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A 3-UK-nation survey on dementia and the cost of living crisis: contributions of gender and ethnicity on struggling to pay for social care

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ABSTRACT

Objectives: The aim of this 3-UK-nation online survey was to explore the impact of the cost of living crisis on the lives of people with dementia and their carers, specifically on their ability to access social care and support services, and the contributions of gender and ethnic background.

Methods: A 3-UK-nation (England, Wales, Northern Ireland) 31-item online survey was conducted in October 2022 asking people with dementia, carers, and people knowing but not caring for someone with dementia about social care and support service access, cost of living crisis, and changes due to the cost of living crisis. Frequency analysis and Chi-square analysis were employed to assess whether forms of payment for services varied by gender. Pearson correlation analysis and binary logistic regression were used to assess whether gender and ethnicity were associated with struggling to pay for care since the crisis.

Results: A total of 1,095 people with dementia, unpaid carers, and people who knew but not cared for someone with dementia participated. Of those, 745 people with dementia were utilising community-based social care and support services. Twenty percent of those with complete data had reduced their spending on care services since the crisis. Men and those from non-white ethnic backgrounds were at significantly increased odds of struggling to pay for care services.

Conclusions: The cost of living crisis has led to exacerbated inequalities in accessing and using dementia care. Men and those from non-white ethnic backgrounds in particular need to receive greater support in accessing care.

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KEYWORDS

Dementia; social care; cost of living crisis; care

Introduction

The number of people living with dementia continuously rises, predicted to reach 1 million in the UK in 2024 (Wittenberg et al., 2019), with over 55 million people estimated to live with the condition worldwide (ADI, 2022). With pre-pandemic dementia care costs estimated at £34.7 billion a year across the UK (Wittenberg et al., 2019), social care (publicly and privately funded) and unpaid care provided by family and friends represent the largest proportions of the costs, with 45% (£15.7 billion) and 40% (£13.9 billion), respectively.

Accessing and utilising social care and social support services prior to the pandemic and the cost of living crisis has been difficult for many people with dementia and their carers (Giebel et al., 2021a; Stephan et al., 2018; Watson et al., 2021), regardless of whether in high-income or lower- and middle-income countries. In the latter, people face additional barriers of high levels of stigma, poor recognition of dementia, as well as limited resources (Nguyen et al., 2023). Using day care, respite care, support groups, social activities, or paid home care however is important to support the mental and physical well-being of the person, and their unpaid carer (Finnanger-Garshol et al., 2022; Tretteteig et al., 2016). Utilising these community-based care services after a diagnosis can also delay care home entry, as lack of access to services and wider cognitive, physical, and social stimulation has been linked to faster deterioration and care home entry in a qualitative study into COVID-19 (Giebel et al., 2022).

Considering that many people with dementia, and their carers, have to pay for social care and support services either fully or partially themselves where services are known of and available (Giebel et al., 2021b), with commissioning of care services differing across areas (Davies et al., 2020), the cost of living crisis is likely to impact negatively on their utilisation. Those who have to fund care themselves either to top up care or by not qualifying for financial support despite coming from middle/lower socio-economic backgrounds are likely to struggle financing social care and may instead have to pay for other basic necessities. With a scarcity of existing research on the impact of the current cost of living crisis on the wider population, but evidence highlighting the link between socio-economic deprivation and poorer health and mental health outcomes, including in older adults (Fernandez-Nino et al., 2014; McCann et al., 2018), the cost of living crisis is likely causing severe implications on people living with dementia which are yet unknown.

A recent evaluation of primary care data reported increased incidence of dementia diagnosis in black women and men and reduced incidence in Asian women and men compared to people from a white ethnic background (Pham et al., 2018). Moreover, people from black ethnic backgrounds in the UK have a 22% higher likelihood to develop dementia compared to white people, with black and South Asian people with dementia dying sooner after the dementia diagnosis compared to white people (Mukadam et al., 2022). This shows how people

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from minority ethnic backgrounds can experience greater disadvantages in terms of dementia, which is amplified in the myriad of barriers which they experience in relation to accessing and using dementia care services. People from minority ethnic backgrounds are less likely to access dementia care services due to cultural stigma, whilst services are often not adapted to cultural (dietary, religious, cultural norms) and linguistic needs (Brijnath et al., 2022; Nielsen et al., 2020). There has been no evidence on the impact of the cost of living crisis on people with dementia from minority ethnic backgrounds and their ability to access social care and support services, to date.

