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Mapping Dementia Awareness and Information Needs among Minority Ethnic Communities in Leicester and Leicestershire: A Descriptive Survey to Inform Communication Interventions

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Abstract

Community awareness and understanding of dementia are important for early recognition, timely help-seeking and access to support. This study examined dementia knowledge, attitudes, information needs and communication preferences among minority ethnic communities in Leicester and Leicestershire, UK. A community-based descriptive survey was conducted between May 2023 and July 2024. Using purposive and convenience sampling, 259 respondents completed questionnaires in English, Gujarati or Hindi. Data were analysed using descriptive statistics. Recognition of common dementia symptoms was relatively high, but misconceptions about ageing and concerns about stigma remained. Although 87.6% expressed willingness to seek professional help, 78.0% reported insufficient information about dementia diagnosis and 66.8% about accessing support. Respondents preferred multilingual, professionally led and community-based awareness activities. Findings highlight the need for culturally responsive dementia communication that addresses misconceptions, stigma and practical information needs through coordinated healthcare and community initiatives.

Keywords: Dementia, awareness, information needs, minority ethnic communities, inequality, survey

Background

Dementia is a significant public health concern in the UK, particularly among minority ethnic communities. The number of older people from minority ethnic backgrounds living with dementia is expected to increase substantially in the coming decades, reflecting demographic changes, migration patterns and the prevalence of specific dementia risk factors, including cardiovascular disease and type 2 diabetes (Dodd et al., 2022). Previous studies have found that people from minority ethnic communities are more likely to experience delayed dementia diagnosis and encounter barriers to accessing healthcare and support services (Subramaniam et al., 2020; Mukadam et al., 2023). These barriers include limited awareness and understanding of dementia, stigma, cultural and religious beliefs, language difficulties and broader inequalities in healthcare provision (La Fontaine et al., 2007; Mukadam et al., 2011; Parveen et al., 2017; Bajwa, et al., 2025). Research has also identified ethnic inequalities in dementia diagnosis and

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access to specialist services, with people from Black and South Asian communities experiencing particular disadvantages (Dodd et al., 2022; Mukadam et al., 2023).

Community awareness and understanding of dementia are important for improving the recognition of symptoms, encouraging timely help-seeking and enabling individuals and families to make informed decisions about care and support. However, previous research suggests that dementia knowledge varies across minority ethnic communities. Symptoms such as memory loss and behavioural changes may be understood as part of normal ageing rather than as potential signs of dementia, while stigma and misconceptions can discourage discussions about the condition and professional help-seeking (Berwald et al., 2016; La Fontaine et al., 2007; Mukadam et al., 2011). Limited knowledge of available services and support may create further difficulties for individuals and families seeking assistance (Subramaniam et al., 2020). Understanding existing levels of knowledge, attitudes and perceived information gaps is therefore an important starting point for developing effective dementia awareness initiatives.

Research on interventions designed to improve dementia knowledge among minority ethnic communities remains relatively limited, particularly outside the United States. A systematic review by Huggins et al. (2022) identified relatively few UK-based intervention studies targeting dementia knowledge among racial and ethnic minority groups. Nevertheless, evidence from dementia awareness initiatives and wider health communication research suggests the importance of culturally appropriate approaches. Rather than relying solely on the provision of standardised health information, communication initiatives need to consider the linguistic, cultural and social characteristics of their intended audiences. Strategies may include translated information, culturally appropriate imagery and language, and the involvement of trusted community organisations and community representatives. Community settings, including faith organisations and local community centres, may provide opportunities to engage individuals who are less likely to access information through conventional healthcare channels. However, the relevance and potential effectiveness of these approaches need to be considered in relation to local communities and their existing knowledge and communication needs.

The demographic characteristics of Leicester provide a particularly relevant context for examining dementia awareness and communication needs. According to the 2021 Census, 43.4% of Leicester City's population identified as Asian, including 34.3% of Indian heritage, while 7.8% identified as Black, Black British, Caribbean or African (Office for National Statistics, 2023). The city includes long-established and multigenerational minority ethnic communities with diverse linguistic, cultural and migration backgrounds. Its population profile also differs considerably from that of the surrounding county of Leicestershire, although the latter is also becoming increasingly diverse.

Previous research has examined ethnic inequalities in access to local dementia services. Subramaniam et al. (2020) analysed memory service referrals in Leicester and Leicestershire between 2011 and 2017 and identified changing patterns of referral across ethnic groups. Their analysis also demonstrated the importance of accounting for differences in population age structures when interpreting inequalities in service use. While this research provides valuable evidence about access to specialist dementia services. Less is known about dementia awareness, attitudes and information needs within the wider community, including among people who have not personally encountered dementia care services. Examining these issues offers a complementary perspective to existing research on dementia diagnosis and service provision.

Local policy also recognises the importance of improving dementia awareness and reducing inequalities in care. The Leicester, Leicestershire and Rutland Living Well with Dementia Strategy 2024–2028 emphasises timely diagnosis, accessible information, community engagement and collaboration across health, social care and voluntary-sector organisations (Leicester City Council, 2024). However, translating these priorities into effective communication initiatives requires an understanding of the populations they aim to reach, including their existing knowledge, perceived information gaps and preferred channels of communication.

Conceptual framework

This study draws on the socio-ecological model, which recognises that individuals' health knowledge, attitudes and behaviours are shaped by interactions between different levels of the social environment, including individual, interpersonal, community, institutional and wider policy contexts (Ewald et al., 2023; Sallis et al., 2008; Stokols, 1996). At the individual level, knowledge, health literacy, attitudes and cultural beliefs influence how dementia symptoms are recognised and understood. At the interpersonal level, communication within families and social networks may shape perceptions of dementia, the sharing of health information and decisions about seeking professional help. At the community level, shared beliefs, social norms and representations of dementia may influence individual understanding and attitudes, while community organisations and social networks can facilitate access to information and support. Institutional and policy contexts, including the availability and accessibility of health information and services, also influence opportunities to acquire knowledge and seek assistance.

