Attitudes to dementia:
Scottish Social Attitudes Survey 2014

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The Scottish Social Attitudes (SSA) survey was launched by ScotCen Social Research in 1999 to provide robust data on changing public attitudes in Scotland. This report uses SSA data from 2014 to explore attitudes to dementia in Scotland and establishes a baseline from which change in future years can be assessed. The research was commissioned by Life Changes Trust and Joseph Rowntree Foundation.

Main Findings

- More than three-quarters (76%) of people in Scotland said they ‘know someone’ with dementia, almost 4 in 10 (38%) said a ‘partner or member of my family’ had dementia, and 1 in 6 (17%) that ‘a friend they know fairly well’ had dementia. Almost 1 in 6 (16%) of people said that their ‘job involves / involved working with people who have dementia’. Women were more likely than men to say they had experience of people with dementia through their work (21% of women compared to 11% of men).
- Around 1 in 5 people (19%) in Scotland have given regular care to someone with dementia either by caring for someone who lived with
them (8%) or by caring for someone on a regular basis who did not live with them (12%).

- More than 4 in 10 people (43%) said they knew ‘a great deal / quite a lot’ about dementia. This figure was particularly high for those who had cared regularly for someone with dementia (74%), for those whose job involved working with dementia (73%), and for those who had a family member or close friend with dementia (54%).

- People in Scotland have low levels of knowledge about how to reduce the likelihood of developing dementia. Just 3% of people correctly identified five risk factors for dementia (high blood pressure, heavy drinking, genetic factors, smoking and diet). 45% identified either none (21%) or one (24%) of the five risk factors correctly.

- Most people have positive attitudes towards people with dementia. Around 7 in 10 people (69%) disagreed that ‘I would find it hard to talk to someone with dementia’ and over 6 in 10 (61%) agreed that ‘someone with dementia can still live life to the full’.

- There is evidence of prejudice and fear, as well as stigmatising attitudes among a small minority of people. For example, around one in five people (19%) said ‘I would find it hard to talk to someone with dementia’ and around one in eight (12%) said ‘I would feel ashamed’ if given a diagnosis of dementia. Two in five people (39%) said they would not want their employer to know if they were diagnosed with dementia.

- If someone close to them was showing early signs of dementia, nearly 4 in 10 (39%) said they would ‘talk to a family member or friend’, 3 in 10 (30%) that they would ‘talk to the person themselves’ and around a quarter (23%) that they would talk to ‘a doctor or nurse’ in the first instance.

- Around two-thirds of people (65%-69%) thought that in the case of mild dementia, the person’s family and friends should provide most of the care. Only a small proportion (5%-22%) thought that this was appropriate for someone with severe dementia.

- Around 9 in 10 (89%) said they would be willing to help a neighbour who had mild dementia while around 8 in 10 (80%) would be willing to help a neighbour with a more severe form of dementia.

- Two-thirds of people (66%) chose dementia as their highest or second highest priority for more government spending on care and support. Almost 4 in 10 people (38%) chose dementia as their highest or second highest priority for more government spending on prevention.
Introduction

This summary report presents an analysis of the main findings in relation to three broad questions relating to public attitudes to dementia in Scotland:

- What is the Scottish public’s understanding, experience and knowledge of dementia?
- What are the public’s attitudes towards people with dementia, and how do they think people with dementia should be supported?
- Which factors differentiate the knowledge, views, experience and attitudes of different groups?

The analysis is based on data collected on the Scottish Social Attitudes (SSA) survey between May and September 2014.

Large numbers of people in Scotland are aware of, and are affected by, dementia

More than three-quarters (76%) of people in Scotland said that they ‘know someone’ who has (or had) dementia, almost 4 in 10 (38%) that a ‘partner or a member of my family’ had (or has had) dementia, 1 in 6 (17%) that ‘a friend they know fairly well’ had (or has had) dementia and 1 in 6 (16%) that their ‘job involves/involved working with people who have dementia’. Women were more likely than men to say they had experience of people with dementia through their work (21% of women compared to 11% of men).

The numbers of people who have been involved in caring for someone with dementia were also fairly high. Around 1 in 5 people (19%) in Scotland had given regular care to someone with dementia either by caring for someone who lived with them (8%) or by caring on a regular basis for someone who did not live with them (12%).