The aim of this study across three UK nations (England, Wales, Northern Ireland) was to explore the impact of the cost of living crisis on the lives of people with dementia and carers, specifically on their ability to access social support and social care services, and the contributions of gender and ethnic background. We hypothesised that people with dementia would experience increased barriers in accessing and paying for social care and support since the cost of living crisis, and that people from minority ethnic backgrounds would face greater struggles than those from white ethnic backgrounds. No hypothesis was made about the contributions of gender based on lack of previous evidence. This is the first study to date to focus on this topic, and can provide important insights to inform Governmental funding support for some of the most vulnerable members of society in trying to access care.

Methods

Participants and recruitment

Eligible participants included anyone living with dementia, those knowing and caring for someone with dementia, and those knowing but not directly caring for someone with dementia living in England, Wales, or Northern Ireland. People with dementia, carers, and those knowing but not caring for someone in Scotland were not included as the Alzheimer's Society does not cover Scotland, only Alzheimer's Scotland does. Inclusion criteria for knowing someone with dementia included present or former unpaid carer, healthcare professional who works or has previously worked with someone living with dementia, or an individual who currently holds a relationship to someone living with dementia but does not care for them. Quality control measures were also asked at the start of the survey to screen participants for accessibility eligibility.

Participants were identified through the Yonder Data Solutions Panel, a fieldwork and data collection company. The recruitment advertisement was put out to eligible participants on the panel (data are gathered on panel participants upon entry) based on the database, with a £2 incentive upon survey completion. Then the inclusion criteria from the survey questions would have filtered out respondents who are no longer associated with dementia (for example if the database is not up to date). Yonder Data Solutions also sought out at least 100 participants from each region in England, Wales, and Northern Ireland to ensure generalisability of the sample.

Yonder Data Solutions did not check for the mental capacity of people living with dementia specifically but included quality control measures within their survey where participants' answers would be excluded if they did not meet these. In addition, only people with dementia with mental capacity would be able to complete the survey remotely.

Ethical considerations

No ethical approval was sought as the Alzheimer's Society commissioned the survey company to collect the data within GDPR parameters, and was only provided with the anonymised data with anonymised IDs for each participant, with data not including any personal identifiable information. The research team only received anonymised secondary data, with full identifiable data stored with Yonder Data Solutions. Informed consent was taken at the beginning of the survey. Specifically, at the start of the survey, participants were shown a screen as required by GDPR to expressively ask permission from respondents to ask them about any sensitive issues. For mental health related questions for example, participants could opt to either answer or not answer those questions.

Data collection

Survey data were collected online via Yonder Data Solutions from the 21st to the 30th of October 2022 via an online link in an email to eligible participants. The survey was co-designed by the Alzheimer's Society, the University of Liverpool, the NIHR Applied Research Collaboration North West Coast, and Dementia Voice (Alzheimer's Society volunteer network of people affected by dementia). The 31-item survey included basic demographic questions (age range, gender, ethnicity, dementia subtype, living situation, relationship to person with dementia (if carer), home ownership), as well as questions on social care and support service usage (specifically paid home care, support groups, day care, and respite care) and how these were funded, experiences and noted changes as a result of the cost of living crisis, and socialising and visitation). All questions focused on the characteristics and experiences of the person with dementia (except 'relationship to person with dementia'). Thus, questions were either self-reported by people with dementia completing the survey, or proxy reports by carers or those knowing someone with dementia. Each survey question had different items, and a full list of the survey questions is attached in Appendix I.

Personal email addresses are held by the Yonder Data Solutions Panel through consent to take part in relevant surveys.

