research article

The value of data visualisation: tracking geographies of informal care in Ireland, 2002–16

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As policy and funding associated with informal/unpaid/family caring develops, more attention has been given to data that support and inform such policy. In particular, evidence around aspects of inequality is often expressed in geographical variations between places in terms of numbers and rates. In general, to date, research on informal caring has focused little on how such variations can be visualised and analysed. This short article looks at the mapping of data from Irish censuses between 2002 and 2016 to: first, explore and visualise patterns of caring, including high-intensity caring. A second broad aim is to use different spatial techniques, including location quotients and clustering, to provide more robust visualisations of spatial variations. Finally, some putative links are but forward between the variable geographical distributions of caring and changes in legislation and policy for carers in Ireland during that same period.

Introduction: evidence bases for informal care

Given the developing nature and widening range of policy related to informal/ unpaid/family caring across the European Union (EU), a variety of approaches to gathering data have been used to provide evidence to inform policy (Foley, 2008; Courtin et al, 2014). In addition, in some EU states, the role of informal care as an important component of long-term care (LTC) has seen carers incorporated into specific policy on LTC budget reform and planning (Zigante, 2018). Data from the Organisation for Economic Co-operation and Development (OECD, 2017) have identified a mean rate of about 13 per cent of all people aged over 50 being involved in some kind of informal caring role. Independently, there has been much debate in the literature on carers about aspects of inequality, related to potential service access, recognition, gender, need and service provision. Much of this can be framed as spatial outcomes of specific policy decisions and wider care system structures

(Milligan and Power, 2010; Da Roit et al, 2015). We fully acknowledge wider debates in the geographies of care literature that frame informal/family caring as assemblages of social relations and spatialised social practices at a variety of scales, spaces and places (Lawson, 2007; England, 2010).

For many people working in health and social care, terms like 'mapping services or demand' or 'exploring carer demographics' are not unfamiliar. Yet, less explicit attention has been paid to the cartographic potential of the term, specifically, how geography frames, shapes and reflects carers' lives. This article addresses this, using what we argue is underused evidence in this format. Questions on caring were included in the last four Irish, as well as in recent UK and other national, censuses (ONS, 2013; CSO, 2017). While such data are often contested when cross-referenced with cross-sectional, longitudinal and utilisation data, they remain the prime source for ecological-level research (CAI, 2018a). This rich source of evidence, gathered at a range of scales, can be mapped across space and time to provide time-specific profiles of carers' lives (Bowlby, 2012). The geographical mapping of these data can provide valuable evidence that reflects and describes the effects of carer policies. While the broad patterns emerging from census data have been used for policy analysis, this rarely extends beyond a broad regional or rural–urban breakdown. Earlier research in the UK and Ireland explored carer geographies with a specific focus on the spatial modelling of funding at local ward-level geography (Foley, 2002; 2008). More recent work in the US has also used geographical information system (GIS) methods to model how neighbourhood context affects the health outcomes of family carers (Beach et al, 2019).

The broad aim of this article is to show that the geographical mapping of carers over a 14-year period can make visible spatial shifts in caring over time in order to better inform policy, and can use a set of 'big data' to visualise the spatial impacts of policy decisions. We map carer data from the Irish national censuses of 2002, 2006, 2011 and 2016 as a case study that can inform wider international comparative study. An additional core objective of the article is to map the relative spread of informal/unpaid/family caring in Ireland between the four dates for which data were available, bearing in mind wider structural policy shifts in this period. In our approach, we chose a timescale covering three broad periods: the end of a period of sustained economic prosperity in Ireland (the so-called 'Celtic Tiger' period) from 2002 to 2008; the period from the 2008 global financial crisis up to around 2012 (the impact of which brought with it a sustained period of austerity); and the period of slow recovery in economic terms across Ireland from 2012 to 2016. Given similar experiences in the UK and elsewhere, we suggest that the Irish example may also provide a valuable case study and route into spatially framed insights about carers in other jurisdictions, while being mindful of specific local factors. While Irish census data are available at multiple geographical scales, from the national to a very fine-grained neighbourhood scale, in this article, we focus on two scales – local authorities (LAs) and small areas (SAs) – to provide the visual evidence. The data collected are based on self-reported responses from all citizens who answered a question on whether they provided 'regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability' and, additionally, how many hours of care they provided. While, as noted earlier, the reliability of census data on carers is contested (CAI, 2018a), the census nevertheless provides a rich and comprehensive national data set that identifies

both levels and amounts of caring, details of carers' characteristics, and, crucially for our purposes, where they live. We analyse these data to produce innovative visual evidence, mapping caring against key 'moments' and shifts in policy relevant to carers over a 14-year period. Exploring how carer demographics may shape or be shaped by policy developments may help support advocacy and inform future policy discussions.