This study places particular emphasis on the interpersonal and community levels of the socio-ecological model. The survey was conducted with members of minority ethnic communities who may or may not have had personal or family experiences of dementia, rather than specifically recruiting people living with dementia or their carers. This focus is important because dementia recognition and help-seeking often involve people beyond the individual experiencing symptoms. As dementia progresses, cognitive impairment may affect an individual's ability to recognise changes in their condition, make decisions or seek professional assistance independently. Family members, friends, neighbours and wider community networks may therefore play an important role in recognising potential symptoms, encouraging help-seeking and facilitating access to information and support.

Community awareness and understanding of dementia are important not only for individuals who may develop the condition but also for those around them. Knowledge, misconceptions and stigma within families and communities can influence how symptoms are interpreted, discussed and responded to. By examining dementia knowledge, attitudes and information needs among community members, this study seeks to understand the wider social and communication environment in which dementia recognition and help-seeking take place. Although the survey does not directly examine interactions between different levels of the socio-ecological model, its findings can inform the development of communication initiatives that engage families, social networks and community organisations in improving dementia awareness and facilitating timely access to support.

Study aims

The present study aims to map dementia awareness, understanding, attitudes and information needs among minority ethnic community members in Leicester and Leicestershire. It forms part

of a wider mixed-methods research project examining dementia awareness and access to information and support, comprising a community survey and in-depth interviews with family carers of people living with dementia. This paper focuses on the community survey, providing a descriptive assessment of respondents' existing knowledge, perceptions and information needs, rather than their direct experiences of navigating dementia care services.

Specifically, the study examines:

1. Respondents' knowledge and understanding of dementia, including awareness of symptoms and common misconceptions;
2. Attitudes towards dementia and professional help-seeking;
3. Perceived gaps in information about dementia symptoms, diagnosis and available care and support; and
4. Existing sources of dementia information and preferences for future awareness and communication initiatives.

Methodology

Study design and setting

A community-based descriptive survey was conducted as part of a wider mixed-methods research project examining dementia awareness, understanding, and information and support needs among minority ethnic communities in Leicester and Leicestershire, England. The wider project also involved in-depth interviews with family carers of people living with dementia and representatives of community organisations. This paper reports findings exclusively from the community survey. The study was conducted between May 2023 and July 2024 by a small multilingual research team. Leicester and Leicestershire provide a particularly relevant setting because of the area's ethnically diverse population, including substantial and long-established South Asian, African and Caribbean communities. The study sought to generate locally relevant evidence to inform dementia awareness and communication initiatives within these communities.

Participant recruitment and data collection

The study used a combination of purposive and convenience sampling to recruit participants from South Asian, African and Caribbean communities in Leicester and Leicestershire. Individuals were eligible to participate if they self-identified as belonging to one of these communities, lived or worked in Leicester or Leicestershire, and were able to provide informed consent. Participants were recruited through both face-to-face community outreach and online distribution. Two multilingual research assistants, fluent in English, Gujarati and Hindi, approached potential participants in minority ethnic neighbourhoods, community centres, community events, local community hubs (including libraries and shops), schools, colleges and universities, shopping centres, food courts and high streets. Recruitment across these different settings was intended to reach community members from varied demographic and socioeconomic backgrounds, including individuals who might not be reached through online recruitment or established community organisation networks alone.

Online recruitment was facilitated through local community organisations, newsletters, social media and WhatsApp groups. The survey was hosted on JotForm, and web links and QR codes were included in digital and printed recruitment materials. Participants accessing the survey online were provided with a project information sheet and asked to complete a consent form before proceeding to the questionnaire. For face-to-face recruitment, potential participants were also provided with information about the study and an opportunity to ask questions before providing written consent, either on paper or digitally.

The questionnaire was available in English, Gujarati and Hindi, in both paper-based and digital formats. Participants could complete the questionnaire independently or with assistance from the research assistants where language or literacy difficulties or visual impairments made independent completion difficult. Providing different questionnaire formats and researcher assistance was intended to accommodate participants with varying language, literacy and accessibility needs. Data collection concluded in July 2024, at the end of the planned fieldwork period, with a total of 259 completed questionnaires. The study aimed to recruit respondents from varied demographic and socioeconomic backgrounds through purposive and convenience sampling. The final sample size reflected the responses obtained during the planned data collection period, rather than a predetermined sample size based on statistical power or population representativeness.

Survey design

The survey questionnaire was adapted from previous studies and further developed by the research team to examine dementia knowledge, understanding, attitudes, awareness and information needs among minority ethnic community members. A preliminary Patient and Public Involvement and Engagement (PPIE) discussion involving two community members, a clinician and a representative of a community organisation informed the questionnaire's development, including the selection and refinement of questions to ensure their relevance to the study population. The questionnaire consisted of four main sections. The first section collected demographic information, including age, gender, ethnic background, migration status, length of residence in the UK, location, educational attainment, preferred language, marital status and employment status. The second section assessed participants' knowledge and understanding of dementia through 16 statements examining dementia symptoms, causes, prevalence, diagnosis and treatment. Response options were ‘True’, ‘False’, or ‘Not sure’ for each statement. The third section examined attitudes towards dementia, including concerns about stigma, family burden, disclosure, social judgement and willingness to seek professional help. Participants were asked to indicate whether they agreed or disagreed with each statement. Questions about potential sources of help were also included. The fourth section explored dementia awareness and sources of information, including previous exposure to dementia, experiences of knowing or caring for someone with dementia, existing information sources, perceived sufficiency of information about dementia symptoms, diagnosis and available support, and preferences for future dementia awareness activities and communication materials. Questions concerning information sources and suggested approaches to dementia awareness promotion allowed participants to select multiple responses. The question about suggested awareness approaches was presented as a follow-up to respondents who had indicated insufficient awareness or information about dementia.