Data analysis

Data were analysed using SPSS Version 28. Demographic characteristics and all outcome variables were analysed using frequency analysis. A Chi-square analysis was conducted to assess whether forms of payment for services (i.e. self-funded, Local authority, or mixed) varied by gender. Bivariate correlation analysis was employed to analyse the association between gender, ethnicity, and dementia subtype with the ability to struggle to pay for social care and social support (Q9). Variables found to be significantly associated with struggling to pay for care were entered into a binary logistic regression model, to explore significant associations and odds ratios, with Q9 (struggling to pay for social care and social support) as outcome variable. Responses on Q9 for 'struggling to pay for social care' and 'struggling to pay for social support' were merged, so that someone either struggled with one of these, or both.

Missing data

Some responses for Q2 were entered for different categories which are self-excluding (i.e. person with dementia and carer,

or relative caring for someone with dementia and person knowing someone but not caring for them), so these had to be counted as missing data with cases excluded ($n=71$). This resulted in a total sample size of 1,095. For Q4, where participants only ticked young-onset dementia, they were classed as 'not sure', as they may have had Alzheimer's Disease dementia or different subtypes of fronto-temporal dementia for example (which were categorised) or other subtypes of dementia. Thus, these cases were categorised as 'not sure'. This is because young-onset dementia is not a subtype but an age-specific categorisation of dementia, contraire to late-onset dementia (diagnosis aged 65+).

Results

Sample characteristics

A total of 1,095 people with dementia ($n=17$), carers ($n=256$), and people who know someone with dementia in a personal or professional capacity but are not providing care ($n=822$) participated in the survey. The findings refer solely to the person with dementia (either via self-report or proxy report). The majority of people with dementia was female ($n=646$, 59.0%), white/white British ($n=991$, 90.5%), and aged 65 or over ($n=951$, 8.2%). The most common subtype of dementia was Alzheimer's Disease dementia ($n=451$; 41.2%), followed by mixed (15.5%), vascular (13.9%), Lewy body dementia (2.3%), Fronto-temporal dementia (1.2%), and other (1.6%). One quarter of participants was unsure of the precise subtype diagnosis (24.3%). A small proportion of people with dementia (5.8%) was living with young-onset dementia. The majority of people with dementia resided in their own home (52.4%), with over a quarter of people with dementia residing in a care home. People with dementia lived across different regions in England, as well as in Wales and Northern Ireland, with the majority of participants from across England ($n=888$, 81.1%). Table 1 outlines the sample characteristics.

Social care service usage and payments

From the total sample, 68% ($n=745$) reported accessing social care and support services. Of these, 41% accessed home care ($n=306$), 25% accessed support groups ($n=184$), 27% accessed day care ($n=202$), 12% accessed respite care ($n=92$), and 7% accessed other services ($n=52$).

Details about changes in service use costs were also elicited from respondents and are shown in Table 2. Of those who answered this question ($n=640$), 46% reported some increase in costs, 38% were unsure and 16% reported no changes.

Most participants (73%) fully self-funded their service usage, 10% relied on Local Authority funding, while 9% reported partially funding their service usage from a mixture of self and other sources of funding. Pearson Chi-square test revealed no significant variations in how service were paid for between women and men [$X^2(5,640)=0.299$].

Two thirds (68%) of respondents experienced increased cost of living in many aspects of their lives, including rent/mortgage, utility bills, fuel, food, taxes, health and social care, clothing, entertainment, and transportation. Of those accessing social care and support services and who responded ($n=518$) to the question on whether they struggled to pay for various items, 16% ($n=82$) reported difficulties in paying for social care services in the last month.

Table 1. Demographic characteristics of people living with dementia.