Policy: landscapes of care and support

Within the geographies of care literature, which partially overlaps with research on voluntarism and geographical gerontology, there is increasing evidence of why place matters and the complex ways in which 'carescapes' are formed (Skinner and Power, 2011; Bowlby, 2012). Where a carer lives may have an immediate effect on how they live and the supports and services they can access, enabling carers to see how well served they are, compared to others with equal needs (Foley, 2002). Within the wider literature on ethics of care and a more relational understanding of how informal caring sits within those debates, interesting spatial analogies have emerged. These range from a recognition of scale in 'carer distance decay models' (Smith, 1998) to identification of the idea of 'care deficits' that might be made evident through tools like mapping and visualisation (England, 2010). These elements emerge regularly in discussions among health geographers on inequalities, accessibility and utilisation, communities of care, and the wider effects of place (Milligan and Power, 2010; Milligan and Wiles, 2010). As Power and Hall (2018) note, the term 'place' has multiple meanings to carers, including getting a 'place' in a respite care scheme, being 'placed' through access to benefits and financial support, or simply sharing a community with other carers. This is a complex process; a community of interest can be both local (clusters of carers in a town or neighbourhood) and distal (carers of a particular type separated by distance), emphasising a more networked geography of caring. Nonetheless, mapping carers on to their home locations is important in examining the complexities of lived experience (Parr, 2003; Bowlby, 2012). Hanly and Sheerin (2017) identify the specific role that carers play in Ireland in supporting formal health and social care services, estimating that they potentially contribute from €2.1 billion to €5.5 billion in financial terms. They also note that despite a national strategic commitment in 2001 to shift from institutional to more community-based care, this has not yet taken place due to ongoing structural, professional and economic preferences for institutional over community care, as well as a lack of funding and support models to develop the latter fully. We argue that the community-level mapping of carers offers useful evidence that can help revive that policy direction.

As mentioned, the period covered includes the end of the 'Celtic Tiger' period and a period of considerable austerity after the 2008 financial crisis. While Ireland's economic boom was a localised phenomenon, associated with a low taxation and high inward investment business model, the period of austerity that followed was also seen in the UK and other parts of Europe and the Global North. This brought dramatic changes in policies that had significant impacts on the lives of family carers and those they care for, a ten-year period that proved to be quite tumultuous. In raw terms, financial support for family carers in Ireland (specifically, the Carers Allowance) increased in generosity by just over 100 per cent, from €102 per week in 2000 to €205 in 2016. This should be seen in context, however; at its height (in 2009), Carers

Allowance (for a person aged under 66 and caring for one person) was paid at €220.50 per week (DEASP, 2019). However, between 2009 and 2011, it was reduced by at least €16 per week, a significant adjustment for those struggling to make ends meet in a country with high living costs. Further, a broad range of health and disability services and supports for the people family carers were supporting were also cut significantly. There are many complex and multiply dependent ways in which formal and informal care services and supports operate in societies, and structural impacts runs across these realist intersections (Parr, 2003; Lawson, 2007; Milligan, 2010), affecting disability support services, older persons' services and mental health services. The year 2012 alone saw a 10 per cent reduction in publicly funded home-care support in Ireland (CAI, 2018b). Related supports that many families with caring responsibilities relied upon, such as the household benefits package, the motorised transport grant (closed to new entrants after 2013), access to discretionary medical cards and bereavement grant, were also cut.

