2015, *Ethics of Care: Critical Advances in International Perspective*, Bristol: Policy: Press

Bass D, Bowman K, 1990, 'The transition from caregiving to bereavement: the relationship of care-related strain and adjustment to death', *Gerontologist*, 30,35–42

Boerner, K, Schulz, R, Horowitz, A, 2004, 'Positive aspects of caregiving and adaptation to bereavement', *Psychology & Aging*, 19, 4, 668-675

Bowlby, S, McKie, L, Gregory, S, Macpherson, I, (2010) *Interdependency and care over the life course*, Abingdon: Routledge

Brown, M. Stetz, K, 1999, 'The labour of caregiving: a theoretical model of caregiving during potentially fatal illness', *Qualitative Health Research*, 9,182-197

Bruhn, J G, Rebach, H.M, 2014, *The Sociology of Caregiving*, Berlin: Springer

Burton, A M, Haley, W E, Small, B, Finley, MR, Dillinger-Vasille, M, Schonwetter R, 2008, 'Predictors of well-being in bereaved former hospice caregivers: the role of caregiving stressors, appraisals, and social resource', *Palliative Support. Care*, 6, 2, 149-158

Bury, M, 1982, 'Chronic illness as biographical disruption', *Sociology of Health & Illness*, 14, 2, 167-182

Bury, M, 2000, 'Health, ageing and the lifecourse', in Williams, S J, Gabe, J, Calnan, M, (eds) *Health Medicine and Society: Key Theories, Future Agendas* (pp144-160), London: Routledge

Care Alliance, 2018, *Life After Care: A resource for those whose Family Caring responsibilities have ended*, (2nd ed.) Dublin: Care Alliance

Carmichael, F, Ercolani, M G, 2016, 'Unpaid caregiving and paid work over life-courses: Different pathways, diverging outcomes', *Social Science & Medicine*, 156 , 1–11

Carers Trust, 2019, *Key facts about carers and the people they care for*, <https://carers.org/key-facts-about-carers-and-people-they-care>, ,last visited 27/03/19

Carers UK, 2011, *Half a Million Voices: improving support for BAME carers* , London: Carers UK

Carers UK, 2014a, *Need to know: Transitions in and out of caring: the information challenge*, London: Carers UK

Carers UK, 2014b, *Caring and family finances inquiry. UK Report*, London: Carers UK

Carers UK, 2015, *Facts about Carers*, London: Carers UK

Carers UK, 2019, *The State of Caring*, London: Carers UK

Cavaye J, Watt, J H, 2016a, 'Experiences of bereaved carers: insights from the literature', *European Journal of Palliative Care*, 23, 4, 200–203

Cavaye J, Watt, J H, 2016b, 'Former carers: Issues from the literature', *Families, Relationships and Societies*. <http://dx.doi.org/10.1332/204674316X14676464160831>

Cronin, P, Hynes, G, Breen, M, McCarron, M, McCallion, P, O'Sullivan, L, 2015, "Between worlds": the experiences and needs of former family carers', *Health & Social Care in the Community*, 23, 1, 88-96

Daly, M, Lewis, J, 2000, 'The concept of social care and the analysis of contemporary welfare states', *British Journal of Sociology*, 51, 2, 281–298

Dalley, G, 1996, *Ideologies of Caring: Rethinking Community and Collectivism*, London: Macmillan (2nd ed.).

Davies, S, Nolan, M, 2004, 'Making the move': relatives' experiences of the transition to a care home', *Health & Social Care in the Community*, 12, 517–526

Davies, S, Nolan, M, 2006, 'Making it better': self-perceived roles of family caregivers of older people living in care homes: a qualitative study', *International Journal of Nursing Studies*, 43, 281–291

Dellasega, C, Nolan, M, 1997, 'Admission to care: Facilitating role transition amongst family caregivers', *Journal of Clinical Nursing*, 6, 443 – 451

Department of Health, 2014, *Carers Strategy: Second National Action Plan 2014 – 2016*, London: Department of Health

Engster, D, 2007, *The Heart of Justice: Care Ethics and Political Theory*. Oxford: Oxford University Press