Demographic	N(%)
Age range	
25–34	22 (2.0%)
35–44	24 (2.2%)
45–54	17 (1.6%)
55–64	64 (5.9%)
65–74	247 (22.9%)
75–84	395 (36.6%)
85+	309 (28.7%)
Gender	
Female	646 (59.0%)
Male	449 (41.0%)
Ethnicity	
White/ White British	991 (90.5%)
Asian/Asian British	54 (5.0%)
Black/African/ Caribbean	22 (2.0%)
Mixed ethnic background	13 (1.2%)
Other	7 (0.6%)
Prefer not to say	8 (0.7%)
Subtype	
Alzheimer's disease dementia	451 (41.2%)
Vascular dementia	152 (13.9%)
Mixed dementia	170 (15.5%)
Lewy Body dementia	25 (2.3%)
Fronto-temporal dementia	13 (1.2%)
Other	18 (1.6%)
Unsure	266 (24.3%)
Living situation	
In a home they own	575 (52.4%)
In a home they rent	106 (9.7%)
In someone else's home	72 (6.6%)
Sheltered housing	38 (3.5%)
Residential long-term care	288 (26.3%)
Other/not sure	16 (1.5%)
Region	
East Midlands	103 (9.4%)
East of England	103 (9.4%)
Greater London	82 (7.5%)
North East	102 (9.3%)
North West	101 (9.2%)
South East	97 (8.9%)
South West	103 (9.4%)
West Midlands	99 (9.0%)
Yorkshire & The Humber	98 (8.9%)
Wales	107 (9.8%)
Northern Ireland	100 (9.1%)

NOTE. Background characteristics provided for whole sample ($n=1,095$). Data were collected about the person with dementia, so that characteristics are describing the person with dementia themselves or the person with dementia cared for.

Associations between cost of living crisis, social background and social care and support service usage

Participants were also asked specifically about whether they had reduced their usage of social care and support services as a result of increased costs. While only 209 participants of the 745 who utilised services responded to the question, one fifth of them reported that they had reduced service usage to save money.

Bivariate correlation analysis showed that gender [$r(518)=-.110, p < .05$] and ethnicity [$r(518)=-.101, p < .05$] were significantly negatively associated with struggling to pay for social care and support. Specifically, women and people with dementia from white ethnic backgrounds were found to struggle less than men and those from other ethnic backgrounds.

Binary logistic regression analysis showed how both gender ($p < .05$) and ethnicity ($p < .05$) were significantly associated with struggling to pay for social care and support. Men and those from non-white ethnic backgrounds were at greater odds of struggling to pay for social care and support with odds ratios below 1 for both gender and ethnicity, and 'male' and 'non-white ethnic background' coded as '0', compared to 'female' and 'white ethnic background' coded as '1' (see Table 3).

Table 2. Social care service usage payments.

Changes in service use costs (n = 640 with data)		N(%)	
Under £10 extra a week		20 (3.1%)	
£11–£20 extra a week		69 (10.8%)	
£21–£30 extra a week		84 (13.1%)	
£31–£40 extra a week		49 (7.7%)	
£41–£50 extra a week		37 (5.8%)	
£51 or more extra a week		33 (5.2%)	
No changes		105 (16.4%)	
Not sure		243 (38.0%)	
Funding for service usage (n = 640 with data)	N(%)	N(%) for female PLWD (n = 348 with data)	N(%) for male PLWD (n = 292 with data)
Self-funded	470 (73.4)	250 (71.8%)	220 (75.3%)
Charity	2 (0.3)	0	2 (0.7%)
Local authority	64 (10.0)	41 (11.8%)	23 (7.9%)
Mixed (self and other sources of funding)	56 (8.8)	33 (9.5%)	23 (7.9%)
Other	7 (1.1)	4 (1.1%)	3 (1.0%)
Not sure	41 (6.4)	20 (5.7%)	21 (7.2%)

Table 3. Binary logistic regression model on social background and struggling to pay for social care and support.

	Odds ratio	p-value	95% CI for Odds ratio
Gender	.555	.017	.342–.900
Ethnicity	.527	.032	.293–.947

NOTE. Gender variable coding – '1' female, '0' male; Ethnicity variable coding – '1' White ethnic backgrounds, '0' Non-white ethnic backgrounds. Odds Ratios less than 1 indicate that the event (struggling to pay for social care and support) is less likely to occur with a greater predictor ('1' = female/White ethnic background) and thus more likely for lower predictor values ('0' = Male/Non-white ethnic backgrounds).

Discussion

This is the first study to report on the impact of the cost of living crisis on people with dementia, showing the negative effect on their ability to finance and utilise community-based social care and social support services, thereby confirming our hypothesis. Specifically, men and those from non-white ethnic backgrounds were at increased odds of struggling to pay for social care and support services as a result of the cost of living crisis.

