



National Children's
Bureau

Young people caring for adults with dementia in England

Report on NCB's survey findings and internet research

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Executive Summary

Dementia is a key health issue in the UK today. Recognising this, the Government has committed to significantly improving care and support for people with dementia and their carers and families by 2020. Reducing the prevalence and incidence of dementia amongst 65-74 year olds is a priority for Public Health England (PHE), which also works to support people with dementia and their carers to live well.

With an ageing population, dementia prevalence is increasing in the UK, and with it, the number of unpaid carers. As young adults are increasingly live at home with their parents, the number of young adults caring for parents with dementia can be expected to increase. There are also 40,000 people with young onset dementia, some of whom will have children under 25 living with or near them.

Providing care and support for a loved one with an illness or disability has a wide range of consequences for individual carers, and young people are affected in ways specific to their life stage. Whilst taking on caring responsibilities may have positive consequences for young carers, a strong body of evidence shows wide-ranging adverse impacts experienced by this group. Young carers need and are legally entitled to appropriate support.

In 2015, PHE asked NCB to produce this report on children and young people who provide regular and ongoing care and emotional support for a person living with dementia. The aim was to explore the limited available evidence about how caring for someone with dementia impacts on children and young people, and how the needs of this group can best be met. NCB conducted a survey aimed at practitioners and managers working in services for young carers, dementia carers and/or carers more generally. This was accompanied by internet-based research. Gathering and interpreting data presented some challenges, explained in 'Limitations'.

This report addresses:

- The prevalence of young people providing care and support for adults with dementia in England
- Characteristics of these young people, e.g. family circumstances, services accessed
- Specific issues for, or needs of, young people caring for adults with dementia.

Services in contact with young people caring for adults with dementia

Based on the number of responses to the NCB survey, it is not possible to establish which services young people caring for adults with dementia are most likely to access. Other research suggests that many young carers, regardless of the particular health concerns of the person they care for, do not use services, and that some prefer to be supported by family and friends.

The majority of NCB survey respondents' organisations collected some data that may provide insight on how many young people caring for adults with dementia access their services, and their particular needs.

Numbers of young people caring for adults with dementia

No information on the prevalence of young people caring for adults with dementia in England was identified. The 12 NCB survey respondents were aware of 51 of these young people with whom they'd had contact in the previous year. The survey findings highlight the difficulty of defining and identifying children, adolescents and young adults who provide care and support for individuals with dementia. These young people represent a small proportion of total service user populations, including when these populations are defined by carer age or dementia.

Individuals living with dementia who are supported by young carers

Professionals who responded to the NCB survey more frequently reported that young people cared for adults in parental roles than grandparents or similar figure. Mostly, the adults with dementia were not living in residential care.

Specific work with, or about, young people caring for adults with dementia

Information relevant to this group is available, but tends to be general information about dementia aimed at children and young people, or information about how dementia affects families, i.e. not fully addressing the care and support provided by children and young people, and their associated needs.

Many of the young people covered by these survey responses will have access to some individualised support from professionals to address the impact of dementia on their lives and families. However, no available practice guidance for professionals supporting this group has been identified, nor have any tailored services or formalised networks for individuals aged under 18 supporting adults with dementia.

Specific issues and needs for young people caring for adults with dementia

Research suggests that young people caring for a loved one with dementia provide a range of practical, emotional and social support. However, in common with many children and young people supporting individuals with other conditions, some do not identify as 'young carers' or feel comfortable with the label.

The available literature describes a range of challenges and issues for young people:

- mood and behaviour changes in the person with dementia
- loss of support and care from a parent with young onset dementia
- strain on relationships with the person with dementia and other family members
- impact on education and future plans
- a lack of professional and public awareness of young people's needs and experiences, and therefore of age-appropriate and relevant support
- limited understanding of, and support for, parents with young onset dementia, since dementia is largely associated with older people
- a lack of information addressing young people's specific circumstances and concerns.

It also discusses the range of young people's responses to their situations, and coping strategies adopted, including:

- grief for the person with dementia as they were, and the imagined future relationship that is no longer possible
- loyalty, love and concern for the person with dementia and other family members
- worries about the future
- a sense of maturity and independence
- avoidance, withdrawal and repressing their own needs and difficulties for fear of burdening family members
- self-destructive behaviours
- feeling stigmatised, misunderstood and isolated

- taking things one step at a time.

Responses to the survey and extracts and quotes from young people who have shared their personal stories echo issues highlighted by the literature.

Young people from different communities who care for adults with dementia

The survey provided insufficient data to generate insights into how young people from different communities experience caring for someone with dementia. However, evidence suggests that young people from black and minority ethnic (BME) communities may be more likely to care for someone with dementia than their white British peers; less likely to be known to services; and less able to access appropriate support.

Implications and next steps

- This exercise has highlighted complexities around defining children and young people providing care and support for adults with dementia. It is necessary to recognise the diversity of families' experiences; how children and young people see their relationships and roles; and variations in professional use of the 'carer' label. At the same time, some way of taking into account the extents to which children and young people's lives are impacted by a family member's dementia is needed, and important to ensure that the legal rights of those who meet the definition of 'young carers' are realised.
- Potential links to existing work on children, young people and families and young carers should be considered by statutory bodies and organisations working in this area. There may be opportunities to raise the profile of young people caring for adults with dementia in other dementia initiatives, such as dementia-friendly communities.
- Statutory bodies and organisations working in this area should consider whether there is a case or need for some awareness-raising activity (e.g. for professionals or the public) and/or for tailored information for children and young people providing care and support; how existing support services could become more sensitive to the needs of families in which young people are supporting adults with dementia; and any scope for further assisting young people to connect with others who share some of their experiences.
- Insofar as this report gathers and adds to the limited body of knowledge on the experiences of young people caring for adults with dementia, it can help to influence commissioning, service design and delivery, and practice.

Introduction

Background to this report

Reducing the prevalence and incidence of dementia amongst 65-74 year olds is one of seven Public Health England (PHE) corporate priorities (PHE, 2014). This primarily includes a focus on raising awareness of dementia risk reduction among the public and professionals, providing better data and intelligence across the system and addressing dementia inequalities where they occur. Alongside this primary objective, PHE also works to support people with dementia and their carers to live well.

In 2015, PHE asked NCB to produce this report on children and young people who provide regular and ongoing care and emotional support for a person living with dementia. The aim was to inform PHE's understanding of the different needs and experiences of subgroups of dementia carers, and the impact these have on interventions. There is limited evidence available about the impact on children of having a parent with dementia, and how the needs of this group can best be met (Svanberg, Stott and Spector, 2010).

This work has been undertaken by NCB in its role as a Health and Care Voluntary Sector Strategic Partner¹. NCB has a long and strong history in pioneering health work for children and young people across life stages, backgrounds and in a range of settings. NCB's Vulnerable Children Programme also comprises practice improvement work targeting children most at risk of experiencing inequalities and poor life chances. Its focus is on those whose experience of multiple, adverse, overlapping factors in their lives makes them vulnerable to significant risk of poor outcomes.

Definition of terms

For the purposes of this work, a young person caring for someone with dementia is defined as 'an individual under the age of 25 who provides regular and ongoing care and emotional support for a person living with dementia.' The term 'young dementia carers' was used in the survey and therefore appears in this report with reference to survey questions. However, during the report writing process, the term was dropped in favour of 'young people caring for adults with dementia', which avoids any confusion between this group and carers (of any age) supporting individuals with young onset dementia.