Fisher, B, Tronto, J, 1990, Toward a Feminist Theory of Caring in Abel, E, Nelson, M (eds.) *Circles of Care. Work and Identity in Women's Lives*, New York: State University Press

Graham, H, 1983, 'Caring: a labour of love', in Finch, J. and Groves, D. (eds.) *A labour of love: Women, work and caring* (pp. 13-30), London: Routledge and Kegan Paul

Green, L, 2010, *Understanding the Life Course. Sociological and Psychological Perspectives*, Cambridge: Polity Press

Greenwood, N, Habibi, R, Smith, R, Manthorpe, J. 2015, 'Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature', *Health & Social Care in the Community*, 23, 1, 64-78

Henwood, M, Larkin, M, Milne, A, 2017, *Seeing the wood for the trees. Carer related research and knowledge: a scoping review*, Available at <https://www.scie-socialcareonline.org.uk/seeing-the-wood-for-the-trees-carer-related-research-and-knowledge-a-scoping-review/r/a110f00000RCtCnAAL>

Hirst, M, 2005, 'Carer distress: a prospective, population-based study', *Social Science & Medicine*, 61, 697–708

Hirst, M, 2014, *Transitions into and out of unpaid care*, York: Working Paper No. CUK 2644

Hochschild, A, 1979, 'Emotion work, feelings and social structure', *American Journal of Sociology*, 85, 551-575

Hughes, N, Locock, L, Zeibland, S, 2013, 'Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis', *Social Science and Medicine*, 96, 78–85

Humphries, R, Thorlby, R, Holder, H, Hall, P, Charles, A, 2016, *Social care for older people: Home truths*, London: The King's Fund

James, N, 1989, 'Emotional labour: skill and work in the social regulation of feelings', *Sociological Review*, 37, 15-42

Katbamna, S, Ahmad, W, Bhakta, P, 2004, 'Do they look after their own? Informal support for South Asian carers', *Health & Social Care in the Community*, 12 5, 398-406

Kelleher, C, McGrath, H, 2016, 'What Comes Next? Family Carers' Experiences of Role and Identity Transition on Cessation of the Caring Role', *Advances in Consumer Research*, 44, 508-509

Kelleher, C, O' Riordan, J, 2017, *Post-caregiving: family carers' experiences of cessation of the caring role. Implications for Policy and Practice*, Cork: Institute of Social Science in the 21st Century, University College Cork

Kittay, E F, 1999, *Love's Labor: Essays on Women, Equality, and Dependency*, London: Routledge

Larkin, M, 2007, 'Group support during caring and post-caring - the role of carers groups', *Groupwork*, 17, 2, 28-51

Larkin, M. 2009, 'Life after caring: The post-caring experiences of former carers', *British Journal of Social Work*, 3 (6): 1026-1042

Larkin, M, Milne, A, 2017, 'What do we know about older former carers? Key issues and themes', *Health and Social Care in the Community*, 25, 4, 1396 -1403

Larkin, M, Henwood, M, Milne, A, 2018, 'Carer related research and knowledge: findings from a scoping review', *Health and Social Care in the Community*, 2, 1, 55 - 67

Lewis, J, Meredith, B, 1988, *Daughters who Care*, London: Routledge

Li, L W, 2005, 'From caregiving to bereavement: trajectories of depressive symptoms among wife and daughter caregivers', *Journals of Gerontology - Series B Psychological Sciences & Social Sciences*, 60, 4, 190-198

Lloyd, L, 2006, 'A Caring Profession? The ethics of care and social work with older people', *British Journal of Social Work*, 36, 1171-85

Lloyd, L, 2012, *Health and Care in Ageing Societies A new international approach*, Bristol: Policy Press

McCarron, M, Breen, M, Cronin, T, Hynes, G, O'Sullivan, L, 2011, *Between worlds the experiences and needs of former family carers*, Dublin: Care Alliance

McLaughlin, E, Ritchie, J, 1994, 'Legacies of caring: the experiences and circumstances of ex-carers', *Health & Social Care in the Community*, 2, 4, 241-53

Marmot, M, 2010, *Fair society, healthy lives. A strategic review of health inequalities in England Post-2010 (Marmot Review)*, London: The Marmot Review

Milligan, C, 2005, 'From home to 'home': situating emotions within the caregiving experience', *Environment and Planning*, 37, 2105-2120