Findings of this 3-UK-nation survey extend previously experienced inequalities for people from minority ethnic backgrounds in accessing dementia care and receiving a diagnosis in the first place (Nielsen et al., 2020; Parveen et al., 2017). In addition to existing barriers, the cost of living crisis has exacerbated access issues to necessary care and is thus creating further inequalities. External support services are already under-utilised by people with dementia from diverse ethnic backgrounds, with many cultures tending to care for their relatives solely or primarily within their families (Brijnath et al., 2022). This is also based on cultural stigma surrounding the diagnosis and wider mental health (Parveen et al., 2017), so that removing access to the already limited used services will create further caring duties for family carers, most of whom receive no support themselves for their caring role. The lack of carer support is not unique to different ethnic backgrounds though, and commonplace across the unpaid carer population, leading to increased unmet needs (Zwingmann et al., 2019). To ensure that people with dementia from any ethnic background continue to and increase their access to social care and support within their community, based on the evidence from this survey, further financial subsidies need to be in place as otherwise many will have to continue choosing basic necessities such as food and heating over care.

Men were also found to be more disadvantaged than women with dementia in terms of struggling to pay for care services since the cost of living crisis. Comparing the sources of funding

for social care and support services, there were no significant variations between men and women, so that men were not more likely to pay for care themselves for example. Similarly, we did not collect any income or wealth data on participants, so are unable to compare the economic background of people with dementia by gender. Differences in financial backgrounds may explain why men were struggling to a greater extent in funding social care and support services. However, this male sample of people with dementia may have similar average financial background compared to female people with dementia, whilst men may have more diverse outgoings and thus had to cut back on paying for care services. Qualitative follow-up research to contextualise these findings and understand these nuanced variations by gender, and ethnicity, is required as a next step.

Besides ethnicity and gender as key barriers to accessing care, this 3-UK-nation survey clearly indicates the generic difficulties for some people with dementia in accessing care since the cost of living crisis. This is in addition to existing difficulties in accessing care regardless of the current financial and economic situation, and highlights the difficulties for many who are faced with financial barriers to receiving care. This key barrier could be addressed by the initially announced, and then delayed and cancelled increase of support for social care funding for those from more disadvantaged backgrounds (HM Treasury, 2022). With a lack of comparable national and international evidence, future research ought to explore the impact of the continued cost of living crisis and ongoing system barriers within social care for people with dementia by building on this survey and advancing it with more detailed background demographics and qualitative contextual research. This will be of particular interest for lower- and middle-income countries also, where dementia care is more limited than in high-income countries and already fewer people access support (ADI, 2022; Ferri & Jacob, 2017; Jacob, 2017).

Limitations

Whilst this survey benefited from having recruited participants from across three UK nations, involving people from diverse backgrounds, there were some limitations to this externally organised survey. There was no confirmation on dementia diagnosis and subtype, and this was based on personal information from the participants instead. However, this is a common approach in the field, and enables larger sample sizes to be

collected, without necessitating the need to approach memory clinics and the National Health Services for subtype diagnosis. Moreover, the analysis of this study was not focusing on specific dementia subtypes, but focused on a general impact of the cost of Living crisis. An additional limitation of the study was the low proportion of people with dementia who participated themselves, and the large proportion of people who knew someone with dementia well, yet were not providing unpaid care to them. This study aimed to provide a timely overview and insights into the situation, so that equal numbers of people with dementia, carers, and non-carers could not be effectively recruited. However, future research needs to specifically investigate the experiences of people with dementia directly, also by contextualising the survey data via more nuanced qualitative explorations. This may also be the result of only recruiting through and conducting the survey via Yonder Data Solutions, which has members of the general public on their registered panel. No dementia targeted recruitment approach, such as via Join Dementia Research, was utilised, due to the time-sensitive nature of the survey as well as the outsourcing of data collection to a company. In terms of the survey variables and missing data, whilst nearly 1,100 people participated in the survey, 745 of whom who had experiences of social care and support service usage, of those, over 200 participants had missing data on their experiences of struggling to pay for items, including care services. This is to be expected in a large survey, and did not impact on generating significant results in the correlation and logistic regression modelling.