Public Health England's Children, Young People and Families team define 'young people' as aged 10-24, in line with World Health Organization and UNICEF definitions. Many services supporting young carers also work with young adults up to age 24. The government's *Carers Strategy: Second National Action Plan 2014–2016* (HM Government, 2014) notes a 25 per cent increase in the number of young adult carers up to age 24 between 2001 and 2011 (England and Wales) and acknowledges the significant impact of caring upon a young adult's health, wellbeing, learning and employment, friendships and relationships.

'Regular and ongoing care and emotional support' can include secondary or indirect care. The breadth of this definition purposely includes young people who provide some care for a person with dementia but may not be that individual's primary carer.

¹ The Health and Care Voluntary Sector Strategic Partner Programme enables Voluntary and Community Sector (VCS) organisations to work in equal partnership with the Department of Health (DH), NHS England and Public Health England (PHE). More information is available at: <http://www.voluntarysectorhealthcare.org.uk/>

Carers' context

Young people caring for adults with dementia is an emerging area in terms of research, policy and practice. This section provides some context for this group of young people as members of broader populations of dementia carers and young carers.

Dementia carers

The term 'dementia' describes 'a set of symptoms that include loss of memory, mood changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, such as Alzheimer's disease or a series of small strokes' (Alzheimer's Society definition).

An estimated 850,000 people were living with dementia in the UK in 2015, of which over 700,000 were in England (Prince and others, 2014). This equals one in every 79 of the entire UK population, and 1 in every 14 of the population aged 65 years and over. Women account for 61 per cent of people with dementia (Alzheimer's Research UK, 2015).

With an ageing population, dementia prevalence, and thus the costs associated with dementia and the number of dementia carers, are increasing in the UK. An estimated 670,000 people in the UK act as primary carers for people with dementia, saving the state £11 billion per year (Prince and others, 2014). Many more will provide support without taking on the role of primary carer. Furthermore, data from the 2011 UK census revealed record numbers of 20-34 year olds living at home with their parents and attributed this to changes in the economy. These trends combined are likely to result in increasing numbers of young adults caring for parents with dementia.

It is important to mention that the UK population of people living with dementia includes over 40,000 individuals with young onset dementia. Dementia is defined as 'young onset' when it occurs in people of working age, usually between 30 and 65 years old. Some individuals with young onset dementia will have children under 25, who may live with or near them.

According to the Carers' Trust's 2013 report, *A road less rocky: supporting carers of people with dementia*, the majority of people with dementia are cared for at home by a relative or friend (Newbrunner and others, 2013). The average age of unpaid family carers is between 60 and 65 years. The report states that 'caring for someone with dementia can be different from caring for people affected by other types of illness or disability, because of the complex, unpredictable and progressive nature of the illness. Carers of people with dementia are likely to have higher than normal levels of stress, and report higher levels of depression than carers of other older people.' It highlights carers' struggles in accessing appropriate information and support.

Young carers

The Association of Directors of Children's Services defines 'young carers' as 'children and young people under 18 who provide regular and ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances'. The upper age limit for defining 'young adult carers' is usually 25. Young carers and young adult carers may take on a variety of responsibilities, including the following as listed on the Carers Trust website²:

- Practical tasks, such as cooking, housework and shopping
- Physical care, such as lifting, helping a parent on stairs or with physiotherapy

'I grew up fast, faster than I could mentally establish. Dealing with adult situations such as money, insurance, care . . . I have gone from happy and care free to mentally and emotionally run down.'

Heather, whose father had frontotemporal dementia, writing at age 20, YoungDementia UK (See References)

² Carers Trust, *What is a carer?* <https://www.carers.org/what-carer> [Accessed 15 March 2016]

- Personal care, such as dressing, washing, helping with toileting needs
- Managing the family budget, collecting benefits and prescriptions
- Administering medication
- Looking after or “parenting” younger siblings
- Emotional support
- Interpreting.

The 2011 Census for England and Wales identified 166,363 young carers aged 5-17 across England (of which 110,073 were under 16). Official statistics are likely to underrepresent the true number of young carers.

The Children’s Society 2013 report *Hidden from view: The experiences of young carers in England* (Hounsell, 2013) analysed data from a government study of 15,000 young people, aged 13 and 14, over a seven-year period, from 2004–2011. *Hidden from View* presents the following findings from the ‘Longitudinal Study of Young People in England’ (LSYPE):

- Young carers are one and half times more likely to have a special educational need or a long-standing illness or disability
- One in 12 young carers is caring for more than 15 hours per week
- Around one in 20 miss school because of their caring responsibilities
- Young carers have significantly lower educational attainment at GCSE level and are more likely than the national average to be ‘not in education, employment or training’ (NEET) between the ages of 16 and 19
- The average annual income for families with a young carer is £5,000 less than families who do not have a young carer
- Despite improved awareness of the needs of young carers, there is no strong evidence that young carers are any more likely than their peers to come into contact with support agencies.

Possible physical and mental health and impacts of caring on young carers include (Carers Trust 2015a; RCGP, 2014; Slatcher and Frank, 2012; YoungMinds, 2015):

- Worry and stress
- Feelings of loss and grief
- Feelings of anger, resentment and guilt
- Depression, anxiety and low self-esteem
- Social isolation and difficulties establishing relationships due to feeling different, lack of time for socialising, embarrassment about their home life, or bullying
- Physical injuries sustained whilst providing care, e.g. back strain
- Poor diet, lack of physical exercise and leisure activities, and difficulties accessing healthcare (e.g. due to financial constraints, lack of time, lack of cooking skills, or absence of support from parents)
- Behavioural problems
- Self-harm, drugs and alcohol and eating problems.

It should be noted that there can be positive aspects to caring for young carers, such as learning skills, feeling useful and closeness to the family (Carers Trust 2015a; Joseph, Becker and Becker, 2012). However, this does not invalidate their need for appropriate support.

Policy context

Policy and legislation relating to care and support for adults, as well as government action on dementia specifically, has a significant impact on the carers of people with dementia. This section outlines policy and legislation as it relates specifically to carers.

Legislation and policy affecting young carers

The Care Act 2014 and the Children and Families Act 2014 require local authorities to adopt a whole system, whole council, whole-family approach, coordinating services and support around the person and their family and considering the impact of the care needs of an adult on their family, including children.

When the Care Act 2014 came into force in April 2015, carers received legal recognition on the same footing as those they care for. The Act strengthened the rights of adult carers and carers under 18 who are 'in transition' to adulthood.

The Department of Health's *Care and Support Statutory Guidance* (DH, 2014a) issued under the Care Act 2014, states that:

Children should not undertake inappropriate or excessive caring roles that may have an impact on their development. A young carer becomes vulnerable when their caring role risks impacting upon their emotional or physical wellbeing and their prospects in education and life.

Under the Children and Families Act³, local authorities must take 'reasonable steps' to proactively identify young carers in their area. All young carers under the age of 18 have a right to an assessment regardless of who they care for, what type of care they provide or how often they provide it. The right to this assessment is based on the appearance of need; an assessment can also be requested. A child or young carer can be referred for a young carer's assessment or a needs assessment under the Children Act 1989, or a young carer's assessment under section 63 of the Care Act 2014.

The Young Carers (Needs Assessments) Regulations 2015 state that the assessment must cover the appropriateness of the young carer's role; their needs for support; the impact of their caring role on education, wellbeing and development; their needs and wishes; and whether they are a 'child in need'⁴. The local authority must consider the care that a young carer provides but also care they plan to or may carry out in the future.

Local authorities' also have duties to identify young carers via assessments of adults' care and support needs, which should consider the impact of an adult's needs on family members (DH, 2014a). This should address whether a young person's caring responsibilities are inappropriate; the parenting responsibilities of the adult in question; and the child's own views.

