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practice paper

Third sector provision of dementia support in the community: results from a scoping exercise of charity involvement in the UK

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Third sector dementia support is characterised by wide variation and a heavy reliance on volunteer engagement. While there has been a growth in the reach and diversity of different schemes, their short-term funding results in a loss of networks, collaborations and local knowledge. This practice paper reflects on strengthening community-based dementia support and care via public and third sector partnerships. National and local data sources could help charities and commissioners begin to identify inequalities of provision.

Key words dementia care • community • third sector • charities • social care • volunteering

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Introduction and background

Enabling people to live well with dementia is a global health priority (WHO, 2017). It is estimated that the total cost of dementia care in the UK 'will increase by 172%, from £34.7 billion in 2019 to £94.1 billion in 2040, at constant 2015 prices'

(Wittenberg et al, 2019: 9). Multiple initiatives globally encourage community engagement to enable people affected by dementia to continue living at home in ways that support their inclusion and participation. While there are some well-known national initiatives in the UK (Brooker et al, 2018; Alzheimer's Society, 2019; DEEP, 2021; TIDE, 2019; Dementia Action Alliance, 2020; Innovations in Dementia, 2020), charities providing community support to people affected by dementia remain vulnerable to funding cuts (The King's Fund, 2019). This leads not only to the discontinuation of services, but also to the loss of networks, collaborations and organisational memory of how to work locally and maintain links with supporters, often through volunteers (Clarke and Bailey, 2016; Cahill, 2020). This is particularly problematic for volunteers working with people affected by dementia because it often requires particular skills in communication and knowledge.

A recent national evaluation of dementia-friendly communities in the UK identified wide variation in the provision of dementia support and care, determined by access to funding, collaboration with local organisations and differences in how volunteering was conceptualised (BSI, 2015; Buckner et al, 2019; Woodward et al, 2019; Goodman et al, 2020). Dementia-related activities in dementia-friendly communities ranged from high-profile awareness-raising campaigns (Alzheimer's Society, 2017) to public involvement in research (Charlesworth, 2018). There was also considerable variation in stakeholder involvement (Heward et al, 2017). Some statutory services worked with third sector groups directly and this affected the reach and impact of their dementia-friendly communities (Goodman et al, 2020). Volunteers often held the local knowledge of what did and did not work for people affected by dementia and participated in key meetings to agree priorities and deliver support. Yet, little is documented about the role of volunteering in the third sector for people affected by dementia or how it is organised (N. Greenwood et al, 2013; Smith and Greenwood, 2014; D. Greenwood et al, 2018; Darlington et al, 2020).

Dementia-focused charities provide community-based, post-diagnostic support (Frost et al, 2020) for people diagnosed with young onset dementia (Mayrhofer et al, 2018), those living with rare dementias (UCL Rare Dementia Support, 2021) and people and their carers needing advice and additional nursing support in the more advanced stages of dementia (Dementia UK, 2019; Harrison Dening et al, 2019). The configuration of support networks accessed by families affected by dementia is likely to change over time as determined by illness progression, which tends to require a transition from volunteer support to engaging with health and social care professionals (McCall et al, 2020; Moore et al, 2020). Voluntary sector contributions to the public sector may ease some of these transitions and provide continuity of support and care through increased partnership working (Abendstern et al, 2018; Munro, 2018).

To explore volunteer engagement in community-based dementia care more systematically, and to understand how charities describe the involvement of volunteers in dementia support in communities across the UK, we reviewed charities registered with the Charity Commission. We mapped areas of involvement, target groups, activities offered, numbers of volunteers involved and annual income. Findings presented in this practice paper will inform wider discussion with charities offering dementia support in the community.

Methods

Charities in England and Wales are registered with the Charity Commission (Charity Commission, 2020). The commission acts as a regulator. The register records the type of services provided by each charity, their focus, their annual income, who their target groups are and how their services are provided. To capture charities that offer dementia services, we used the advanced search option of the register and applied the keyword 'dementia' and search option 'provides services'. The search was undertaken during March/April 2020 with no time restriction.

Data were imported into the statistical package SPSS (IBM Corporation, 2019), coded by focus of service provision, activities offered, length of time registered and annual income, and analysed using percentages, the median and the interquartile range (IQR). Charities with an explicit focus on providing dementia services were compared on annual income for 2019 with those offering dementia services as part of their broader provision, using the Mann-Whitney U test.

Findings

In total, 314 organisations were listed as providing dementia services but 109 charities were excluded from analysis, leaving 205 charities in the analysis (see Table 1).

Of the 205 charities, 88 had an explicit focus on providing dementia services while 117 offered dementia services as part of their broader service offer ('nested' services). There was a marked increase in the registration of charities that have an explicit focus on dementia from 2010–14, with figures doubling between 2015 and 2019 (see Table 2). Nested service charities had a longer history of stable provision (see Table 2 and Figure 1) but seemed to have reduced their service offer for dementia support as more dementia-focused charities entered the sector.