Data processing and analysis

Completed paper questionnaires were manually entered into JotForm by the research assistants to facilitate data processing and analysis. Responses collected through the digital questionnaires were recorded directly on the platform. Gujarati and Hindi responses were translated into English before analysis. Survey data were exported from JotForm into Microsoft Excel. A total of 259 survey responses were collected in English (n = 235), Gujarati (n = 22) and Hindi (n = 2). Responses from the three language versions were combined into a single dataset, which was cleaned and organised for analysis. Data preparation involved checking for missing and duplicate responses and standardising variables to ensure consistency across the dataset. Unanswered questions were coded as 'Answer not provided' during data cleaning.

Descriptive statistics, including frequencies and percentages, were calculated to summarise respondents' demographic characteristics, dementia knowledge, attitudes, perceived information sufficiency, existing information sources and preferences for future dementia awareness activities. For single-response questions, percentages were calculated using the total sample (N = 259), including responses recorded as 'Answer not provided' in the denominator. For multiple-response questions, percentages were calculated using the number of respondents with recorded responses to each question. Accordingly, the analysis of existing dementia information sources was based on 253 responses (Table 6), while the analysis of suggested approaches to dementia awareness promotion was based on 185 responses (Table 7) who selected at least one response to the follow-up question. As participants could select more than one option, percentages for these questions do not sum to 100%.

Ethical approval for the study was obtained from the University of Leicester. All participants were provided with information about the study and gave informed consent before taking part. Participation was voluntary, and respondents could choose not to answer individual questions. Data were stored securely on university-provided, encrypted laptops used by the researchers.

Findings

Sample overview

A total of 259 questionnaires were collected from respondents recruited through minority ethnic communities in Leicester and Leicestershire, including 235 completed in English, 22 in Gujarati and two in Hindi. Respondents varied in age, gender, ethnicity, educational attainment, migration background and language preference (Tables 1 and 2).

Table 1. Demographic characteristics of survey respondents

Characteristic	N = 259, n (%)
Age (years)	
18-30	63 (24.3)
31-40	42 (16.2)
41-50	29 (11.2)

Characteristic	N = 259, n (%)
51-60	38 (14.7)
61-70	38 (14.7)
71-80	32 (12.4)
81+	13 (5.0)
Answer not provided	4 (1.5)
Gender	
Male	85 (32.8)
Female	163 (62.9)
Answer not provided	11 (4.2)
Ethnic group / background	
Asian group (combined subtotal)	170 (65.6)
Asian/ Asian British	19 (7.3)
Indian	120 (46.3)
Pakistani	7 (2.7)
Bangladeshi	21 (8.1)
Other	3 (1.2)
Black group (combined subtotal)	77 (29.7)
Black/ Black British/ Caribbean/African	25 (9.7)
Caribbean	22 (8.5)
African	28 (10.8)
Other	2 (0.8)
Mixed / multiple ethnic groups (subtotal)	10 (3.9)
Mixed / Multiple ethnic groups	1 (0.4)

Characteristic	N = 259, n (%)
White and Black Caribbean	1 (0.4)
White and Black African	1 (0.4)
White and Asian	2 (0.8)
Other	5 (1.9)
Prefer not to say	2 (0.8)
Preferred language	
Gujarati	69 (26.6)
Urdu	3 (1.2)
Hindi	6 (2.3)
Bengali	14 (5.4)
Punjabi	6 (2.3)
English	147 (56.8)
Other	5 (1.9)
Answer not provided	9 (3.5)

The largest age group was 18–30 years (24.3%, n = 63), while nearly one-third of respondents were aged 61 or above (32.0%, n = 83). Women accounted for 62.9% (n = 163) of the sample, compared with 32.8% (n = 85) men. Most respondents identified with categories grouped under Asian or Asian British (65.6%, n = 170), followed by Black, Black British, Caribbean or African (29.7%, n = 77). Indian was the largest individual ethnic category, accounting for 46.3% (n = 120) of all respondents. The remaining 12 respondents included 10 who identified with mixed or multiple ethnic groups and two who preferred not to state their ethnic background.

Table 2. Migration background and location of respondents

Characteristic	N = 259, n (%)
Migration status	
Born in the UK	85 (32.8)

Characteristic	N = 259, n (%)
Born abroad – go to next question 'Country of birth (not reported in this paper)'	161 (62.2)
Answer not provided	13 (5.0)
Years of residency in the UK	
Under 1 year	8 (3.1)
1-2 year	8 (3.1)
3-5 years	16 (6.2)
6-10 years	6 (2.3)
11-15 years	11 (4.2)
16-20 years	35 (13.5)
21-25 years	10 (3.9)
26-30 years	12 (4.6)
30 years +	138 (53.3)
Other	4 (1.5)
Answer not provided	11 (4.2)
Current location	
North West Leicestershire	5 (1.9)
Hinckley and Bosworth	3 (1.2)
Blaby	4 (1.5)
Leicester City	178 (68.7)
Harborough	4 (1.5)
Rutland	1 (0.4)
Melton	1 (0.4)

Characteristic	**N = 259, n (%)**
Charnwood	28 (10.8)
Other	29 (11.2)
Answer not provided	6 (2.3)

Most respondents lived in Leicester City (68.7%, n = 178), followed by Charnwood (10.8%, n = 28). Nearly two-thirds (62.2%, n = 161) reported being born outside the UK, while 32.8% (n = 85) were UK-born. Nevertheless, more than half of respondents (53.3%, n = 138) reported having lived in the UK for over 30 years. English was the most frequently reported preferred language (56.8%, n = 147), followed by Gujarati (26.6%, n = 69), reflecting the linguistic diversity of the surveyed population. These characteristics describe the composition of the sample rather than the wider local communities.