Young carers are entitled to person-centred 'transition assessments' as they approach adulthood. 'Transition assessments and planning must consider how to support young carers to prepare for adulthood and how to raise and fulfil their aspirations' (DH, 2014a).

In 2014, the government published *Carers Strategy: Second National Action Plan 2014–2016* (HM Government, 2014), which explained the progress on supporting carers since 2010 and the main actions for the following two years. The document includes significant detail on activity around young carers and young adult carers, as well as the changes in legislation described above.

³ Section 96 of the Act amends Section 17 of the Children Act 1989, introducing sections 17ZA, 17ZB and 17ZC. The Young Carers (Needs Assessments) Regulations 2015 exercise of the powers conferred by section 17ZB(8).

⁴ A child in need is defined under the Children Act 1989 as a child who is unlikely to reach or maintain a satisfactory level of health or development, or their health or development will be significantly impaired, without the provision of services, or the child is disabled.

Action on dementia

In 2012 the Prime Minister launched a national challenge to fight dementia, which was followed up by the Prime Minister's challenge on dementia 2020 (DH, 2015). The later challenge sets out a vision 'to create a society by 2020 where every person with dementia, and their carers and families, from all backgrounds, walks of life and in all parts of the country – people of different ages, gender, sexual orientation, ability or ethnicity for example, receive high quality, compassionate care from diagnosis through to end of life care'. The role of unpaid carers is recognised in the document, which mentions carers throughout. Government aims for 2020 include 'carers of people with dementia being made aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring'.

Dementia is one of Public Health's England priority areas as stated in *From evidence into action: opportunities to protect and improve the nation's health* (PHE, 2014), which was published in tandem with NHS England's *NHS Five Year Forward View* (NHS England, 2014a). The *Five Year Forward View* formally recognises the importance of carers, stating that 'the five and a half million carers in England make a critical and underappreciated contribution not only to loved ones, neighbours and friends, but to the very sustainability of the NHS itself.' The planning document promises that the NHS will 'find new ways to support carers, building on the new rights created by the Care Act, and especially helping the most vulnerable amongst them' – citing approximately 225,000 young carers.

Earlier, NHS England had published a *Commitment to Carers* (NHS England, 2014b), informed by an engagement process that involved young carers. The document included 37 commitments across eight priorities, which included raising the profile of carers; education, training and information; service development; and person-centred, well-coordinated care. The *End of Year Progress Summary* (NHS England, 2015) published in August 2015 included an announcement of progress for young carers, and an update on NHS England's commitment 'to support timely dementia diagnosis and the best available treatment for everyone who needs it, including support for their carers.'

Creating 'dementia-friendly communities' was one of the commitments in the Prime Minister's 2012 challenge on dementia. A Dementia Friendly Communities champion group was established and identified schools and colleges as a key part of its strategy. In 2012 Alzheimer's Society began working on the Dementia4Schools Project. In 2013, the organisation launched and supported the adult-focused Dementia Friends initiative with funding from the Department of Health and the Cabinet Office.

The Prime Minister's challenge on dementia 2020 states that 'with the support of Alzheimer's Society and their ambassador Angela Rippon, younger people are more educated and aware about dementia than ever before. Hundreds of schools have taken part in the dementia friendly schools programme and awareness is gathering pace within youth movements around the country.' Because 'we need to continue to recruit Dementia Friends, with a particular focus on reaching children and young people, who will form the "dementia friendly generation" of the future', the vision set out for 2020 is for all primary and secondary schools, Further Education colleges and universities to be encouraged to include dementia awareness in their work programmes.

Methodology

Survey

In October 2014, NCB conducted a confidential online survey to find out about:

- The prevalence of young people providing care and support for adults with dementia in England
- Characteristics of these young people, e.g. family circumstances, services accessed
- Specific issues for, or needs of, young people caring for adults with dementia
- Interventions that aim to address any specific issues or needs.

The survey was aimed at practitioners and managers working in services for young carers, dementia carers and/or carers more generally. It included multiple choice questions and open-ended questions with space for free text.

The survey was publicised amongst NCB and voluntary sector networks, and promoted directly to relevant organisations and services identified by NCB, including those focused on dementia or older age; on families or young carers; on young onset dementia; or on carers in general.

Despite extensive dissemination efforts, only 12 respondents completed the survey (see 'Limitations' below). However, a low response rate was anticipated. The survey aimed to gauge whether and how this issue may be emerging and to explore the needs of young people providing care and support, upon whose lives the potential impact of a loved one's dementia is expected to be significant.

NCB had email discussions with several individuals working in this field, and received indications that this scoping exercise is welcome and needed.

Each survey answer relating to proportions of relevant young people accessing a service has been interpreted to reflect the number of relevant young people known to respondent's service⁵.

Internet research

Alongside the survey, NCB carried out internet-based research into young people providing care and support for adults with dementia. This included:

- Using a search engine to seek information on "young dementia carers" and adjusting search terms as necessary
- Exploring the websites of key organisations, e.g. Alzheimer's Society, YoungDementia UK and Children's Society, to identify relevant content
- Investigating relevant content linked to or referenced by websites, reports, literature reviews and articles
- Exploring Alzheimer's Society's online forum, *Talking Point*⁶, which includes threads that are publicly visible⁷.

NCB's library catalogue, in which journal articles and reports are indexed, was also searched.

⁵ For example, if a respondent reported contact with 5-10 young people caring for adults with dementia in the last year, and indicated that over half of those young people have supported a parent figure, whilst one third to half have supported a grandparent figure, it was inferred that the former group represents 3-6 young people and the latter 2-5 young people. All figures are approximate and represent minimums, as respondents were asked to provide numbers of young carers in ranges (which included 'more than 10') on the basis that confirming exact numbers can be difficult.

⁶ Alzheimer's Society, *Talking Point* <http://forum.alzheimers.org.uk/> [Accessed 15 March 2016]

⁷ Descriptions of content from *Talking Point* have been agreed with Alzheimer's Society in condition with 'Terms and Conditions of Use of Talking Point'.

Limitations

Gathering and interpreting data presented some challenges that highlight issues relevant to this area of work:

- The lack of quantitative data on the numbers of young people caring for adults with dementia in England.
- The low survey response rate mentioned above. The invisibility of young people caring for adults with dementia reflects their relatively small number compared with older carers or young carers of people with other conditions, as well as difficulties identifying them for reasons explored in this report. Potential underreporting is a consideration. Given the low profile of this issue and capacity constraints, the survey may not have been disseminated to all relevant professionals within organisations.
- Difficulties for respondents in providing exact numbers of young people caring for adults with dementia, which were anticipated. The survey design allowed for this uncertainty, which is therefore manifested in the findings.
- The likelihood that not all of the young people NCB and Public Health England would consider relevant to this report will consider themselves to have 'caring responsibilities' or self-identify as 'carers'. These issues with labels commonly arise in work with or relating to young people who provide care and support. The definition of 'carer' may also vary across professional groups, with the young carers sector possibly classifying certain responsibilities as 'caring' that, when undertaken by an adult, may not be seen as defining a 'carer'.
- Not all of the young people concerned accessing or being known to services, or those services represented in the survey.
- The lack of a diagnosis for many adults with dementia symptoms, which may prevent them and any young people providing care from accessing services and being represented in data or survey responses. Diagnosis rates on average in England are just 48 per cent⁸. In particular, parents with young onset dementia may remain undiagnosed for a long time, as 'medical professionals often misdiagnose younger people as being depressed, experiencing relationship difficulties, suffering from the effects of stress or, for women, it may be put down to the onset of the menopause' (Alzheimer's Society, 2014).