Income

Charities that offered nested service provision reported, on average, a greater annual income (median £226,000, IQR £65,100 – £1,070,000) than those focused on dementia services (median £67,200, IQR £14,400 – £261,000) ($p < 0.001$). This is unsurprising as income for nested charities was raised for related issues, for example support of people as they age, and purposed primarily for services other than dementia care and support. An annual income of less than £500,000 was submitted by 155

Table 1: Reasons for charities being excluded from the analysis

Reason for exclusion	Number of charities
Incomplete information or insolvent	10
Records reflected no income for 2019 (of these, 18 were only registered in 2019/20)	60
Care homes	36
Charities registered for the sole purpose of fundraising	3
Total excluded	*109*
Total remaining for analysis	*205*

Table 2: Date of registration

	Year registered	Dementia focus	Nested service	Total
	2015–19	42 (48%)	18 (15%)	60 (29%)
	2010–14	20 (23%)	26 (22%)	46 (22%)
	2000–09	13 (15%)	26 (22%)	39 (19%)
	1990–99	9 (10%)	23 (20%)	32 (16%)
	1950–89	4 (5%)	24 (21%)	28 (14%)
Total		**88 (100%)**	**117 (100%)**	**205 (100%)**

Figure 1: Number of charities registered over time, by type of service provision

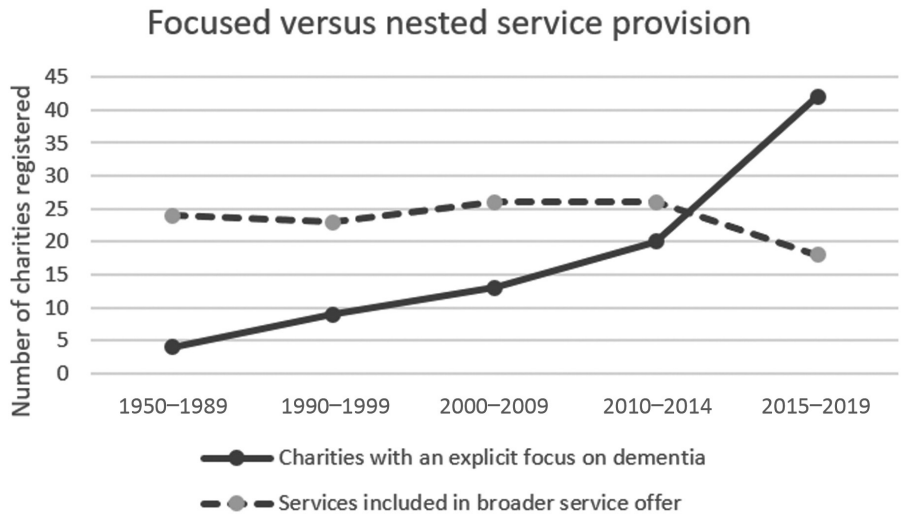

Table 3: Charity income

		Dementia focus	Nested service	Total
Income	£1 – £499,999	78 (89%)	77 (66%)	155 (76%)
	£500,000 – £999,999	4 (5%)	12 (10%)	16 (8%)
	£1,000,000 – £4,999,999	5 (6%)	16 (14%)	21 (10%)
	£5,000,000 – £89,999,999	1 (1%)	11 (9%)	12 (6%)
	£90,000,000 and above	0 (0%)	1 (1%)	1 (0.5%)
Total		**88 (100%)**	**117 (100%)**	**205 (100%)**

(76%) of the charities, with 78 of these focused exclusively on dementia services (see Table 3).

Number of employees and volunteers

Information on the number of employees and volunteers working with the charities was limited. Of the 205 charities, 153 (75%) provided no indication of the number of employees; and 159 (78%) did not indicate how many volunteers

delivered or supported services. In some cases, although the description of activities clearly stated volunteer involvement, either the charity did not list the number of volunteers involved, or this information was not made publicly available via the charity register.

Focus of dementia services

The main activities offered by dementia-focused charities were providing information and advice, befriending services, cognitive stimulation therapy (CST) and organising social events (see Table 4). Some offered day care, carers' support groups and support groups for both the person with dementia and their carer. Activities included creative arts for people with dementia, offered in Alzheimer's cafés, memory cafés and meeting

Table 4: Services by dementia-focused charities versus nested services

	Main activities offered by charities that have an explicit focus on dementia	**Total**
Activity	General support	42 (47.8%)
	Day care	9 (10.2%)
	General support plus day care	3 (3.4%)
	Carers' support groups	6 (6.8%)
	Support groups (people living with dementia and carers)	5 (5.7%)
	Weekly or fortnightly memory café	4 (4.5%)
	Alzheimer's café	3 (3.4%)
	Meeting centres	2 (2.3%)
	Creative arts (music/singing/choir) (people affected by dementia)	5 (5.7%)
	Reminiscence therapy	2 (2.3%)
	Biographical films for people living with dementia	1 (1.1%)
	Holidays	1 (1.1%)
	Admiral nursing	1 (1.1%)
	Linked to dementia-friendly community structures	3 (3.4%)
	Provides information, conducts research	1 (1.1%)
Total		**88 (100%)**
	Main focus of charities offering nested services	**Total**
Focus	Community	42 (35.9%)
	Older people	28 (23.9%)
	Arts/media	13 (11.1%)
	Disabilities/complex needs	10 (8.5%)
	Health and social care providers	7 (6.0%)
	Mental health	6 (5.1%)
	Accommodation for supported living	5 (4.3%)
	Services for the over 50s/55s/60s	4 (3.4%)
	Agency offering domiciliary care/day care	2 (1.7%)
Total		**117 (100%)**

centres. There were charities with a focus on providing biographical films or holidays for people diagnosed with dementia and their families.