When the economy began to recover, the benefits of the recovery were not seen by family carers or those they cared for; the first increases in the rate of Carers Allowance and Carers Benefit took place only in 2017, four years after the economic recovery began. Some welfare measures that were abolished during the economic downturn have yet to be restored (examples include bereavement and motorised transport grants). The latter part of the study period was associated with the lingering effects of the financial shocks of the previous decade. Ongoing consequences of this may be increased precarity across the board for carers, which may take time to filter through in the data, and the longer-term effects of austerity may only become apparent in the 2021 and 2026 censuses. At time of writing, we expect the COVID-19 pandemic to deepen that precarity, producing many potentially negative effects for carers; multiple lockdowns have brought some families closer, or have 'spread the care', but this has not been evenly felt or distributed (Chan et al, 2020; ONS, 2020).

While there were significant gains and losses in the period 2002–16 in terms of social welfare supports for family carers (specifically, direct income and allied supports), broad policy changes and developments also had further impacts. In 2006, the official government social partnership policy framework, *Towards 2016* (Government of Ireland, 2006), was published; this included a commitment to develop a (separate) national carers strategy (initially planned by the end of 2007) that would guide policy affecting Ireland's family carers. Just two years later, however, the Celtic Tiger had begun to wane, and the fiscal crash of 2009 led to significant cuts in the funding of services and the curtailment of progressive policy developments. The planned national carers strategy was not published until 2012 and became a 'cost-neutral' strategy (itself a direct consequence of austerity thinking), with no budget for implementation and many specific recommendations by carer advocacy groups removed or scaled back. The 2012 *National Carers Strategy* remains (in 2020) the core policy for family carers in Ireland. Its core guiding principle is that Ireland's family carers should be 'recognised and respected as key care partners' (Department of Health, 2012). The strategy contains 42 actions to achieve this, but without a dedicated budget (or an implementation plan in place), progress has been slow (National Carers Strategy Monitoring Group, 2018). While these broad policy shifts are specific to Ireland, similar shifts in caring policies have been seen in other jurisdictions, with both country–specific (local) and common structural (global) dimensions (Milligan, 2001; McEwan and Goodman, 2010).

Data and method: location quotients and clusters

The data on carers used in this article are from the four most recent Irish censuses, collected between 2002 and 2016. Ireland is unusual in having a census every five years (though its 2001 census was delayed by one year due to an outbreak of foot-and-mouth disease). The data we use are drawn from a self-reported answer to a specific question: 'Do you provide regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability? Include problems which are due to old age. Personal help includes help with basic tasks such as feeding or dressing' (text from the 2016 census). An identical question was asked in the UK in its 2011 census as part of an attempt to align data between the two jurisdictions of the island of Ireland (Gleeson et al, 2008). A follow-on section asked an open-ended question about the hours per week of help provided (coded in subsequent analysis). Question wording differed slightly over time and has been criticised for its lack of nuance and complexity. It is thought that the Irish census significantly underestimates the percentage of informal/family carers, at around 5 per cent of the adult population, relative to the OECD figure noted earlier (Robards et al, 2015; CAI, 2018a). In the 2002 and 2006 censuses, respondents could tick boxes to indicate the relevant category of weekly hours spent caring: 1–14 (low intensity [LI]), 15–28 (medium intensity [MI]), 29–42 (high intensity [HI]) and 43+ (maximum intensity [XI]). The 2011 and 2016 censuses asked respondents to enter the number of weekly hours they spent caring (subsequently coded by the Central Statistics Office [CSO] into the four categories used earlier, plus a 'not stated' category). In the 2021 census (planned at time of writing), a prompt will be added for people who feel they are '24/7' carers (168 hours).

Our mapping analysis was conducted using databases imported from the census and joining these with digital boundary maps within the GIS software product ArcMap v10.7. In Ireland, it is possible to map carers at various scales: national, regional, local authority and at very local scales, such as electoral divisions (EDs) and the neighbourhood-level SAs. (The latter are similar to output areas [OAs] in the UK.) Figure 1 shows a national pattern (with an inset for Dublin) of the percentage of carers at the SA scale for 2016. The is shows the level of detail provided by the CSO, first used in the 2011 census.

The complexity and detail of the pattern at this scale, though useful for local needs assessment, is too dense to really interpret meaningful patterns, though we revisit it later in the article for a separate form of spatial analysis. In the next section, we present map location quotients (LQs) at the county/LA scale that we generated for the selected time periods. We did this: first, to provide a broad, detailed picture of use to policymakers; and, second, because it is at this scale that the very local politics of Irish society are acted out. While there are some slight variations over the time period of the study,[1] these data provide a relatively stable and policy-useful scale against which to map carers, especially in relation to wider policy impacts during the period. In interpreting the census data, we could identify associations at this geographical scale with other variables, such as employment, social class and housing. Emerging data on self-reported health, limiting-long term conditions and deprivation are also useful in explaining aspects of the mapping of LQs (though these were not applied consistently across all four censuses due to data unavailability) (Foley, 2008).