Dementia knowledge and misconceptions

Respondents demonstrated varying levels of knowledge about dementia. Recognition of familiar symptoms and certain aspects of diagnosis was relatively high, but responses concerning ageing, prevalence and everyday functioning were more mixed (Table 3).

Table 3. Understanding of dementia: responses to knowledge statements

Survey statement	**True n (%)**	**False n (%)**	**Not sure n (%)**	**Answer not provided**
1. The majority of people over the age of 80 have dementia.	138 (53.3)	90 (34.7)	27 (10.4)	4
2. Persons with dementia develop physical and mental problems.	203 (78.4)	37 (14.3)	14 (5.4)	5
3. Alzheimer's disease the most common form of dementia.	175 (67.6)	32 (12.4)	48 (18.5)	4
4. Trouble handling money or paying bills is a common early symptom of dementia.	167 (64.5)	64 (24.7)	24 (9.3)	4
5. The major symptom of dementia is memory loss (e.g. forgetfulness).	225 (86.9)	21 (8.1)	9 (3.5)	4
6. Dementia is caused by a disease of the brain.	190 (73.4)	42 (16.2)	22 (8.5)	5
7. Dementia is a form of insanity.	61 (23.6)	158 (61.0)	35 (13.5)	5

Survey statement	True n (%)	False n (%)	Not sure n (%)	Answer not provided
8. Dementia can be inherited, or passed down through families.	142 (54.8)	75 (29.0)	36 (13.9)	6
9. Dementia is natural part of aging, like greying of hair or wrinkles	91 (35.1)	131 (50.6)	33 (12.7)	4
10. People with dementia cannot drive.	154 (59.5)	66 (25.5)	33 (12.7)	6
11. There is currently no cure for dementia	184 (71.0)	30 (11.6)	41 (15.8)	4
12. Elderly men are more likely to develop dementia than elderly women.	111 (42.9)	93 (35.9)	50 (19.3)	5
13. The majority of people that suffer from dementia live in institutions, like care home.	106 (40.9)	110 (42.5)	39 (15.1)	4
14. Dementia can be diagnosed with a blood test.	74 (28.6)	113 (43.6)	67 (25.9)	5
15. Dementia can be diagnosed in a memory clinic at hospital.	192 (74.1)	26 (10.0)	35 (13.5)	6
16. Early detection of dementia increases the chance to treat the disease better.	196 (75.7)	26 (10.0)	33 (12.7)	4

Most respondents identified memory loss as a major symptom of dementia (86.9%, n = 225), while 73.4% (n = 190) recognised dementia as being caused by a disease of the brain. Nearly two-thirds (64.5%, n = 167) identified difficulties handling money or paying bills as a possible early symptom. Furthermore, 71.0% (n = 184) recognised that there is currently no cure for dementia, and 75.7% (n = 196) agreed that early detection could improve opportunities for treatment. A similar proportion (74.1%, n = 192) identified hospital memory clinics as a setting where dementia can be diagnosed.

However, misconceptions about dementia and ageing remained evident. More than half of respondents (53.3%, n = 138) believed that the majority of people over the age of 80 have dementia, while a further 10.4% (n = 27) were unsure. Over one-third (35.1%, n = 91) regarded dementia as a natural part of ageing, with an additional 12.7% (n = 33) expressing uncertainty. Responses also indicated misconceptions concerning the nature of dementia and the independence of people living with the condition. Nearly one-quarter (23.6%, n = 61) believed that dementia is a form of insanity, while 13.5% (n = 35) were unsure. A majority (59.5%, n = 154) agreed with the statement that people with dementia cannot drive, and 40.9% (n = 106) believed that most people living with dementia reside in institutions such as care homes. These

responses suggest that recognising dementia as a medical condition does not necessarily correspond to an accurate understanding of its prevalence, progression or implications for everyday life. The statement about driving, however, requires cautious interpretation, as driving ability depends on individual circumstances and the progression of the condition, rather than dementia diagnosis alone.

Attitudes towards dementia and help-seeking

Respondents expressed a range of anticipated attitudes towards dementia, including concerns about stigma, disclosure, social judgement and the potential impact of a diagnosis on family relationships (Table 4).

Table 4. Attitudes towards dementia and confidence in obtaining support

Survey statement	**Agree n (%)**	**Disagree n (%)**	**Answer not provided**
1. If I had dementia, I would not want my family to know.	69 (26.6)	184 (71.0)	6
2. If I had dementia, I would not want my community (e.g. colleagues, neighbour, friends) to know.	80 (30.9)	174 (67.2)	5
3. If I had dementia I would be depressed.	156 (60.2)	95 (36.7)	8
4. If I had dementia I would be ashamed and embarrassed.	95 (36.7)	158 (61.0)	6
5. If I had dementia I would be feel ashamed as I bring burden to my family.	128 (49.4)	125 (48.3)	6
6. If I had dementia I would no longer be taken seriously.	137 (52.9)	114 (44.0)	8
7. If had dementia I would be considered stupid and unable to do things.	119 (45.9)	135 (52.1)	5
8. I would be willing to seek help from health professional if I suspect my family member or myself have dementia.	227 (87.6)	27 (10.4)	5
9. Do you feel confident about finding clinical, financial and social care help to support someone with dementia.	137 (52.9)	116 (44.8)	6

These questions explored different dimensions of anticipated stigma and attitudes towards dementia rather than measuring stigma through a validated scale. While most respondents disagreed that they would conceal a dementia diagnosis from their family, 26.6% (n = 69) indicated that they would not want family members to know. A slightly higher proportion (30.9%, n = 80) reported that they would not want people in their wider community, including friends, neighbours or colleagues, to know about their diagnosis.