Milligan, C, Wiles, J, 2010, 'Landscapes of Care,' *Progress in Human Geography*, 34 (6): 736-754

Milne, A, 2020, *Mental Health in Later Life: Taking a Life Course Approach*, Bristol: Policy Press

Milne, A, Hatzidimitriadou, E, 2003, 'Isn't He Wonderful? Exploring the contribution and conceptualisation of older husbands as carers,' *Ageing International*, 28, 4, 389-408

Milne, A, Larkin, M, 2015, 'Knowledge generation about care-giving in the UK: a critical review of research paradigms', *Health and Social Care in the Community*, 23, 1, 4–13

Moore, K J, Dow, B, 2015 'Carers continuing to care after residential care placement', *International Psychogeriatrics*, 27, 6, 877–880

NHS England, 2014, *NHS England's Commitment to Carers*, Leeds: NHS England

Newman, R, 2005, 'Partners in care: being equally different: lesbian and gay carers', *Psychiatric Bulletin*, 29, 7, 266-267

Nolan, M, Walker, G, Nolan, J, Williams, S, Poland, F, Curran, M, Kent, B C, 1996 'Entry to care: positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers', *Journal of Advanced Nursing*, 24, 265-274

Nolan M, Davies S, Brown J, Keady J, Nolan, J, 2004 'Beyond 'person-centred' care: a new vision for gerontological nursing', *International Journal of Older People Nursing in association with Journal of Clinical Nursing*, 13 (3a), 45–53

OECD, 2011, *Informal carers. In Health at a Glance 2011: OECD Indicators*, OECD Publishing. http://dx.doi.org/10.1787/health_glance-2011-en

Office for National Statistics, 2013, *2011 Census Analysis: Unpaid Care in England and Wales, 2011 and comparison with 2001*. Available at: http://www.ons.gov.uk/ons/dcp171766_300039

Orzeck, P, Silverman, M, 2008, 'Recognizing post-caregiving as part of the caregiving career: implications for practice,' *Journal of Social Work Practice*, 22: 211–220

Phillips, J, 2007, *Care*, Cambridge: Polity Press

Plüss, C, 2013, 'Migrants' social positioning and inequalities: The intersections of capital, locations, and aspirations,' *International Sociology*, 28, 1, 4-11

Pulla, V, Woods, J, 2014, 'The resilient Chinese in Australia: Ethnicity, identity and 'Chineseness', *International Sociology*, 29, 5, 388-395

Purkis, M E, Ceci, C, 2015, 'Problematizing care burden research', *Ageing & Society*, 35,1410-1428

Rand, S, Forder, J, Malley, J, 2017, 'A study of dyadic interdependence of control, social participation and occupation of adults who use long-term care services and their carers', *Quality of Life Research*, 26, 12, 3307–3321

Ray, M, Bernard, M, Phillips, J, 2009, *Critical issues in social work with older people*, Basingstoke: Palgrave Macmillan

Ray, M, Milne, A, Beech, C, Phillips, J, Richards, S, Sullivan, M.P, Tanner, D, Lloyd, L, 2015 'Gerontological Social Work: Reflections on its Role, Purpose and Value', *British Journal of Social Work* 45, 4, 1296-1312

Ray, M, Sullivan, M P, 2016, *Care homes and older people*,
e.communitycare.co.uk/?qs=d53159ed593d38530968fe6c9163ec9493e354ec6b3d9
23af3f79b31a4a3733920392680efbeaec1

Roland, K P, Chappell, N L, 2015, 'A typology of care-giving across neurodegenerative diseases presenting with dementia', *Ageing & Society*, 35, 1905-1927.