Figure 1: Percentage of carers at the SA (neighbourhood) level, 2016
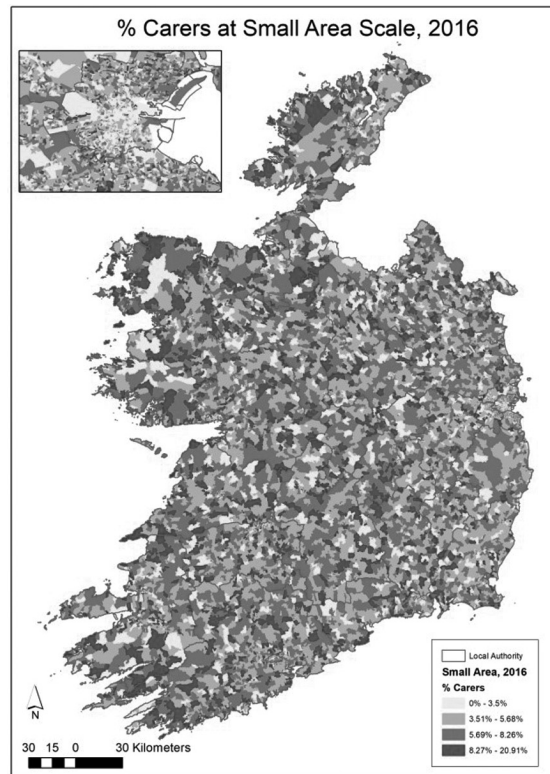
In mapping the data, studies within the medical and health geography literature have consistently explored equity issues, as expressed through relative levels of supply and demand (Foley, 2008). Joseph and Philips (1984) used LQs (loosely similar to Gini coefficients used by economists) to provide a simple and effective comparative measure offering a national visualisation of the relative level of caring activities. The basic formula is expressed as:

$$LQ\,[ti] = \frac{SP\,[ti]\,/P\,[ti]}{\Sigma i\;SP\,[ti]\,/\Sigma iP\,[ti]},$$

where: $LQ[ti]$ is the LQ for region i at time t; $SP[ti]$ is the number of carers in region i at time t; and $P[ti]$ id the total population of region i at time t.

LQs express the extent to which an identified area varies from the national average. Thus, an LQ score of 2.0 identifies an area with twice the expected number of carers, while an LQ score of 0.5 refers to an area with half the expected number of carers, in both cases, based on the national average. LQs are a relatively simple measure but an effective tool for visualising distributions and levels of caring, especially at fine-grained geographies, and for establishing national patterns at multiple scales.

One final piece of spatial analysis, the results of which are described in more detail in the discussion section (see Figures 5a and 5b), was the application of a specialist GIS tool to look at the spatial clustering of carers at different scales. This used cluster

and outlier analysis, taking a set of weighted features (here, data on the percentage of carers) and identifying statistically significant 'hot spots', 'cold spots' and spatial outliers, using the Anselin Local Moran's I statistic. This takes one geographical area at a time and looks at the values of all adjoining or neighbouring areas. If areas are statistically similar, they are grouped into clusters, based on sharing relatively high, or relatively low, values. 'Hot spots' are coded as high–high, and 'cold spots' as low–low. The tool also creates two other outliers: spatially significant clusters, where low values are surrounded by high values (low–high); and those where areas with high values are surrounded by low values (high–low). Finally, it codes all other areas as statistically not significant. This removes a lot of 'noise' and 'zooms in' on areas with clusters of especially high caring responsibilities that may be particularly useful for policy analysis.