Concerns about potential stigma and negative social judgement were more common than an expressed intention to conceal a diagnosis. Approximately half of respondents (49.4%, n = 128) agreed that they would feel ashamed about becoming a burden to their family. More than half (52.9%, n = 137) anticipated that they would no longer be taken seriously if they developed dementia, while 45.9% (n = 119) believed that they would be considered stupid or unable to perform everyday activities. Despite these concerns, willingness to seek professional help was high. Most respondents (87.6%, n = 227) agreed that they would seek help from a healthcare professional if they suspected that they or a family member had dementia.

However, confidence in finding available support was less widespread. While 52.9% (n = 137) reported feeling confident about finding clinical, financial and social care support for someone living with dementia, 44.8% (n = 116) did not. These findings show relatively high stated willingness to seek professional help alongside considerable uncertainty about finding practical support. The survey measured anticipated attitudes and intentions rather than actual help-seeking behaviour, and the descriptive analysis did not establish whether these responses were associated at the individual level.

Perceived dementia information needs

In addition to assessing factual knowledge, the survey asked respondents whether they felt they had sufficient awareness, understanding or information about dementia symptoms, diagnosis and available support (Table 5).

Table 5. Dementia experience, perceived information sufficiency and language preference

Survey question	Yes n (%)	No n (%)	Answer not provided
1. Has anyone you have known well had dementia?	123 (47.5)	132 (51.0)	4
2. Have you ever cared for a family member or friend with dementia?	71 (27.4)	184 (71.0)	4
3. Have you heard of dementia from the media?	194 (74.9)	60 (23.2)	5
5. Do you think you have enough awareness/ understanding/ information about dementia symptoms?	86 (33.2)	169 (65.3)	4

Survey question	Yes n (%)	No n (%)	Answer not provided
6. Do you think you have enough awareness/understanding/information about how to diagnose dementia?	52 (20.1)	202 (78.0)	5
7. Do you think you have enough awareness/understanding/information about how to seek medical, financial and social care support)?	82 (31.7)	173 (66.8)	4
8. Would you be happy to receive more dementia awareness materials in your preferred language?	190 (73.4)	65 (25.1)	4

These questions captured respondents' perceptions of their information needs rather than their actual ability to navigate dementia services. Substantial perceived information gaps were reported across all three areas. Approximately two-thirds (65.3%, n = 169) felt that they did not have sufficient awareness, understanding or information about dementia symptoms. A larger proportion (78.0%, n = 202) reported insufficient information about how dementia is diagnosed. Similarly, 66.8% (n = 173) considered themselves insufficiently informed about how to obtain medical, financial and social care support.

Information relating to dementia diagnosis represented the most frequently reported area of perceived insufficiency. Although a substantial proportion of respondents recognised memory clinics as a setting where dementia can be diagnosed, an even larger proportion felt that their overall understanding of dementia diagnosis was insufficient. These findings distinguish recognition of specific information about diagnosis from respondents' broader perceptions of their information needs. The survey did not establish which aspects of the diagnostic process were least understood. Respondents also reported different levels of personal experience with dementia. Nearly half (47.5%, n = 123) indicated that someone they knew well had dementia, while 27.4% (n = 71) had previously cared for a family member or friend with the condition.

Information sources and communication preferences

Respondents reported accessing dementia-related information through a range of healthcare, digital, interpersonal and community sources (Table 6).

Table 6. Reported sources of dementia information (multiple responses)

Information source	n (% of 253)
NHS website (e.g. nhs.uk)	141 (55.7)
Government website (e.g. GOV.UK)	75 (29.6)
My local council website	47 (18.6)
TV/Radio	97 (38.3)

Information source	n (% of 253)
Newspaper/Online news websites	62 (24.5)
Social Media (Facebook, WhatsApp)	99 (39.1)
Friends/relatives	111 (43.9)
GP practice, pharmacy, clinic or hospital	93 (36.8)
Letter, leaflet or poster	58 (22.9)
Community organisations (Belgrave neighbourhood centre, Caribbean court)	60 (23.7)
A person with dementia or their family/friends	93 (36.8)
Other	11 (4.3)
Can't recall	16 (6.3)

Note: Percentages are based on the 253 respondents who answered this question; six respondents had no recorded response. Multiple responses were permitted; therefore, percentages do not sum to 100%.

Nearly three-quarters (74.9%, n = 194) reported having heard about dementia through the media. Among the 253 respondents who answered the question about information sources, the National Health Service (NHS) website was the most frequently selected source (55.7%, n = 141), followed by friends and relatives (43.9%, n = 111), social media platforms such as Facebook and WhatsApp (39.1%, n = 99), and television or radio (38.3%, n = 97). Healthcare settings, including GP practices, pharmacies, clinics and hospitals, were selected by 36.8% (n = 93). The same proportion reported obtaining information from people living with dementia or their families and friends. Community organisations, including neighbourhood and community centres, were identified by 23.7% (n = 60), while local council websites were selected by 18.6% (n = 47).