Despite these limitations, which make it difficult to generate an England-wide picture of young people caring for adults with dementia, the survey responses and internet search findings provide some rich detail on individual experiences.

⁸ Diagnosis rates are from the government's QOF (Qualities and Outcomes Framework) data for 2013-14, which is the number of people registered with GPs as living with dementia.

Findings from survey and internet research

Services in contact with young people caring for adults with dementia

Findings

Survey respondents were asked 'What kind of services does your organisation or provider offer, which young dementia carers might come into contact with?'

Respondents' organisations supported various groups in various ways, but half provided services specifically for young carers (which some services extend to include young adult carers). Four respondents worked for organisations supporting dementia carers. Four services focused on people with young onset dementia and their families were represented, including one supporting young adult carers of people with young onset dementia. Others reported that young people caring for adults with dementia may come into contact with their general services for all carers, or their services for individuals with dementia.

Respondents were asked whether their organisations' routine data collection was able to capture how many young people caring for adults with dementia may come into contact with their services. Seven out of 12 stated that their data collection did allow this detail to be logged. The next question asked whether routine data collection would record information on the needs of any young people caring for adults with dementia. Seven said yes (including one whose systems wouldn't capture numbers of young dementia carers); four said no; one didn't know.

Some respondents clarified their answers with points including:

- whilst relevant information may be recorded, it is not necessarily highlighted or immediately extractable from the core data set
- each service user has information about their family member on file but statistics on dementia are not collected distinctly
- information held is based on details provided upon referral and from families, so the service may work with more young people caring for adults with dementia than it has identified.

In a survey of 25 young people caring for adults with dementia (Young Carers' Experiences of Caring for a Family Member with Dementia, 2014)⁹, family emerged as the most important source of support for young people in their caring roles, cited by 17 respondents. This was followed by professional input: nine individuals identified carers' services as a source of support, whilst six identified charities (e.g. Alzheimer's Society, Age UK). The author's commentary suggests that agencies working with young carers were favoured by this sample of young people: 'All carers received some support, and some had multiple support, however not everyone found it helpful. Young carer groups and the activities and events that they organised were repeatedly identified as providing helpful support and being vital in sustaining young carers in their caring role.'

Five of the 25 young people caring for adults with dementia identified friends as a source of support for them, and two identified school/college/university.

Analysis

Based on the number of responses to the NCB survey, it is not possible to establish which services young people caring for adults with dementia are most likely to access. More responses came from

⁹ The report was posted on the website of Pembrokeshire Young Carers Project in 2014. Its title is the same as that used in a 2013 survey by Emma Thompson, then a student nurse at the University of Nottingham. It has not been possible to confirm the report's authorship. The report is available at <http://www.pembsyc.org.uk/766/>; the survey page was <https://nottingham.onlinesurveys.ac.uk/youngcarers>; and a notice about it is at <http://www.ymca-fg.org/wp-content/uploads/2013/08/Nott-Univ-Research-Project.pdf> [Accessed 11 March 2016]

professionals providing specialist support for young carers or dementia carers than from more generic providers of carers' services. However, there are various possible explanations for this, including exposure to information about the survey. The report of findings from 25 young people caring for adults with dementia (Young Carers' Experiences of Caring for a Family Member with Dementia, 2014) suggests that young carers' organisations may be the preferred source of professional support, but also indicates that, overall, respondents associated support more strongly with family than with services. This indicates that young carers' practitioners in particular may benefit from information and support to help address the specific needs and issues explored in this report; however, further exploration of young people's preferred sources of professional support is needed.

Low uptake of services by young carers is an evidenced phenomenon: *The Lives of Young Carers in England* report published by the Department for Education (TNS BMRB for DfE, 2016) states that 'a significant proportion of young carers have not disclosed their caring responsibilities to their school, they are no more likely to be in contact with social services than are their peers, and only a minority have had an assessment of their needs or been informed about sources of help'.

The majority of NCB survey respondents' organisations collected data that may provide insight on how many young people caring for adults with dementia access their services, and their particular needs. Some organisations store relevant information on individual carers and their families, but this is not always easy to collate and interpret at the collective level.

Numbers of young people caring for adults with dementia

Findings

The internet search did not identify any information on prevalence of young people caring for adults with dementia in England.

Ten respondents to the NCB survey answered a question on how many young dementia carers (aged under 25) they or their organisation/service had come across in the last year. As expected, the number of young people caring for adults with dementia reported by survey respondents collectively (estimated minimum 51) represents a small proportion of services' total carer populations (at least 1 per cent, as approximate numbers provided total 4,954 carers).

One respondent from a service supporting at least 79 young carers answered that, whilst none of their young carers had been referred as having a specific caring role around dementia, dementia has been present within some families, i.e. with a young person's parent being the primary carer for a grandparent.

Another respondent from a service supporting 100 young carers also reported knowing of young person referred for caring for a parent who had no diagnosis, but symptoms of dementia. Subsequent survey questions were answered with this young person in mind.

Four respondents were aware of fewer than five young people caring for adults with dementia in contact with their services. One respondent from a service supporting people with young onset dementia and their families identified 5-10 young carers out of 150 carers.

Three respondents reported contact with more than 10 young people caring for adults with dementia in the previous year. One service aimed at young adults (up to age 35) caring for people diagnosed with young onset dementia had a reported total carer population of 150. Another respondent's organisation worked with a total population of 800+ young carers, though at present young people are not identified as dementia carers so selecting the answer 'more than 10' may reflect an estimate. The other organisation supported 3,200 carers in the past year, including but not limited to young carers.

Analysis

The survey findings highlight the difficulty of defining and identifying children, adolescents and young adults who provide care and support for individuals with dementia (see 'Limitations' in 'Methodology'). These young people represent a small proportion of total service user populations, including when these populations are defined by carer age or dementia. Although this may be expected, even for the services represented by the survey it is reasonable to assume that some young people whose lives are severely impacted by a loved one's dementia are unaccounted for in responses.

Individuals living with dementia who are supported by young people

Findings

The survey attempted to establish who young people are supporting to live with dementia. Respondents were asked what proportion of relevant young people accessing services in the previous year were caring for parental, grandparental or other figures respectively. The results below reflect findings from 10 individuals who answered the question.

Relationship of individual with dementia to young carer	Minimum number of young carers known by respondents in the last year to support a person with this relationship
Parent or parent figure	≥22
Grandparent or similar figure	≥12
Unknown	≥11

Seven respondents indicated that over half of relevant young people supported a parental figure, of which four represented organisations providing specialist support around young onset dementia.

The survey also asked where individuals with dementia known to be supported by young people lived.

Place of residence of individual with dementia supported by young carer	Minimum number of young carers known by respondents in the last year to support a person in this place of residence
Living with the young carer	≥19
Living in another household	≥13
Living in, or moving into, residential care	≥4
Unknown	≥11

All respondents who stated that, in the majority of cases, young carers lived with the individual with dementia had also answered that over half of the relevant young people known to them were supporting a parent or parental figure. Only one respondent answered that over half of the more than 10 relevant young people in contact with their service lived in a different household from the individual with dementia. This professional reported that the majority of young people they knew to provide care for adults with dementia supported a grandparent or similar figure.

One survey of 25 young people caring for adults with dementia (Young Carers' Experiences of Caring for a Family Member with Dementia, 2014) suggests that young people caring for adults with dementia are more likely to be caring for female relatives than male. Of the 25 participants, 10

supported their grandmother and five supported their mother. This may reflect gender differences in dementia prevalence.