Conclusions

The cost of living crisis has exacerbated existing difficulties in utilising vital social care and support services for dementia, by hindering more people from accessing the care they need, specifically men and those from non-white ethnic backgrounds. If people with dementia fail to access these services, they are more likely to deteriorate faster and enter residential long-term care, which is less affordable than community-based care and the heaviest cost factor of the dementia trajectory (Wittenberg et al., 2019). In addition, without the social care support to keep well and independent at home, people are more likely to utilise health care services and reach crisis point with their health. After the COVID-19 pandemic, the cost of living crisis generates new barriers and underscores the need for systemic changes and support for people with dementia to access care within their community. Future research needs to expand on these survey findings and explore the impact of the crisis in other countries and settings, especially lower- and middle-income countries.

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Disclosure statement

No potential conflict of interest was reported by the authors.

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Appendix I. Survey questions

#	Question	Possible answers
1	Which UK region do you/the person living with dementia currently reside in?	<ul style="list-style-type: none"> a. North East b. North West c. Yorkshire & The Humber d. East Midlands e. West Midlands f. East of England g. Greater London h. South East i. South West j. Wales k. Northern Ireland
2	Which of the following best describes your experience of dementia?	<ul style="list-style-type: none"> a. I have a diagnosis of dementia b. I look after someone with a diagnosis of dementia in a personal capacity (i.e. not as part of formal employment), at least some of the time c. I know someone with a dementia diagnosis, but do not look after them d. I knew someone with dementia, but they have passed away e. Other (please specify)
3	Which of the following best describes your relationship to the person you know living with dementia? If you know more than one person living with dementia, please think about the person you would consider yourself to have the closest relationship with.	<p>[If Q2 is B or C]</p> <ul style="list-style-type: none"> a. A family member or close friend (e.g. partner, child, parent, grandparent, sibling, close friend) b. Someone you know well (e.g. aunt, uncle, cousin, wider social circle, someone you work with) c. Someone you know less well (e.g. more distant family, more distant colleague, friend-of-a-friend)
4	What type(s) of dementia do you/this person have?	<p>[If Q2 is A, B or C]</p> <ul style="list-style-type: none"> a. Alzheimer's disease b. Vascular dementia c. Mixed dementia d. Dementia with Lewy bodies e. Frontotemporal dementia (FTD) f. Young-onset dementia (under 65 years-old) g. Posterior cortical atrophy (PCA) h. Alcohol-related brain damage i. Other (please specify) j. Not sure
5	Where do you/the person with dementia currently live?	<ul style="list-style-type: none"> a. In a home that they own, for example, mortgaged / owned outright b. In a home that they rent c. In a home that someone else owns, for example, a family home d. In a home that someone else rents e. Sheltered housing / supported living f. Residential care home g. Nursing home h. Other (please specify) i. Not sure

(Continued)

Appendix I. Continued.