Results: spatially modelled intensities of caring

Figures 2 and 3 show the LA scale LQs for: (1) all carers; and (2) XI carers who provide care for over 43 hours a week. There are interesting variations in both, and they shift and change over the four time periods. Figure 2, showing LQs for all carers, shows that in 2002 and 2006 (top two maps), the rural and more marginal areas in the south and west consistently had high LQ scores (up to 1.31/1.32). There is also a clear pattern of low LQs in the east of the country, consistent with commuter belts with relatively young populations. In 2011 and 2016, two variations emerged (lower two maps). First, the highest LQ scores fall to 1.18 and 1.11, respectively, suggesting a reduction nationally in spatial variation. Geographically, there remain low LQ scores in the east, with a shift of higher scores along the whole of the western side of the country, suggesting that informal/family caring continues to be disproportionally associated with more rural areas. When individual LQ scores and relative LA ranks are considered across the same period, there are increases between 2011 and 2016 in the east of the country. This can be partially explained by a slight shift in the population profile back to the mean (as population cohorts age within commuter belts and with the post-boom emigration of younger cohorts in the east of the country).

While the observed patterns of overall caring tell one story, it is also instructive to look at the parallel geographies of XI carers in the same period. Figure 3 shows the percentage of XI carers within the carer cohort. Across the board, there is a visible U-curve in terms of carer intensity, with higher percentages in the LI (0–14 hours a week) and XI categories, and lower percentages in the MI and HI categories (Foley, 2008). Again, there is a slight reduction in the range of values, from 0.73–1.34 in 2002 to 0.83–1.14 in 2016, indicating a narrowing of the spatial variation for this subgroup of carers. There is also a more mixed pattern compared to the more westerly and rural concentration for all carers, suggesting that commuter-belt areas especially saw a rise in caring brought on by cuts in services.

In terms of shifting geographies, the North-West, Kerry (South-West) and Wexford (South-East) show the highest variations between 2002 and 2006, and between 2011 and 2016 there are shifts eastward and southward. This may indicate post-austerity impacts, with the worst impacts of the financial crisis occurring in 2011 and a lag effect up to 2016. Geographically, the main effects of the period of austerity were in more distant commuter belts, though this may also be an effect of the ageing of suburban society in this period; more detailed analysis from cross-sectional and longitudinal data was not undertaken for this article but might be worthy of further investigation.

Figure 2: Percentage of all carers at the LA scale, 2002–16

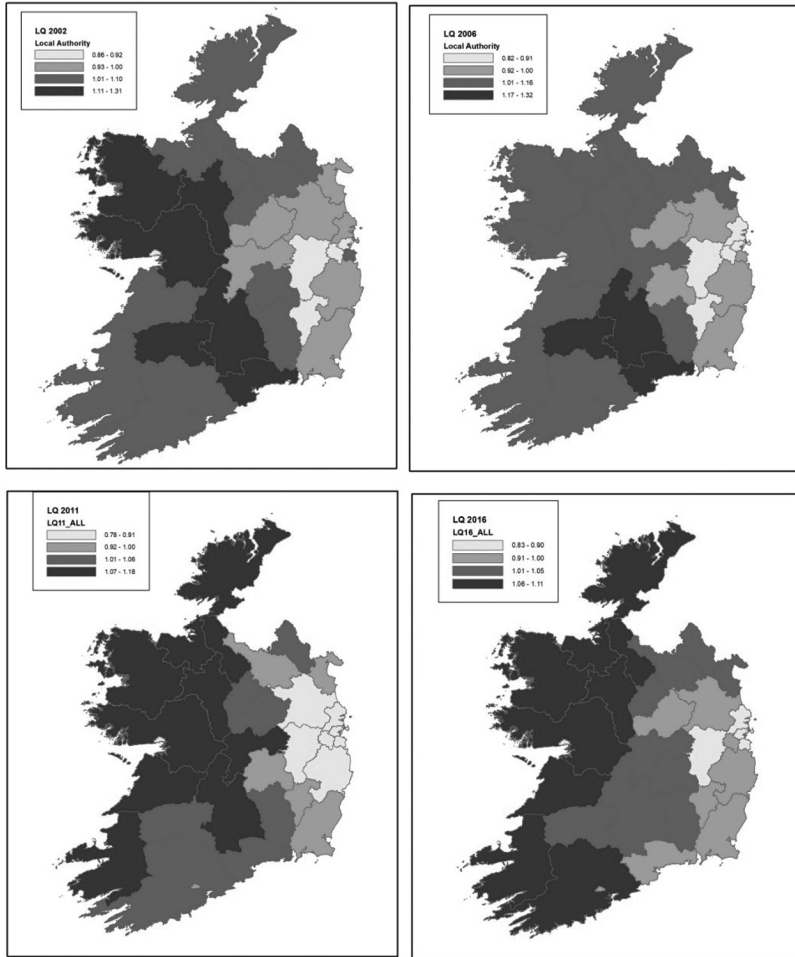Location Quotient, All Carers, 2002-2016, LA Scale