Analysis

It is not possible to draw general conclusions about who is most frequently being supported by a young person to live with dementia, and whether they tend to share a household with the young person. However, amongst the young people covered by the survey responses, supporting an adult in a parental role was more common than supporting a grandparent or similar figure. Mostly, the adults with dementia were not living in residential care, which reflects the fact that two thirds of individuals with dementia live in the community (Prince and others, 2014). Responses suggest that young people supporting parents with dementia tend to be living together with them.

Specific work with, or about, young people caring for adults with dementia

Findings

Survey respondents were asked if they or their organisations did any specific work with, or about, young people caring for adults with dementia, from the following options:

- Groups or sessions aimed specifically at young people caring for adults with dementia
- *Ad hoc* support for individuals or families
- Additional data collection
- Other.

Only one respondent, from the specialist service for young adult carers of people with young onset dementia, reported tailored group work or additional data collection. Seven of 10 professionals who answered indicated that they would provide *ad hoc* support for individuals or families. Another respondent commented 'we would provide information if required by young person', and one stated 'we support the child as a young carer' although the child would not be identified by the organisation as a young person caring for someone with dementia.

No service provision tailored to dementia carers aged under 18 was identified through either the survey or internet search. Online research identified services for adults with young onset dementia, many of which have associated support provided for carers. However, the age focus is primarily on the person with dementia rather than the carer, apart from Alzheimer's Society London-based peer support groups for people aged 18-35 who have a parent diagnosed with young onset dementia. Another survey respondent whose work focuses on young onset dementia stated 'we have trialled social support groups for adult children of younger people with dementia but had little take-up'.

There are some international online forums and Facebook groups for people with young onset dementia and their carers¹⁰, and a UK Facebook group called 'Dementia support for under 21's'¹¹ set up by a young adult, Heather (see next chapter).

Information addressing the impact of dementia on children and young people is available. The Alzheimer's Society website includes a section presenting information for children, teenagers and young adults themselves; parents; schools and colleges; and youth groups¹². Resources include personal stories (see below).

The factsheet *Explaining dementia to children and young people* (Alzheimer's Society, 2013)

¹⁰ YoungDementia UK, *Support & friendship online*. <http://www.youngdementiauk.org/support-friendship-online> [Accessed 15 March 2016]

¹¹ Facebook group *Dementia support for under 21's* accessible via YoungDementia UK, *Heather's Story* <https://www.youngdementiauk.org/heathers-story> [Accessed 15 March 2016]

¹² Alzheimer's Society, *Dementia information for children, teenagers and young adults* <https://www.alzheimers.org.uk/youngpeople> [Accessed 15 March 2016]

includes information about how a loved one's dementia may impact on a child or young person, as well as signs that may indicate a child or young person is struggling, and tips on how to support them.

Analysis

Information relevant to this group (though not addressing caring responsibilities in detail) is available, i.e. educational resources on dementia aimed at children and young people, and information about how dementia affects families. Many of the young people covered by these survey responses will have access to some individualised support from professionals to address the impact of dementia on their lives and families. However, probably due to small numbers of young carers, this is not informed by any available practice guidance, and there are currently no tailored services or formalised networks for individuals aged under 18 supporting adults with dementia.

Specific issues and needs for young people caring for adults with dementia

NCB's survey respondents were asked if, through their contact with young people caring for adults with dementia, they had identified any specific issues or needs *that differentiate them from most other carers* with whom they work. Their responses echo available information on the impact on young people of caring for a person with dementia.

Several young people who have had a parent with dementia, or parents whose partners have experienced young onset dementia, have shared their stories publicly or in published research. Extracts and quotes have been included to illustrate findings in young people's own words. Fuller accounts of young people's experiences that have been published or filmed are available online:

- Alzheimer's Society has produced films, including two that each feature a young woman speaking about supporting her mother with early onset dementia (Chamelle and mum Trisha; Christine and daughter Jennifer-Rose), and a short documentary about a family coming to terms with dementia¹³.
- YoungDementia UK shares three young womens' written stories on its website (Gemma, Heather and Rebecca) plus Gemma's advice for children¹⁴.

This section refers to research by Professor Pat Sikes and Dr Melanie Hall at the University of Sheffield, which is ongoing until October 2016. With funding from Alzheimer's Society, Professor Sikes and Dr Hall are researching *Perceptions and experiences of children and young people with a parent with dementia*¹⁵. This work responds to 'a growing number of under 25s who have a parent with

'Feeling lost and confused. The well parent having to care for the one with dementia and so having less time for them. Feeling disloyal. Not knowing how to relate to the behaviour of parent with dementia.'

NCB survey respondent

'One day am I going to come downstairs and she's going to look at me and go, who are you? I never take anything for granted. There's not a day that goes past where I never say: 'I love you Mum.'"

Chamelle, *Early onset vascular dementia - A daughter's perspective - My mum has dementia* (Alzheimer's Society, 2011)

¹³ Alzheimer's Society, *Dementia videos and resources for children and young people*

https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2894 [Accessed 15 March 2016]

¹⁴ YoungDementia UK, *Living with young onset dementia* <https://www.youngdementiauk.org/living-young-onset-dementia> [Accessed 15 March 2016]

¹⁵ University of Sheffield, *Perceptions and experiences of children and young people with a parent with dementia* <https://www.sheffield.ac.uk/education/research/groups/ccpe/dementia> [Accessed 22 February 2016]

dementia both as a result of the rise in early onset diagnoses and also because of demographic changes including increasing postponement of childbearing and changes in family patterns and structures with more people having second and subsequent families'.

Broader information on the needs and experiences of young carers, which may have relevance to young people supporting adults with dementia, is available. For example, *The Lives of Young Carers in England* report published by the Department for Education (TNS BMRB for DfE, 2016) explores 22 families' experiences in depth, covering a wide range of aspects.

Experiences of caring tasks, and links to identity

Young Carers' Experiences of Caring for a Family Member with Dementia (2014) states that, of 25 young people aged 13-24 who provided care for someone with dementia and participated in a survey, just over half cared for their family member with dementia every day. The report states that young carers undertook a wide range of caring tasks. 'Emotional and/or psychological support was rated by far the most difficult task. However, it was also the task half (47 per cent) of the young carers rated as rewarding. No one said that they found shopping or providing transport difficult, and none found helping with finances rewarding.'

'Seeing a massive smile across his face when I visit him is what keeps me going, all that hard work pays off.'

Heather, whose father had frontotemporal dementia, writing at age 20, YoungDementia UK (See References)

Millenaar and others (2014) interviewed fourteen 15-27 year old children of parents with young onset dementia in the Netherlands. The caring tasks most frequently reported by them were housekeeping and chores (eight participants) followed by 'social contact, doing activities together' (three participants) and 'giving guidance and supervision, answering questions' (three participants). One participant stated that 'she sometimes felt like a prison guard in her own home because of the constant supervision that her parent required'.

Research in Australia by Hutchinson, Roberts and Kurrle (2014) noted the difficulty for children of people with dementia in Australia of becoming legal guardians for parents at age 18.

Early findings from research led by Professor Pat Sikes (see above) suggests that 'young people are reluctant to take on the role and identity of a "carer"' (Alzheimer's Society, 2015). Svanberg, Stott and Spector also found that some children of parents with dementia said 'they cannot be called "young carers" as they were not doing enough', revealing a feeling that 'they are not able to fulfil the role expected of them' (Svanberg 2010).