#	Question	Possible answers
6	Who, if anyone, do you/the person with dementia currently share your/their home with?	<ul style="list-style-type: none"> a. With me b. A partner or spouse c. One or more other family members d. Other residents, for example, in a nursing home e. They/I live alone f. Not sure
7	'Cost of living' refers to everyday costs such as rent / mortgage, utility bills, fuel, food, taxes, health and social care, clothing, entertainment, and transportation. Over the last month, has the cost of living changed for you/the person living with dementia?	<p>[If Q5 is A, B, C, D or E]</p> <ul style="list-style-type: none"> a. Their/my cost of living has increased b. Their/my cost of living has stayed the same c. Their/my cost of living has decreased d. Not sure
8	How do you/the person living with dementia feel about the increase in your/their cost of living?	<p>[If Q7 is A]</p> <ul style="list-style-type: none"> a. Extremely worried b. Very worried c. Somewhat worried d. Not very worried e. Not at all worried f. I am not sure what they think (or skip)
9	Has the main bill payer in your household/the household of the person living with dementia struggled to pay for any of the following in the last month?	<p>[If Q5 is A, B, C, D or E]</p> <ul style="list-style-type: none"> a. Rent or mortgage b. Social care or support service fees c. Council Tax d. Utility bills e. Food / drink f. Communications in the home, for example, telephone, mobile, or internet access g. Vehicle running costs, such as fuel h. Public transport or taxis i. They/I have struggled to pay other bills (please specify) j. Not sure k. They/I can comfortably pay their bills
10	Which one, if any of the following statements, best applies to your current financial situation/the current financial situation of the person living with dementia?	<p>[If Q7 is A]</p> <ul style="list-style-type: none"> a. They/I have taken significant steps to reduce their outgoings b. They/I have taken some steps to reduce their outgoings c. They/I are planning / considering taking steps to reduce their outgoings d. They/I are confident they won't have to take any steps to reduce their outgoings e. They/I are unable to take any steps to reduce their outgoings
11	What steps have you/they taken to reduce your/their outgoings?	<p>[If Q10 is A or B]</p> <ul style="list-style-type: none"> a. Spending less on food shopping and essentials b. Started using food banks c. Using food banks more d. Cooking less often e. Using the TV less often f. Staying in bed more g. Keeping the lights turned off h. Keeping the heating low i. Keeping the heating off j. They stay in one room, to avoid heating their whole home k. Using less water l. They/I have reduced or stopped attending support services, for example, social activities or peer support groups m. They/I have reduced or stopped using social care, for example, paid home carers or day care n. They/ I have cancelled a communication service, for example, telephone, mobile phone or internet o. They/ I have reduced the number of visits to the hospital / GP p. Other (please specify) q. None of the above r. Not sure
12	How much has the cost of your/their current place of living fees changed, if at all, in the last three months?	<p>[If Q5 is E, F or G]</p> <ul style="list-style-type: none"> a. Under £10 extra per week b. £11 - £20 extra per week c. £21 - £30 extra per week d. £31 - £40 extra per week e. £41 - £50 extra per week f. £51 or more extra per week g. They have stayed the same h. They have decreased i. Not sure
13	Which, if any, of the following services do you/the person living with dementia use?	<ul style="list-style-type: none"> a. In-home carer b. Support groups c. Day care d. Respite care e. Other (please specify) f. They/I do not use any services g. Not sure

(Continued)

Appendix I. Continued.

#	Question	Possible answers
14	How has the cost of these services changed, if at all, in the last three months?	[If Q13 is A, B, C, D or E] a. Under £10 extra per week b. £11 - £20 extra per week c. £21 - £30 extra per week d. £31 - £40 extra per week e. £41 - £50 extra per week f. £51 or more extra per week g. They have stayed the same h. They have decreased i. Not sure
15	Who pays for the support services you use/used by the person living with dementia?	[If Q13 is A, B, C, D or E] a. The person living with dementia/ myself b. A family member c. Myself / skip d. Charity funding e. Their/my local authority f. Other (please specify) g. Not sure
16	Approximately how much time do you/the person living with dementia spend away from home on a typical day? For example, shopping, going for a walk, or going to a social group.	[If Q5 is A, B, C or D] a. They/ I do not typically go out anywhere b. Less than 1 h c. 1 – 2 h d. 3 – 4 h e. 5 – 6 h f. 7 – 8 h g. 8 h or more h. Not sure
17	Which of the following, if any, applies to you/the person living with dementia?	a. They/I often forget to turn off lights b. They/I often forget to turn off taps c. They/I often forget to close the fridge door d. They/I have special dietary requirements e. They/I find it difficult to control their thermostat or other heating controls f. They/I use the washing machine / dryer regularly due to incontinence g. They/I feel the cold more than they used to h. They/I frequently have the lights on at night, for example, due to insomnia or fall risk i. None of the above j. Not sure
18	Which of the following benefits are you/the person living with dementia currently in receipt of?	a. Attendance allowance b. Personal independent payment c. Disability living allowance d. Universal credit e. Employment Support allowance f. State pension g. Pension credit h. Income support i. Cold weather payments j. Medical cost benefit scheme k. Support for mortgage interest l. Housing benefit m. Council tax support n. They/I do not receive any benefits o. The benefits they/I receive are not listed p. Not sure
19	Have you/the person living with dementia ever used a price comparison site? Price comparison websites let you filter and compare products	a. Yes, by themselves/myself b. Yes, with some help, for example from a friend or family member c. No, but they/I do use the Internet d. No, they/I do not use the Internet at all e. Not sure
20	In the past three months, approximately how often have you/the person living with dementia visited, or been visited by, friends / family?	a. Every day or more often b. Two to six days a week c. One day a week d. Less than one day per week e. Never f. Not sure
21	'Cost of living' refers to everyday costs such as rent / mortgage, utility bills, fuel, food, taxes, health and social care, clothing, entertainment, and transportation. What negative impact, if any, do you think the cost of living has had on the number of times you/the person living with dementia has visited, or been visited by, friends / family in the past three months?	a. Extremely negative impact b. Very negative impact c. Somewhat negative impact d. Slightly negative impact e. No negative impact f. Not sure