These findings show that respondents encountered dementia information through both formal healthcare sources and wider interpersonal, media and community channels. However, the frequency with which sources were selected does not establish how regularly they were used or how much respondents trusted the information received. Respondents also expressed considerable interest in receiving additional dementia information. Nearly three-quarters (73.4%, n = 190) indicated that they would welcome further dementia awareness materials in their preferred language. When asked about approaches to improving dementia awareness, 185 respondents selected at least one option (Table 7).

Table 7. Preferred approaches for dementia awareness promotion (multiple responses)

Suggested approach	n (% of 185)
Organise dementia awareness talks by doctors who speak my language.	130 (70.3)
Organise dementia awareness talks at religious venues such as mosques.	92 (49.7)
Organise dementia awareness talks at community activity (Hindu Navaratri dance) venues.	88 (47.6)
Be given dementia leaflets translated in my language (e.g. Gujarati, Hindi)	99 (53.5)
Be given dementia information on social media platforms (e.g. WhatsApp group)	92 (49.7)
Other	7 (3.8)

Denominator = 185 respondents recorded as answering this conditional question (74 did not respond). Question wording: "If you answer any 'no', do you have any suggestion on how to promote awareness/understanding about dementia?" Percentages do not sum to 100%.

Note: Percentages are based on the 185 respondents who provided responses to this question. The question was phrased as a follow-up for respondents who had answered 'No' to an earlier question about dementia awareness or information sufficiency. Multiple responses were permitted; therefore, percentages do not sum to 100%.

The following percentages refer to this subset rather than the full survey sample. The most frequently selected approach was awareness talks delivered by doctors who spoke participants' preferred language (70.3%, n = 130), followed by translated dementia information leaflets (53.5%, n = 99). Awareness talks organised at religious venues and information shared through social media platforms such as WhatsApp were each selected by 49.7% (n = 92). Community activities and events were also identified as potentially suitable settings for dementia awareness talks (47.6%, n = 88). These preferences indicate interest in a combination of professional-led education, language-appropriate materials, digital information and face-to-face activities in established community settings. Although they do not demonstrate the effectiveness of particular approaches, they identify potential communication methods that could be explored further with local communities and healthcare providers.

Discussion

Dementia awareness and understanding: Beyond symptom recognition

This community-based survey of 259 respondents from minority ethnic communities in Leicester and Leicestershire provides insights into dementia knowledge, attitudes, perceived information needs and communication preferences. Three findings are particularly important. First, recognition of familiar dementia symptoms was relatively high, yet misconceptions about ageing

and everyday life with dementia remained evident. Second, many respondents reported insufficient information about dementia diagnosis and available support, despite considerable willingness to seek professional help. Third, respondents encountered dementia information through multiple formal and informal sources and expressed preferences for multilingual, professionally informed and community-based approaches to improving awareness.

These findings suggest that dementia awareness should not be understood simply in terms of recognising symptoms or knowing basic facts about the condition. Understanding the diagnostic process, knowing how to find support and recognising the stigma surrounding dementia are also important dimensions of awareness. Drawing on the socio-ecological model (Ewald et al., 2023; Sallis et al., 2008; Stokols, 1996), the findings can be considered in relation to individual knowledge and attitudes, interpersonal and community relationships, and the wider organisation of health information and services. Although the survey does not directly examine interactions between these levels, the framework provides a useful perspective for considering how dementia awareness and information needs are situated within a broader social and communication environment.

Previous research has identified gaps in dementia knowledge, misconceptions about ageing and barriers to recognising the need for professional assessment among minority ethnic communities in the UK (Berwald et al., 2016; Hossain & Khan, 2020). Our findings are consistent with this literature, while providing locally grounded evidence of different aspects of dementia knowledge and understanding. Although most respondents recognised memory loss as a common symptom, misconceptions about dementia and ageing remained noticeable. Responses concerning everyday functioning also suggested generalised assumptions about the independence and capabilities of people living with dementia.

At the individual level of the socio-ecological model, these findings highlight the importance of addressing misconceptions alongside improving factual knowledge. Awareness initiatives should extend beyond symptom recognition to explain the nature of dementia, its progression and its different effects on individuals. In particular, communication that presents dementia primarily through decline and incapacity may reinforce misconceptions and negative expectations about life with the condition. More balanced information could help people recognise dementia symptoms while challenging assumptions about an immediate or complete loss of independence.

Understanding diagnosis and finding support

A particularly important finding is the distinction between recognising where dementia can be diagnosed and feeling sufficiently informed about the diagnostic process. Although 74.1% of respondents identified memory clinics as a setting where dementia can be diagnosed, 78.0% reported insufficient information or understanding about dementia diagnosis. While these aggregate findings do not establish a relationship between individual responses, they suggest that familiarity with particular aspects of diagnosis may coexist with broader uncertainty about the process. This has implications for dementia awareness initiatives, which often emphasise symptom recognition and encourage timely help-seeking. Such messages are important, but they may be insufficient if individuals remain unclear about what happens after seeking professional advice. Clearer information is needed about how to raise concerns with healthcare professionals, how dementia assessments and referrals work, what a diagnosis may involve and where to find support afterwards.

A similar distinction emerges between willingness to seek professional help and confidence in finding support. Although 87.6% of respondents expressed willingness to consult a healthcare professional if they suspected dementia, 44.8% did not feel confident about finding clinical, financial and social care support. Seeking professional advice and navigating the wider support system involve different information needs and potentially different challenges. The latter may require individuals and families to identify relevant services, understand eligibility and referral arrangements, and obtain information from several healthcare, social care and voluntary-sector organisations.