Difficulties with the 'young carer' label are not unique to young people affected by dementia. Research undertaken for the Department for Education, which involved 22 families (TNS BMRB for DfE, 2016), found that:

Young carers known to local services did identify with the term 'young carer'. Young carers were proud of their caring role but also recognised that it was used as a label which carried with it negative connotations. Young carers not receiving formal support services did not self-identify with the term 'young carer' and parents of these children and young people expressed concerns about their child being labelled as a young carer – a label which they felt reflected negatively on them as a parent.

Relationship to the person living with dementia and wider family

In *Young Carers' Experiences of Caring for a Family Member with Dementia* (2014), negative experiences of caring were related by many participants to changes in their family member's mood or behaviour: 'they spoke of their family member becoming aggressive, and one person even spoke of having to restrain their relative which caused them a lot of pain.'

Comments from a young person below also illustrate the strain dementia can place on relationships between teenagers and parents, and the strangeness of 'losing' a loved one who is still physically there but emotionally unavailable and unable to engage with the day-to-day unfolding of a teenager's life.

'I'd be like, what mood is Mum going to be in now when I get home? Is she going to be nice or is she going to snap at me just for saying hi, nice day at school ... You just take every day as it comes.'

Chamelle, *Early onset vascular dementia - A daughter's perspective - My mum has dementia* (Alzheimer's Society, 2011)

Losing the parent you knew

She looks like Mum and she sounds like Mum and she's saying stuff like Mum. But she's not. It's just really weird ... It's not her fault, but yeah... she doesn't remember what I do, she's rude, always talking about herself, really negative, bringing the conversation down... talks over you and doesn't let you talk to anyone else.

Participant in University of Sheffield study *Perceptions and experiences of children and young people with a parent with dementia* (Alzheimer's Society, 2015)

Young adult children of parents with young onset dementia interviewed in the Netherlands (Millenaar and others, 2014) 'often felt responsible for the well-being of their parent, and they worried about the strain on their healthy parent caused by the caring process. Consequently, many children provided not only instrumental care [...] but also emotional care because they often had to comfort their healthy parent, mediate conflicts, and protect and support their family members'. Family situations had the potential to cause tension, but also to bring family members closer.

Jade Rolph, who was 21 when her mother was diagnosed with early-onset Alzheimer's, described in an interview for the *Independent* how the loss of a loved one as they were before dementia can impact on a young adult, and how young people can feel responsible not only for a parent with dementia but their other 'well' parent. Jade moved home after university to help her parents prior to her mother's move into residential care.

Coping alongside the 'well' parent

The mum I knew has gone and I do look back and miss her. I feel cheated of our adult friendship, but I try to focus on the positive ... [Dad] is 57, working full time, facing retirement on his own with little money, and he is incredibly lonely. He has a very limited social life. Sometimes people tell him to move on, and it makes him angry. He takes his marriage vows very seriously. I see him in limbo.

Jade Rolph (Rhodes, 2014)

Rebecca's story¹⁶ highlights the impact of changes in a parent's behaviour on family relationships and social interactions. It also illustrates a young person's loss of the expected role of her parent in her future life.

Losing the parent you expected to have in the future

[Dad] started to behave oddly. He'd always liked to be the centre of attention, a real joker, but his behaviour became very out of character and social situations became difficult. Family relations became strained and we stopped going on family holidays together.

Dad's illness has been really hard for my mum. She needed support too; we all felt helpless. She is supported by Emeline, a YDUK family support worker who has advised and helped with many practicalities as well as emotional support.

He reached a point where he couldn't live independently anymore and had to go into a care home. It is difficult to come to terms with dad being unable to be part of my life. I've got my 21st birthday coming up. My sister Emily had a big party for hers, but dad won't be there for mine. I want him to come, but there is no way he can be there. I won't have a dad to walk me down the aisle if I ever get married either.

Extracts from *Rebecca's story* (YoungDementia UK)

In one Australian case described by Hutchinson, Roberts and Kurrle (2014), a young person was accused by his extended family of being a 'troublemaker' and separated from his parent with dementia. The researchers also noted understanding and living with symptoms before diagnosis has also been noted as a difficulty for young carers of people with dementia.

One NCB survey respondent mentioned that young people are 'sometimes managing their own young families, managing feelings around not being the main carer and accessing support aimed at main carers, caring at a distance'.

Stigma and social impacts

'I battled through school which was hard as people didn't understand and peers used to taunt me saying, "Your Mam's mad", and trying to start fights with me. I felt so alone.'

Gemma, whose mother was diagnosed with young onset Alzheimer's in the mid-1990s when Gemma was 11, YoungDementia UK (See References)

One NCB survey respondent highlighted stigma as a particular issue for this group of young people, and referred to 'not being able to share experiences with friends or feeling able to bring friends home'.

Dr Mel Hall, co-investigator working with Professor Pat Sikes to interview children of people with young onset dementia, has said that 'our participants feel that their experience is not well recognised. They are often fed up because in the public perception it often seems that dementia is always Alzheimer's and the people affected are always "old". This is not their situation and the lack of representation makes them feel very alone' (Alzheimer's Society, 2015).

Hutchinson, Roberts and Kurrle (2014) identified difficulties for young people relating to responses to their family situation from the extended family and community. These included discrimination linked

¹⁶ YoungDementia UK, *Rebecca's Story* <http://www.youngdementiauk.org/rebeccas-story-0> [Accessed 15 March 2016]

to assumed drug addiction in the person with dementia prior to diagnosis. The young people appear to play a key role in keeping their families together in the face of wider social isolation, whilst struggling with their own need to escape their situations.

Adapting, coping and impacts on emotional and mental health

Svanberg, Stott and Spector (2010) interviewed twelve young people aged 11-18 who lived with, or had lived with, a parent with diagnosed young onset dementia¹⁷. Four themes emerged: discovering dementia; developing a new relationship; learning to live with it and going through it together. The researchers found that 'few participants showed depressive symptomatology, but more than half showed high levels of burden and most showed moderate levels of resilience'. The authors proposed a three-stage process model of adapting to dementia:

- 'Grief for the "parent before dementia"' including for 'the loss of the parent they used to know before the dementia developed, and the loss of the relationship they had and expected to have'
- 'Emotional detachment', enabling young people to "get on with" caring 'without acknowledging any distress this could cause'
- 'Becoming a grown up', including 'feeling more grown up, proud and mature', though 'little recognition was given to their own needs or contribution'.

A study by Allen, Oyeboode and Allen (2009) investigated the impact of having a father with young onset dementia on young people's wellbeing. The researchers identified five major themes from interviews with 12 participants aged 13-23 years: damage of dementia, reconfiguration of relationships, caring, strain and coping. An overarching theme of 'one day at a time', reflecting a response to the perception of severe threats in the future, appeared to run throughout the young people's experiences. Natasha D. Lord conducted a follow-up study in 2010¹⁸.

Of the young carers represented in *Young Carers' Experiences of Caring for a Family Member with Dementia* (2014), 54 per cent reported that they were coping 'well' and 21 per cent reported that they were not. Stress was the most frequently reported negative impact of caring, and 21 per cent of participants indicated they could not find a way to relieve the stress they were feeling.

Self-destructive behaviours by young carers (e.g. excessive drinking, self-harm) are noted in literature on young carers in general, and within the particular group of those affected by dementia (e.g. Hutchinson, Roberts and Kurlle, 2014).

'I needed her to tell me it was going to be OK, to tell the bullies to go away, I needed her to help me grow into a woman, I needed her there when I wanted to talk about clothes, make up boys and school discos.'