(Continued)

Appendix I. Continued.

#	Question	Possible answers
22	You have said that the cost of living has had a negative impact on the level of social contact you/the person living with dementia has had in the past three months. As a result of this, have you/the person living with dementia felt/appeared to feel lonelier compared to previous months?	<ul style="list-style-type: none"> a. Much lonelier b. Slightly lonelier c. No change d. I am not sure how they feel/skip
23	In the next three months, how often are you/the person living with dementia likely to visit, or be visited by, friends / family?	<ul style="list-style-type: none"> a. Every day or more often b. Two to six days a week c. One day a week d. Less than one day per week e. Never f. Not sure
24	What negative impact, if any, do you think the general cost of living will have on the number of times you/the person living with dementia visits, or is visited by, friends / family in the next three months? As a reminder, 'Cost of living' refers to everyday costs such as rent / mortgage, utility bills, fuel, food, taxes, health and social care, clothing, entertainment, and transportation	<ul style="list-style-type: none"> a. Extremely negative impact b. Very negative impact c. Somewhat negative impact d. Slightly negative impact e. No negative impact f. Not sure
25	How would you say you/the person living with dementia is feeling generally about Christmas this year?	<ul style="list-style-type: none"> a. Really looking forward to Christmas b. Somewhat looking forward to Christmas c. Not really looking forward to Christmas d. Not looking forward to Christmas at all e. Not sure f. They/I do not celebrate Christmas
26	Compared to last year's Christmas, are you/the person living with dementia likely to make fewer visits to, or have fewer visits from, friends / family this year?	<p>[If Q25 is A, B, C, D, or E]</p> <ul style="list-style-type: none"> a. Fewer visits due to symptom increase b. Fewer visits due to concerns over infection, for example, covid or flu c. Fewer visits due to concerns over cost of living, for example, cost of fuel d. Fewer visits for another reason (please specify): [OTHER TEXT] e. About the same number of visits f. More visits g. Not sure
27	You have said you/the person living with dementia is not really/not looking forward to Christmas at all. Why do you think the person living with dementia is feeling this way about Christmas?	Open text
28	You have said you/the person living with dementia is not really/not looking forward to Christmas at all. What negative impact, if any, has the rise of cost of living had on how you/they are feeling about Christmas? Please think about the person's own cost of living, as well as other possible knock-on effects, such as fewer people visiting due to the cost of fuel. As a reminder, 'Cost of living' refers to everyday costs such as rent / mortgage, utility bills, fuel, food, taxes, health and social care, clothing, entertainment, and transportation.	<p>[If Q25 is C or D]</p> <ul style="list-style-type: none"> a. Extremely negative impact b. Very negative impact c. Somewhat negative impact d. Slightly negative impact e. No impact <p>Not sure</p>
29	What is your age/the age of the person you know with dementia?	<ul style="list-style-type: none"> a. Under 18 b. 18–24 c. 25–34 d. 35–44 e. 45–54 f. 55–64 g. 65–74 h. 75–84 i. 85+ j. Prefer not to say
30	What is your gender/the gender of the person you know with dementia?	<ul style="list-style-type: none"> a. Female b. Male c. Non-binary d. Other (please specify) e. Prefer not to say
31	Which of the following best describes your ethnic group/the ethnic group of the person you know with dementia?	<ul style="list-style-type: none"> a. White / White British b. Asian / Asian British c. Black / African / Caribbean / Black British d. Mixed ethnic group e. Other (please specify): f. Prefer not to say