Figure 4 provides a representative visualisation of the changing data on caring against some of the policy interventions mentioned previously. In the chart, the individual percentages for different intensities of caring show the trend noted earlier (an increase in MI and HI care) as more responsibility landed on families during austerity. (Text markers of key policy shifts in this period are provided to visualise this.) The increase in the number of carers self-identifying in the MI group, and other increases between 2006 and 2011, coincides with a period of an increased number of people reporting providing care, alongside reduced welfare provision. Using this method to align carer numbers and geographies with significant shifts in national policy may be of value in other countries.

Discussion: prosperity and austerity

While Figures 2 and 3 show changes over time, the detail provided in Figure 1 emphasises the value of modelling carer data for planning meaningful needs

Figure 3: Percentage of XI carers at the LA scale, 2002–16

Location Quotient, High-Intensity Carers, 2002-16, LA
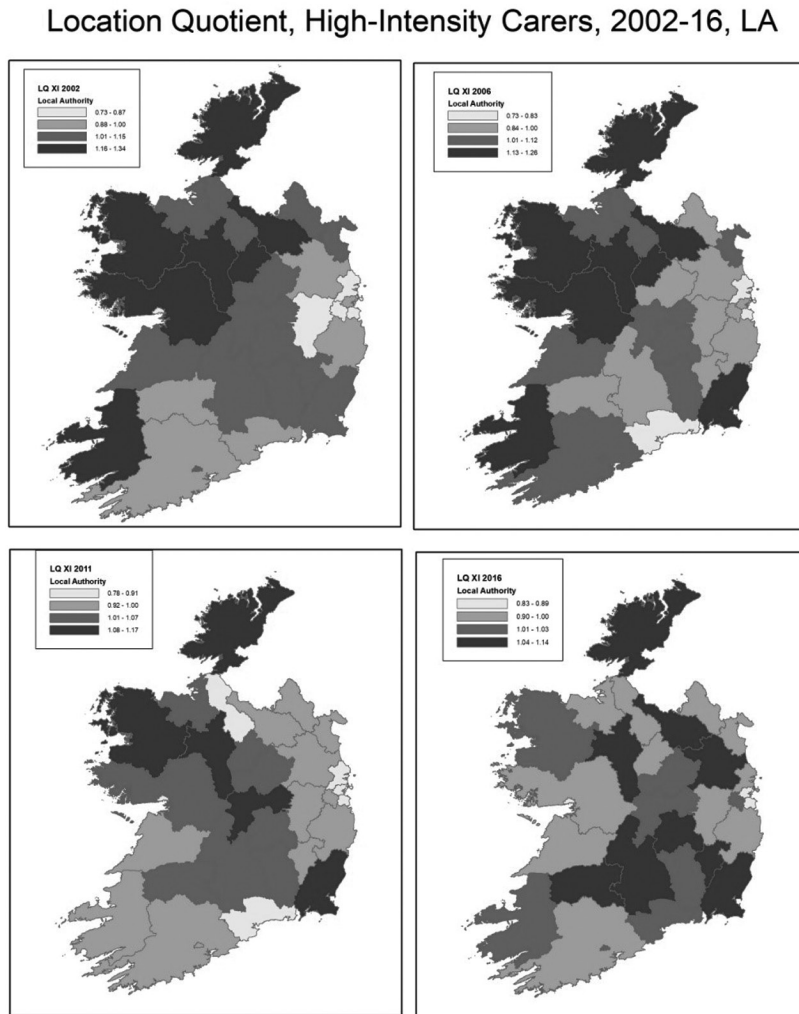
assessment, especially in relation to shifts over time in national prosperity and austerity measures (Schwiter et al, 2018). Relative scores, such as percentages and LQs, can emphasise spatial variation in carer data. Yet, for planning and service delivery purposes, and perhaps from a need/demand perspective, absolute numbers can be equally important (Foley, 2008). We acknowledge that not all countries collect detailed information on carers through regular censuses, as Ireland and the UK do, but note recent efforts to establish country profiles of caring (Robards et al, 2015; EuroCarers, 2021). Many European countries collect administrative data on carers and have longitudinal and other surveys with capacity for spatial tagging and mapping (Foley, 2008; Zigante, 2018). There is value in mapping and manipulating shifts in the actual geographies of carers, broken down by the intensity of caring across different scales and time periods. These geographical patterns of caring can also be used to generate hypotheses and may reveal associations with social class, family structures, age and gender.