Gemma, whose mother was diagnosed with young onset Alzheimer's in the mid-1990s when Gemma was 11, YoungDementia UK (See References)

'The worst part is that no one can turn around and say everything will be OK in the end.'

Heather, whose father had frontotemporal dementia, writing at age 20, YoungDementia UK (See References)

¹⁷ Svanberg, Spector and Stott also conducted a literature review (2011) exploring the experiences of younger people with dementia and their families in the UK, and outcomes for carers. It includes 26 studies, encompassing a variety of themes concerning this population, which reveal a number of negative outcomes for the individual with dementia and for carers. The review also highlights the need for further research in this area.

¹⁸ Lord's findings are presented in a thesis submitted to fulfil the requirement of a Clinical Psychology Doctorate. Available at <http://etheses.bham.ac.uk/3558/> [Accessed 3 March 2016]

'Often we all suffer in silence as we all are just trying to battle through it ... I didn't want to add to my Dad's stress levels as he had more than enough to cope with.'

Gemma, whose mother was diagnosed with young onset Alzheimer's in the mid-1990s when Gemma was 11, YoungDementia UK (See References)

young onset dementia progressed, 'some children would leave to avoid confrontations and discussions'. In the earlier stage of dementia, the researchers associated avoidant ways of coping with young people's struggle to understand what was happening to their parents, and the implications.

However, Millenaar and others noted that 'even the children who were comfortable and who did not feel the need to escape their home situation, occasionally felt the need to withdraw and give themselves a time out'. Leaving the family situation temporarily to focus on other aspects of life may be necessary to retain some sense of normality; over half of the participants in this study 'stated that it was important to rest and to attempt to live their lives as normally as possible to reduce the strain of caring and the emotional problems and worries'.

Coping mechanisms described as being used by children and young people (Alzheimer's Society, 2013) include behaviours overtly indicating distress; appearing unaffected; withdrawing; and getting overly involved in caring for the person with dementia. Relinquishing caring responsibilities and accepting help is noted as a challenge for young carers in general information and literature.

Whilst taking on caring responsibilities for a parent may have some positive consequences for young people, the early assumption of adult roles can be 'dangerous when the child is burdened excessively in an unsupportive environment' (Svanberg, 2010).

Impact on education and future plans

Impacts on young carers' education reported in some of the dementia-specific sources and findings from young carers more broadly include physical and mental exhaustion; being unable to complete homework or study for exams; and questions of whether and how to discuss their situations with teachers.

Rebecca's story¹⁹ shows how the sense of losing the support previously provided by a parent with dementia can affect a young person's ability to manage academic work.

Losing parental support

I was 14 when my dad first became ill ... When I was younger, my dad helped me loads with my homework and was really involved in things at the school, like being Father Christmas every year. But when he got ill, he was completely oblivious when I was doing my GCSEs. I had no parental support and I didn't get the grades I could have done.

Extract from *Rebecca's story* (YoungDementia UK)

Svanberg, Stott and Spector noted that the young people interviewed 'began to act as an equal to the other parent (where one was present)' and becoming self-sufficient, 'sharing the burden on the family without drawing attention to any difficulties they were having' (Svanberg, 2010). To cope with this, young people detached emotionally, beginning 'to see the parent as a new person, frequently like a child, who they were then able to separate from', and physically, 'leaving when things became too much'. Millenaar and others (2014) also learned from adolescents and young adults in the Netherlands that, as a parent's

¹⁹ YoungDementia UK, *Rebecca's Story* <http://www.youngdementiauk.org/rebeccas-story-0> [Accessed 15 March 2016]

Supporting someone with dementia or another illness or disability can also affect a young person's transition to adulthood, presenting particular challenges around leaving home.

Young people's awareness of the inevitable worsening of their loved one's condition, and uncertainty about the implications of that for the person with dementia, the young person themselves and their family, emerged repeatedly throughout the literature and personal stories. Despite this, young people seem strongly committed to supporting their loved one with dementia for as long as possible (e.g. Millenaar and others, 2014).

Access to, and experiences of, support

Young people face challenges in accessing support appropriate to their stage of development and personal circumstances.

Amongst 25 young people caring for adults with dementia (Young Carers' Experiences of Caring for a Family Member with Dementia, 2014), family was the most widely reported source of support, followed by carers' services. Whilst all the young carers had received some form of support, just over half of the young carers wanted more. Some young people surveyed wanted 'more information and to be able to understand the disease, whilst others wanted hospitals to be more aware of young carers and their situation. Many spoke of wanting extra support from young carer groups such as one to one support or groups and activities'.

'I planned to move out a while ago, but now I feel like I cannot leave anymore since my mother will be alone with him. I did not tell her that because I do not want her to feel guilty.'

27-year old male supporting a father with young onset dementia in the Netherlands (Millenaar and others, 2014)

'I had bottled everything up for too long and had tried to be too strong for too long and I just broke. It took me six months off work to sort myself out but I needed it.'

Gemma, describing what she experienced at age 22, a year after her mother died, following her diagnosis with young onset Alzheimer's when Gemma was 11, YoungDementia UK (See References)

The need for age-appropriate support

Their needs are specific to their maturational development and the life stage they are at as well as the level of support and recognition of their needs from others who are in their lives including schools, colleges and universities and other family members. Family members can act as gatekeepers to access to them and while this is at times appropriate, sometimes it can mean they are prevented from gaining access to the support they need.

NCB survey respondent

One NCB survey respondent highlighted young people's 'need to meet people their own age in a similar situation, less formal support / social or informal peer support via forums or email'. Heather's story²⁰ highlights the loneliness of not knowing others in a similar situation. Heather has set up an informal Facebook group called 'Dementia support for under 21's'²¹ to address this need.

²⁰ YoungDementia UK, *Heather's Story* <https://www.youngdementiauk.org/heathers-story> [Accessed 15 March 2016]

²¹ Facebook group *Dementia support for under 21's* accessible via YoungDementia UK, *Heather's Story* <https://www.youngdementiauk.org/heathers-story> [Accessed 15 March 2016]

Isolation

Up to this date I have never met anyone my age (20) nor my sister's age (15) going through what we're going through ... Knowing someone else our age who was going through this would show us we are not alone ... My family and friends are truly incredible and always there for me, but they can't comprehend what it's like to live with this on my mind all the time.

Extract from *Heather's story* (YoungDementia UK)

On Alzheimer's Society's *Talking Point* forum, young people occasionally seek connections with other dementia carers of a similar age, and other forum users try to facilitate this. However, the critical mass needed to sustain an online community of young people caring for adults with dementia, or encourage those who do seek out their peers to check in regularly, is not there. There is no dedicated online space, created and moderated by professionals, for children and adolescents affected by dementia within or beyond *Talking Point*. However, children over 13 are welcome to use *Talking Point* (those under the age of 13 can register but only with parental permission). Volunteers and staff endeavour to offer support, including signposting users aged under 25 to online communities run by the Carers Trust for young carers and young adult carers.

Millenaar and others (2014) found, from their interviews with 15-27 year old children of parents with young onset dementia in the Netherlands, that most participants were 'quite resistant to professional help'. Where acceptable, a 'family-centred approach in which service providers focus on the needs of the entire family is preferred because children are mainly concerned about the needs of their parents as opposed to their own'. Several interviewees preferred to talk with a familiar professional who could keep abreast of the family situation over time, rather than 'sporadically visiting healthcare professionals, which felt too impersonal'.

Svanberg, Stott and Spector (2010) advocated whole family working by both dementia and children's services. Their interviews with young people aged 11-18 (reported by Svanberg, 2010) revealed that counselling and personal support could be helpful, and that 'small changes to tackle each stage of the process of adapting to dementia, such as including children in decision-making and encouraging them to talk about dementia, may allow these children to recognise their distress, maintain a fulfilling relationship with the family and enjoy a continued childhood'.