These findings are consistent with previous research identifying practical, institutional and informational barriers to accessing dementia services (Leone et al., 2025; Peel & Harding, 2014; Wheatley et al., 2021). They also complement findings from the interview component of the wider research project, in which family carers described difficulties finding accessible and culturally appropriate dementia information and support (Gong et al., under review). While the survey identifies perceived information gaps among community members, the interview findings provide further insight into how information and communication difficulties may be experienced when families seek and navigate dementia services.

From a socio-ecological perspective, information needs extend beyond the individual level to the institutional and wider service environment. Individuals may be willing to seek professional advice but still encounter difficulties identifying appropriate services or understanding how different forms of support are connected. Improving dementia communication therefore requires attention not only to what people know, but also to how information is organised, communicated and made accessible across services. Clearer signposting and better coordination between healthcare, social care and community organisations could help individuals and families obtain relevant information as their needs change.

Stigma, social judgement and help-seeking

The findings also reveal important concerns about stigma and the anticipated ways in which individuals might be perceived and treated if they developed dementia. Respondents were more likely to express concerns about no longer being taken seriously (52.9%) or feeling ashamed about becoming a burden to their families (49.4%) than to indicate an intention to conceal a diagnosis from family members (26.6%) or the wider community (30.9%). These responses suggest that concerns about dementia extend beyond embarrassment or disclosure to include expectations of diminished social standing, negative judgement and changes in family relationships.

Stigma is not simply an individual attitude but a social process through which particular characteristics become associated with negative stereotypes, social devaluation and potential discrimination (Link & Phelan, 2001). In dementia research, a distinction is commonly made between public stigma, involving negative stereotypes and discriminatory attitudes towards people living with dementia, and self-stigma, in which individuals internalise negative societal beliefs about the condition (Nguyen & Li, 2020). These dimensions may also influence how individuals anticipate being treated by others. Our findings are particularly relevant to anticipated stigma. Respondents' concerns about being dismissed, regarded as incapable or becoming a family burden suggest an awareness of negative social expectations surrounding dementia. These concerns may arise even before individuals or families have direct experience of the condition. However, as the survey asked respondents how they thought they would feel or

behave if they developed dementia, the findings should not be interpreted as evidence of experienced discrimination or internalised stigma among people living with dementia.

The socio-ecological model is a useful theoretical framework but has not been widely used in health communication research. In particular, previous research has not combined analyses across multiple levels of the socio-ecological model or considered the interactions between these levels and their impact on health information seeking. This study therefore makes a unique contribution in this respect. The socio-ecological model helps situate these concerns within wider interpersonal and community contexts. At the individual level, anticipated stigma may involve shame, embarrassment or concerns about losing independence. At the interpersonal level, expectations about family responsibilities and relationships may influence attitudes towards disclosure and seeking support. At the community level, wider beliefs about ageing, cognitive impairment and dementia may contribute to negative stereotypes and concerns about social judgement and consequently to delays in seeking help about dementia. Community understanding and perceptions of dementia play an important role in shaping individual attitudes and beliefs. Negative stereotypes and stigma surrounding dementia may be reinforced through social relationships, community beliefs and wider representations of the condition in society.

Despite these concerns, most respondents expressed willingness to seek professional help if they suspected dementia in themselves or a family member. This is important because anticipated stigma does not necessarily indicate reluctance to seek professional help. The findings suggest that concerns about how people might be treated and positive attitudes towards professional help-seeking can both be prominent within the same surveyed population. These findings have implications for how dementia is represented and discussed in awareness initiatives. Communication that focuses predominantly on decline, incapacity or family burden may reinforce negative stereotypes and expectations about living with dementia. Beyond providing factual information, awareness initiatives could seek to challenge stigmatising representations, encourage more open discussions and promote respect for the dignity, individuality and continuing capabilities of people living with dementia. Addressing stigma is therefore an important part of dementia communication, alongside improving knowledge and awareness of available services.

Information sources and preferences for dementia communication

The findings provide further insight into the information environment through which community members encounter dementia-related information. Respondents reported accessing information through healthcare websites, healthcare professionals, social media, interpersonal relationships and community organisations. The NHS website was the most frequently selected source, but friends and relatives, social media, traditional media and healthcare settings also featured prominently. These findings point to a complex health information ecology, in which dementia information is available through multiple, potentially interconnected sources rather than a single provider or communication channel. Individuals and families may encounter dementia information through everyday conversations, social media and community networks, while also consulting formal healthcare sources. Different channels may serve different information needs, including raising initial awareness, interpreting symptoms, seeking reassurance and identifying sources of professional advice and support.

Although the survey did not directly examine how respondents moved between different information sources, the range of reported channels suggests the importance of considering

dementia communication as a process involving multiple sources and forms of engagement. Official healthcare websites, such as the NHS website, can provide clinically informed information about symptoms, diagnosis and services, while interpersonal networks and social media offer opportunities for information to be circulated, discussed and interpreted within everyday social relationships. Platforms such as WhatsApp, for example, may facilitate the sharing of dementia information through existing family and community networks. However, the availability of multiple information sources also raises questions about the consistency, reliability and accessibility of the information provided. Effective dementia communication requires more than increasing the volume of available information. Trustworthy sources should be better connected and coordinated so that individuals and families can move more easily from general awareness information to reliable medical advice and appropriate practical support. Healthcare services, local authorities and community organisations could work collaboratively to ensure that information communicated through different channels is accurate, consistent and clearly linked to relevant services.