Figure 4: Relationships between policy shifts and carer proportions, 2002–2017
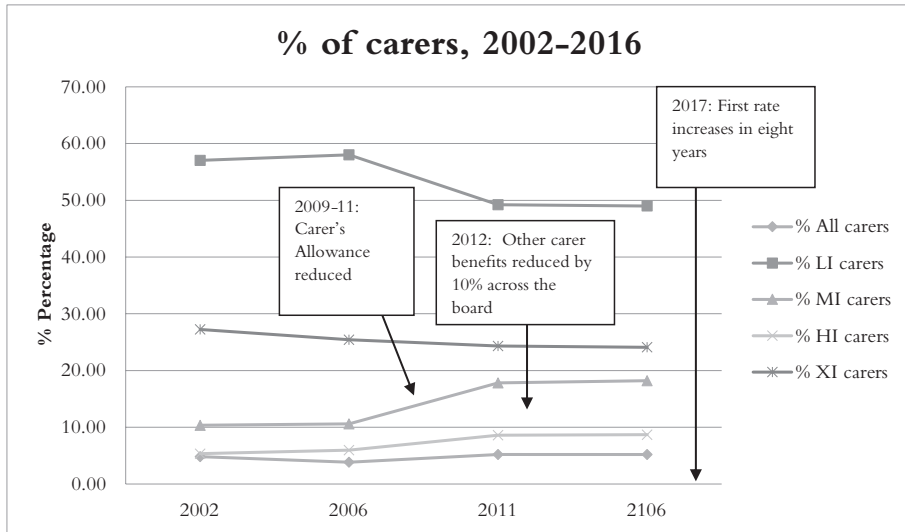
A spatial modelling technique that provides some interesting insights is the application of cluster techniques to the data. While the literature suggests a need to pay attention to the shift from proximal/local to more dispersed and relational models of care (England, 2010; Milligan and Wiles, 2010), there is still value in visualising the spatial ecology of care evident in neighbourhood or urban clusters. Figure 5 shows the results of using a clustering algorithm (for all carers) at two different scales and for two different periods. (Figure 5a shows clusters at the ED scale for 2002, and Figure 5b does the same for the percentage of carers at the SA scale for 2016.) The clusters enable visualisation of five categories. The geography of the 'high–high' (areas with a statistically significant prevalence of carers) and 'low–low' clusters (areas with a statistically significant low prevalence of carers) is of most interest. The clustering tool also identifies 'high–low' and 'low–high' outliers (as previously explained). By visualising the data thus, the complex map shown in Figure 1 can be simplified to present a statistically robust but more readily understandable spatial representation of clustering within the data. At the other end of the scale, it also extends the often-simplified patterns of variation available at the LA level.

The detail shown in Figures 5a and 5b shows that Dublin City (see the boxes at the top left) has mostly 'low–low' and 'high–low' clusters, with few 'high–high' clusters, whereas, nationally, the areas with a substantial clustering of carers are west of the Dublin region, with caring at a higher level most prevalent in rural areas. Within urban areas, more varied employment options, greater access to home care and a potentially greater prevalence of shared caring within families may partially explain these associations. While the scales of analysis are different, and the data in both reflective of periods of prosperity, there is good consistency between Figures 5a and 5b. They also suggest, in a starkly visual way, where one might target areas with persistent clusters of high prevalence if one were to consider where best to situate policy interventions.