Young carers interviewed by Hutchinson, Roberts and Kurlle (2014) in Australia commonly 'found that service providers were so overwhelmed by the young person's situation that they inadvertently contributed to their despair and were unable to help them move forward'.

Beyond dementia-specific literature, *The Lives of Young Carers in England* (TNS BMRB for DfE, 2016) explores the uptake of services by families in which young carers support parents or siblings with physical or mental health illnesses/disabilities. It includes young carers' responses to propositions for different types of provision.

Information for and about children and young people affected by dementia

Explaining dementia to children and young people (Alzheimer's Society, 2013) provides an overview of how children and young people can be affected by someone close to them having dementia. One NCB survey respondent highlighted young carers' need for understanding about dementia and how to cope with the changes in their family member's behaviour and memory, whilst another noted that there is 'little general information targeted for them', and a third highlighted 'the need for age-appropriate literature for those with a parent with dementia (as opposed to a grandparent)'.

Millenaar and others (2014) found that adolescent and young adult children of parents with young onset dementia expressed a 'specific need for practical information to help them with the

problems they faced when dealing with their parent'. Participants in this Dutch study had also received limited information about young onset dementia and often found open communication about dementia within the family difficult. Several participants 'found non-specific or overly confrontational information' after searching themselves. The researchers concluded that 'the avoidance displayed by some of the children may be partly explained by ignorance about the disease'.

Recognising this need for information aimed at young audiences that addresses the personal impact of dementia on children and young people themselves, the University of Sheffield study led by Professor Pat Sikes (see the introduction to this section) 'aims to co-produce materials that young people themselves believe would be useful and supportive to other young people in a similar situation'.

The FAD (Familial Alzheimer's Disease) Support Group website includes a section about young people²², which mentions a need to address young people's understanding of the risk of inheriting the gene for this disease. One NCB survey respondent raised 'the question of genetic testing and associated psychological support needs'.

Analysis

The NCB survey responses and internet search findings illustrate children and young people's struggles, as one survey respondent put it, to 'maintain normality within a family circumstance that is changing all the time'.

Findings consistently describe effects, experiences and feelings that are, in one way or another, common to many young carers supporting individuals with different conditions (see 'Young carers' in 'Carers' context'). They also highlight more 'dementia-specific' issues, which tend to relate to behaviour and personality changes in the person with dementia (e.g. loss of the person they knew, loss of empathy and care from the parent, anxiety about social situations, and even physical abuse). The significance of dementia being degenerative and incurable is also mentioned, and will have implications for young people's experience.

Information about young onset dementia also describes how the incongruity of the disease with a person's expected life course impacts on families, in practical and emotional terms but also in terms of stigma, lack of public awareness, and being anomalous within services and settings for people with dementia and their carers.

Whilst some support is available for young people caring for adults with dementia, they appear to be a very isolated group with limited access to age-appropriate support that addresses the particularities of caring for someone with dementia.

Young people from different communities who care for adults with dementia

Findings

NCB survey respondents were asked whether they had identified any particular characteristics or circumstances that differentiate young dementia carers from most other carers with whom they work; for example, they may have noticed that a particular ethnic group seems disproportionately represented. Four individuals answered this question; all said they had not noticed any particular differences.

The available literature suggests that people from black and minority ethnic (BME) communities are disproportionately represented amongst people with dementia and young carers separately.

Young carers are more than one-and-a-half times as likely to be from BME communities as white

²² FAD Support Group, *Supporting Young People* <http://www.fadsupportgroup.org.uk/supporting-young-people/> [Accessed 15 March 2016]

British backgrounds, and are twice as likely to not speak English as their first language (Hounsell, 2013). Hounsell reports that, according to research and experience, young people from BME communities 'are less likely to self-identify as young carers. They often do not recognise that they have taken on a caring role by looking after their parents and siblings and may be less likely to know where to go to get help. This results in them regularly being underrepresented in statistics.' Furthermore, carers from BME communities face barriers in accessing appropriate support (Engage London, 2015).

Some black and minority ethnic communities experience higher prevalence of dementia than the white British population. In 2011 there were approximately 25,000 people with dementia from black and minority ethnic groups in England and Wales (Centre for Policy on Ageing, 2013). A report from the All-Party Parliamentary Group on Dementia (APPG on Dementia, 2013) reports that that number is expected to increase seven-fold by 2051, compared to an expected two-fold increase across the whole UK population in the same time period. Reasons for this increased prevalence are explored in the APPG report and also a systematic review of international literature on the prevalence of dementia in population groups by protected characteristics (PHE, 2015).

Research by Dr Parveen at the University of Bradford (Parveen and others, 2014) suggests that whilst dementia-related stigma exists across communities, the nature and experience of stigma varies according to culturally accepted explanations of dementia. It also interacts with different attitudes towards ageing, gender, ethnicity, familial obligation and use of services that prevail within communities and wider society. The following example is relevant to young carers: 'Younger members of South Asian families where someone has dementia may also be affected by courtesy stigma as their marriage prospects may be reduced due to the perception from the community of "bad blood in the family"'.

Dr Parveen's previous research found that south Asian carers in the UK feel more obligated to provide care than white British carers; however they did not differ in their levels of willingness to care. The south Asian carers who participated in her study were much younger than the white British carers, although still adults (Parveen and others, 2013).

Dr Parveen is currently researching *Familism, willingness to care and preparedness of current and prospective carers to support a person with dementia*, funded by the Alzheimer's Society²³.

Analysis

The survey provided insufficient data to generate insights into how young people from different communities experience caring for someone with dementia. However, evidence suggests that young people from BME communities may be more likely to care for someone with dementia than their white British peers; less likely to be known to services; and less able to access appropriate support.

²³ (October 2015-September 2018) Parveen, S. *Familism, willingness to care and preparedness of current and prospective carers to support a person with dementia*. Alzheimer's Society. £225k

Implications and next steps

- This exercise has highlighted complexities around defining children and young people providing care and support for adults with dementia. A focus on 'children and young people affected by dementia' may better reflect the diversity of families' experiences; how children and young people see their relationships and roles; and variations in professional use of the 'carer' label. On the other hand, some way of taking into account the extents to which children and young people's lives are impacted by a family member's dementia is needed. Young people identified as 'young carers' also have important legal rights.
- Potential links to existing work on children, young people and families and young carers should be considered by statutory bodies and organisations working in this area. There may be opportunities to raise the profile of young people caring for adults with dementia in other dementia initiatives, such as dementia-friendly communities.
- Statutory bodies and organisations working in this area should consider, informed by the findings detailed in this report and their own experiences:
 - whether there is a case or need for some awareness-raising activity (e.g. for professionals or the public)
 - whether there is a case or need for tailored information for children and young people, specifically relating to their possible caring roles²⁴
 - how existing support services could become more sensitive to the needs of families affected by dementia and/or young people supporting adults with dementia
 - any scope for further assisting young people caring for adults with dementia to make connections with each other.
- Insofar as this report gathers and adds to the limited body of knowledge on the experiences of young people caring for adults with dementia, it can help to influence commissioning, service design and delivery, and practice.

²⁴ As mentioned above in 'Action on dementia', general dementia awareness activities are already happening in schools through the dementia-friendly schools programme.

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National Children's Bureau
8 Wakley Street
London, EC1V 7QE
T: +44 (0)20 7843 6000
F: +44 (0)20 7278 9512
www.ncb.org.uk



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