Respondents' preferences for future dementia awareness activities provide further insight into how such communication might be developed. Among those who answered the follow-up question, talks delivered by doctors who spoke their preferred language were the most frequently selected approach, followed by translated information leaflets, talks in religious settings, social media information and awareness activities in community venues. These preferences highlight the potential importance of combining professional expertise with language accessibility and engagement in familiar community settings. Multilingual talks delivered by healthcare professionals could provide opportunities not only to communicate medical information but also to answer questions and address misconceptions. Religious and community venues may offer accessible settings for face-to-face discussion, while translated materials and digital platforms could provide additional opportunities to access and share information.

The socio-ecological model is particularly useful here because information seeking and communication extend across individual, interpersonal, community and institutional levels. Healthcare professionals can provide clinical expertise, while families and social networks may influence how information is interpreted and shared. Community organisations can help identify appropriate languages, communication formats and settings, while institutions and service providers have a role in ensuring that accurate information and support are accessible. This suggests the value of a multi-channel approach in which different organisations contribute complementary forms of expertise and engagement. Rather than developing separate awareness initiatives in isolation, collaboration between healthcare providers and community organisations could support a more connected communication approach, linking community-based awareness activities to reliable healthcare information and appropriate service pathways. Nevertheless, respondents' stated preferences should be interpreted as possible approaches for further development, rather than evidence of intervention effectiveness. Future research would need to examine the accessibility, acceptability and effectiveness of these approaches within different communities.

Implications for local practice

The demographic characteristics of Leicester and Leicestershire provide an important context for interpreting these findings. The sample included respondents with varied migration backgrounds, lengths of residence in the UK and language preferences. Although a majority were born outside the UK, more than half reported living in the UK for over 30 years. English was the most

frequently reported preferred language, followed by Gujarati, while nearly three-quarters expressed interest in receiving additional dementia awareness materials in their preferred language. These characteristics highlight the diversity of backgrounds and communication preferences within the surveyed population. Ethnic background alone does not fully capture differences in migration experiences, language preferences or information needs. They also suggest that culturally responsive communication should not be reduced to translating existing information into different languages. While language accessibility remains important, initiatives also need to consider the relevance of their content, the format in which information is presented and the sources through which it is communicated.

For local dementia communication, the findings suggest two closely related priorities: improving the content and practical usefulness of information, and developing accessible and coordinated approaches to communicating it. First, information should extend beyond general symptom awareness to explain how dementia diagnosis works and what medical, financial and social care support may be available. Guidance on recognising symptoms, seeking an assessment and accessing subsequent support could be presented as connected stages of an information pathway, with clear signposting between relevant services. Such information should also address common misconceptions and stigma, including negative assumptions about ageing, dependence and the capabilities of people living with dementia. Second, the delivery of this information should reflect the communication preferences and social contexts of local communities. Multilingual talks, translated materials, community-based awareness activities and digital communication could be used in complementary ways rather than as separate initiatives. Collaboration between healthcare providers, local authorities and community organisations could help ensure that information is clinically accurate, culturally and linguistically accessible, and connected to appropriate sources of further advice and support.

The socio-ecological perspective reinforces the importance of these complementary approaches. Individual knowledge and attitudes can be addressed through accessible information and education, while interpersonal and community-level engagement can provide opportunities for discussion and challenge misconceptions and stigma. At the institutional level, coordination between services and information providers can help ensure that people are directed towards appropriate support. Future research could involve community members, healthcare professionals and voluntary-sector organisations in co-designing dementia communication materials and activities, followed by evaluations of their accessibility, acceptability and effectiveness. This would help establish whether locally preferred approaches improve dementia understanding, reduce stigma and increase confidence in seeking information and support.

Conclusion

This study examined dementia awareness, understanding, attitudes and information needs among minority ethnic community members in Leicester and Leicestershire. The findings show that while many respondents recognised common dementia symptoms and expressed willingness to seek professional help, misconceptions about dementia and ageing remained. Concerns about stigma, negative social judgement and becoming a burden to family members were also evident. Substantial proportions of respondents reported insufficient information about dementia diagnosis and available support, highlighting the need to move beyond general dementia

awareness towards providing practical information and guidance. An important strength of this study is its community-based approach. Participants were recruited through a range of community settings, and questionnaires were available in English, Gujarati and Hindi, in both paper and digital formats. Face-to-face recruitment and assistance from multilingual research assistants helped make the survey more accessible to people with different language and literacy needs. The recruitment process also highlighted the challenges of engaging diverse communities and the time required to develop trust and relationships.

Several limitations should be acknowledged. The use of purposive and convenience sampling means that the findings cannot be considered representative of all minority ethnic communities in Leicester and Leicestershire. Recruitment through community organisations, public spaces and online networks may have been more likely to reach people already connected to these settings. Although the questionnaire was available in three languages, it may not have accommodated the language needs of all potential participants. Responses were self-reported, and anticipated attitudes and intentions to seek professional help may not reflect actual experiences or behaviour. The descriptive analysis also did not examine associations between demographic characteristics, knowledge, attitudes and information needs. In addition, the stigma-related questions were not part of a validated stigma scale and cannot establish respondents' experiences of discrimination. Future research could investigate these relationships and explore how knowledge, stigma and information needs vary across different community groups.

Despite these limitations, the study provides locally grounded evidence to inform dementia communication. Viewed through a socio-ecological perspective, improving dementia awareness involves more than addressing individual knowledge gaps. It also requires attention to the social stigma surrounding dementia, the role of family and community networks, and the accessibility and coordination of information across healthcare and support services. Respondents' preferences for multilingual doctor-led talks, translated materials and community-based awareness activities offer practical approaches for future development and evaluation. Greater collaboration between healthcare providers, local authorities and community organisations could help ensure that dementia information is accurate, accessible and useful to individuals and families when they need it.

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Competing interests

The author(s) declared no competing interests.

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