Sandberg, J, Lundh U, Nolan, M, 2001, 'Placing a spouse in a care home: the importance of keeping', *Journal of Clinical Nursing*, 10, 3, 406-16

Schulz, R, Newsom, J T, Fleissner, K, Decamp, R, Nieboer, A P, 1997, 'The effects of bereavement after family caregiving,' *Ageing & Mental Health*, 1, 3, 269-282

Scrutton, J, Creighton, H, 2015, *The emotional wellbeing of older carers*, London; International Longevity Centre

Seltzer, M M, Krauss, M W, Hong, J, Orsmond, G I, 2001, 'Continuity or discontinuity of family involvement following residential transitions of adults who have mental retardation.' *Mental Retardation* 39, 3, 181-194

Sevenhuijsen, S, 1998, *Citizenship and the ethics of care: feminist considerations of justice, morality and politics*, London: Routledge

Stryker, S, Burke, P J, 2000, 'The past, present and future of identity theory,' *Social Psychology Quarterly*, 63, 4, 284-297

Szakolczai, Á., 2009, 'Liminality and experience: structuring transitory situations and transformative events,' *International Political Anthropology*, 2, 1, 141– 172

Tajfel, H, Turner, J C, 1979, 'An integrative theory of intergroup conflict', in Austin, W. G. and Worchel, S. (eds), *The Social Psychology of Intergroup Relations* pp33-47, Monterey: CA: Brooks/Cole

Tanner, D, Glasby, J, McIver, S, 2015, 'Understanding and Improving Older People's Experiences of Service Transitions: Implications for Social Work', *British Journal of Social Work*, 45, 2056–2071

Thomas, S, Dalton, J, Harden, M, Eastwood, A, Parker, G, 2016, *Updated Meta-Review of Evidence on Support for Carers*, Southampton: NIHR HS&DR

Tronto, J, 1993, *Moral Boundaries. A Political Argument for an Ethic of Care*, London: Routledge

Trusson, D, Pilnick, A, Roy, S, 2016, 'A new normal?: Women's experiences of biographical disruption and liminality following treatment for early stage breast cancer', *Social Science & Medicine*, 151, 121–129

Turner, V, 1969, *The Ritual Process: Structure and Anti-structure*, New York: P De Gruyer

Twigg, J, 1989, 'Models of carers: how do social care agencies conceptualise their relationship with informal carers?', *Journal of Social Policy*, 18, 1, 53-66

Twigg, J, 2006, *The body in health and social care*, Basingstoke, Palgrave Macmillan

Twigg, J, Atkin, K, Perring, C, 1990, *Carers and services. A review of research*. London: HMSO

Ungerson, C, 1983, 'Why do Women Care?' in Finch, J. and Groves, D. A. *Labour of Love: Women, Work and Caring* (pp45-59), London: Routledge and Kegan Paul

van Walsum, S, Alpes, M J, 2014, 'Transnational Households: Migrants and Care, at Home and Abroad', in Anderson, B. and Shuts, I. (eds) *Migration and care labour: theory, policy and practice* (pp. 151-169), London: Palgrave Macmillan

Victor, C, 2010, *Ageing, health and care*, Bristol: Policy Press

Walmsley, J, 1993, 'Contradictions in caring: reciprocity and interdependence,' *Disability, Handicap and Society*, 8, 2, 129-141

Werbner, P, Modood, T, 1997, (eds.) *Debating Cultural Hybridity*, London: Pluto

Westacott, D, Ragsdale, S, 2015, 'Transition into permanent care: the effect on the family,' *Nursing in Residential Care*, 17, 9, 515 – 518

Weicht, B, 2010, 'Embracing dependency: rethinking (in)dependence in the discourse of care', *The Sociological Review*, 58, s2, 205–224

Wetherell, M, 2012, *Affect and Emotion: a new Social Science Understanding*, London: Sage Publications

Whalley-Hammell, K, 2006, *Perspectives on Disability & Rehabilitation*, Canada: Churchill Livingstone

White, D, 1994, 'On being the relative of someone in a home', *Elders: the Journal of Care & Practice*, 3, 2, 6–13

Willis, P, Ward, N, Fish, J, 2011.' Searching for LGBT Carers: Mapping a Research Agenda in Social Work and Social Care', *British Journal of Social Work*, 41, 7, 1304-1320

Williams, F, 2012, 'Care relations and public policy: social justice claims and social investment frames', *Families, Relationships and Societies*, 1, 1, 103-119

Williams, F, 2010, 'Themes and Concepts in Migration, Gender and Care', *Social Policy and Society*, 9, 3, 385-396

Williams, F, 2018, 'Care: 'Care: intersections of scales, inequalities and crises' , *Current Sociology*, 66, 4, 547–561