Organisations with a 'focus on community' typically offered activities such as lunch clubs and friendship clubs that were open to anyone, including people living with dementia and their carers. Charities with a focus on older people included dementia-specific day services, support groups, drop-in sessions and/or carer support and respite in their portfolio. These kinds of services were more likely to be provided by national charities such as Age UK. Some third sector organisations offered supported living schemes, worked with housing associations and linked with national initiatives such as the Dementia Action Alliance. Nested support by organisations that were based in the community ranged from services possibly funded by the statutory sector, to one-off services such as a library that offers a book-lending scheme for people affected by dementia, a sports club offering dementia-friendly gymnastics and an arts charity offering dementia-specific sessions.

Service providers also included community trusts. The difference between a charity and a trust is their legal structure. Some trusts support organisations that in turn focus on broader societal issues, such as homelessness, unemployment, poverty and dementia. Such organisations, however, tend to have annual incomes that are significantly higher than £500,000 and have been established for longer (see Table 3). Findings illustrate the benefits of diversity in dementia support and being able to tailor what is on offer to fit the requirements of people affected by dementia.

We were unable to identify from the register which charities were providing standalone activities in response to local need, and which were providing local authority-funded services and support to people affected by dementia.

Discussion

The charities included in this study offered a wide range of services. The recent increase in dementia-specific charity registrations with the charity commissioner might reflect a response to the UK National Dementia Strategy (Department of Health, 2009), the *Prime Minister's Challenge on Dementia 2020: Implementation Plan*, published in 2016 (Department of Health, 2016), and to the growing number of people affected by dementia. An evaluation of the Health and Social Care Volunteering Fund (Warwick-Booth et al, 2020) highlights the diversity of the voluntary sector's involvement in providing care at both system and community levels (Davies et al, 2020).

The register does not provide any information on how charities link with, or substitute for, statutory provision, and the roles of their volunteers remain unclear. Closer integration of charitable work with statutory services might increase the sustainability of dementia support in the community (NCVO, 2019; Damm, 2020), especially after the COVID-19 pandemic (McDonnell et al, 2020). Such an approach may be desirable, but may raise questions around the professionalisation of the voluntary sector (Kim and Charbonneau, 2020). Such considerations feed into longstanding debates about the relationship between the charitable and statutory provision of support and care, especially in relation to social care needs in the community (Naylor et al, 2013; Warwick-Booth et al, 2020).

In ageing societies, ensuring the sustainability of local support and care networks is essential. The growing interest in dementia-friendly and compassionate communities

(Abel, 2018) means that this work will become increasingly important and is likely to require more widespread integration of third sector organisations with local authorities and health and social care. An understanding of the current roles that volunteers play in dementia care, how these roles contribute to health and social care, and how they are supported by the organisations they volunteer for, is needed. The findings highlight the difficulties of capturing the range of provision and standardising how information is recorded in terms of focus, who delivers the support and how it is funded.

Future policy and research should consider creating national and local data sources that capture provision to help commissioners and charities identify inequalities of provision and likely need. This could provide a needed platform to begin to address the known wide variation in dementia support and heavy but ad-hoc reliance on volunteer engagement.

Limitations

The secondary analysis of the Charity Commission's publicly available records was constrained by the lack of information regarding volunteering. This practice paper may underreport the range of work that charities are engaged with for people affected by dementia. In addition, not all organisations providing dementia care and support are registered as charities, but may operate as community interest companies, charitable incorporated organisations or community trusts (TBL Accountants, 2019; Dickinson et al, 2012). One such example is Innovations in Dementia (Innovations in Dementia, 2020). This demonstrates the difficulties in identifying how health and social care professionals, volunteers with different skills and people affected by dementia receive support from different organisations. However, the Charity Commission's data-sharing portal was recently redesigned and now offers enhanced access to information. Most notably, information is now available for download in widely compatible formats (Charity Commission, 2021).

Conclusion

While the Charity Commission's website provided much information for this research, additional data on staffing and volunteers are needed to gain a fuller understanding of volunteer involvement in dementia support and care in the community through the third sector. We know that charities are reliant on volunteers, yet it is difficult to access information about them. Future work needs to consider how local charities are connected with each other and with statutory providers, and whether particular configurations might be more effective. This would complement the wider research agenda on home-based care, on integrated care and on care coordination in dementia-friendly communities, especially when third sector organisations are commissioned by local authorities to provide longer-term care in ageing societies.

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Conflict of interest

The authors declare that there is no conflict of interest.

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