This article has only scratched the surface of the role that geography can play in better informing carer policy. The national census also contains information

Figure 5: Clusters of carers. a: ED scale, 2002. b: SA scale, 2016
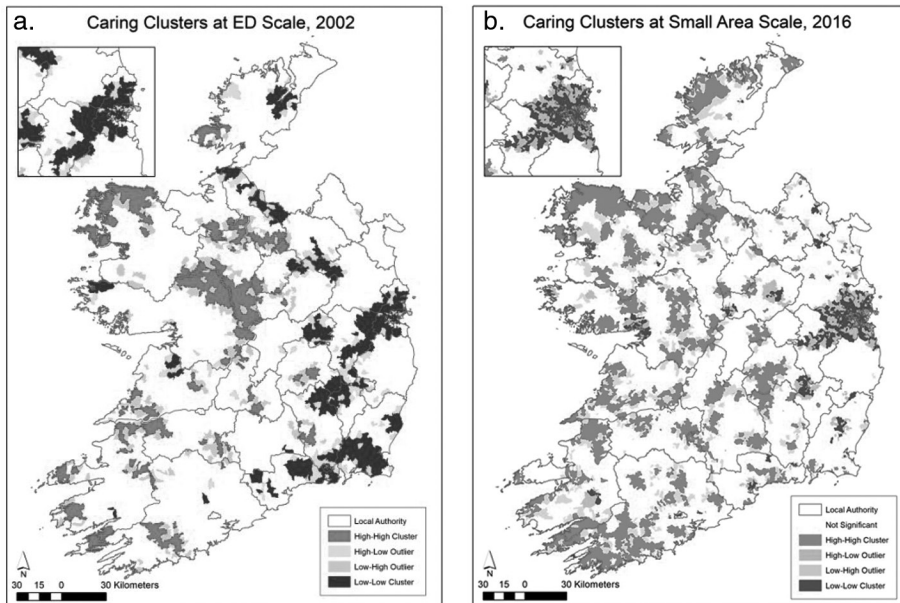
on general health and disability, and broad information at a national scale on carer health is reported based on cross-tabulations of these data (CSO, 2017; Family Carers Ireland, 2019). Other national health surveys, while they typically suppress detailed information on location, can also be explored in safe environments to explore individual-level effects of caring. The Irish Longitudinal Study of Ageing (TILDA) is one substantial data set being explored in this way and contains coding for carers alongside detailed self-reported and measured data on health status (Dempsey et al, 2018). TILDA data span four waves, being taken every two years from the first wave in 2009/10 to the latest Wave 4 in 2016. While such individual-level (compositional) research is important, the bigger spatial approach suggested here is still needed to explore contextual, ecological and cross-sectional dimensions together. Finally, an important consideration, and one explored more fully in the UK and other European countries, is the routine mapping of regularly collected administrative data on carers, such as benefits, drug payments and take-up of carer budgets (Power and Hall, 2018).

This article has looked at the longer-term impacts and effects of policy change. In a world where 'big' spatial data are increasingly common, it may be possible in future to map shifts in carers' lives in a more immediate way than is currently possible. There are understandable dangers and concerns about this type of work, related to data privacy and ethics, but it can and should be approached in a positive way to improve the everyday lives of carers, in which place, geography and location continue to play an important role. While it was difficult to match policy shifts in our 14-year timescale to dramatic spatial impacts, our analysis does show the potential for mapping spatial data on to policy. The identifiable impacts of the current global COVID-19 pandemic may also be likely to shape the relative and absolute numbers of carers around the world over the next decade (Chan et al, 2020). Regular statutory collection of detailed information on carer locations, including clusters of high need, means that the scale of this, either at estate or at neighbourhood level, can potentially be used to inform

a community-led approach to planning. There are plans in several healthcare system models to better align primary and community care – and given the enhanced visibility of public health, it should also be possible to map geographical data on caring to make carers more visible in such models. Milligan and Wiles (2010) use of the term 'topographies of care', hinting at a sometimes-hidden underpinning of societal needs by the necessary work of carers. While carers remain somewhat outside the statutory system, this more aligned and integrated approach to spatial planning may help carers' organisations gain a better sense of, and make more visible, the 'place' of carers and how they fit as a crucial piece within that wider service assemblage.

Note

[1] Data for 34 LAs were recorded for 2002, 2006 and 2011. The number of LAs was reduced to 31 in 2016, with the amalgamation of Limerick and Waterford cities and counties, and of South and North Tipperary into a single county.

Conflict of interest

The authors declare that there is no conflict of interest.

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