These high levels of ‘exposure’ to dementia translate into fairly high levels of self-assessed knowledge of dementia

More than 4 in 10 people (43%) said they knew either ‘a great deal’ or ‘quite a lot’ about dementia. Self-assessed knowledge was particularly high for those who had cared regularly for someone with dementia (74% said they knew ‘a great deal’ or ‘quite a lot’), whose job involved working with people with dementia (73% said they knew ‘a great deal’ or ‘quite a lot’), or who had a family member or close friend with dementia (54% said they knew ‘a great deal’ or ‘quite a lot’). It is notable that much of this knowledge about dementia was gained through personal experience (over 2 in 5 said this was their main source of learning); work, the media, and ‘word of mouth’ were each identified by around 1 in 6 people as their main source of learning.
Knowledge of how to reduce the likelihood of developing dementia is low

SSA 2014 showed that there is a disconnect between how much people thought they knew about dementia (as indicated by their level of self-assessed knowledge) and how much they actually knew about a range of risk factors for dementia. This suggests that work needs to be done in informing and educating the public about how to minimise the risk of developing dementia or delaying the onset of dementia.

People were asked about risk factors for dementia in relation to heavy drinking, genetic factors, smoking, diet, and high blood pressure\(^1\). In each case only between about a quarter and a half of people correctly identified the risk factor. Overall, just 3% of people identified all five risk factors correctly, with almost one-half (45%) identifying either none (21%) or one (24%) factor correctly. The average number of correct answers given was 1.86. Even among those who said they knew ‘a great deal’ or ‘quite a lot’ the average number of correct answers was only slightly higher (2.23 for those who knew ‘a great deal’ and 2.04 for those who knew ‘quite a lot’). This suggests that any educational initiatives should be targeted at the whole population.

Knowledge of high blood pressure as a risk factor for dementia is particularly low.

High blood pressure is an important risk factor especially in relation to vascular dementia. This was correctly identified as a risk factor by just 22% of people. Even amongst the best performing subgroup (those who have cared for someone on a regular basis) less than a third of people (31%) correctly identified high blood pressure as a risk factor for dementia. This suggests that a focus on educating people about the importance of maintaining a healthy blood pressure is particularly important in terms of dementia prevention.

Most people have positive attitudes towards people with dementia

A substantial majority of people hold positive attitudes towards people with dementia, and do not see it as a stigmatising condition. Around 7 in 10 people (69%) disagreed that ‘I would find it hard to talk to someone with dementia’; over 6 in 10 (61%) agreed that ‘someone with dementia can still live life to the full’ and 83% agreed that they would ‘want their family and friends to know’ if they had just been told they had the first signs of dementia. This may in part be related to the high proportion of people in Scotland who know someone with dementia (76%). Previous evidence has shown that people were less likely to hold discriminatory attitudes towards people from particular groups if they knew someone from that group (Ormston, 2011).

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\(^1\) All these five factors are known risk factors for dementia.
There is evidence of prejudice and fear, as well as stigmatising attitudes towards people with dementia amongst a small minority of respondents.

Whilst many people hold positive attitudes towards people with dementia there is also evidence of prejudice and fear, as well as stigmatising attitudes towards people with dementia amongst a small minority. In particular: around one in five people said ‘I would find it hard to talk to someone with dementia’ (19%), around one in eight people said ‘I would feel ashamed’ if given a diagnosis of dementia (12%) and most extreme perhaps, one in twelve people (8%) ‘would not want their family and friends to know’ if they were diagnosed with dementia.

These stigmatising attitudes are slightly more likely to be found amongst those who do not know anyone with dementia, or whose self-assessed knowledge of dementia is low; by contrast stigmatising attitudes are slightly less likely to be held by those who know someone well who has dementia, whose work involves people with dementia, or whose self-assessed knowledge is high.

There is a fairly widespread view that people would not tell their employer about a diagnosis of dementia.

In addition to the stigmatising attitudes put forward by a relatively small number of respondents, there is a wider view held by two in five people (39%) that they would not want their employer to know if they were diagnosed with dementia. This view was uniformly held across all social, demographic, experiential and knowledge groups. This suggests that there is more to be done to build confidence that employers would act fairly in this situation.

It is vital that the population at large - and not just health care professionals - understand how to respond if someone shows the first signs of dementia.

The sources of help that people identified as the most relevant and helpful if they were worried about themselves or someone close to them developing the early signs of dementia were by and large family, friends and healthcare professionals. Only small numbers would seek help from the internet, a helpline or support group. Almost a third of people (30%) would talk to the person showing early signs of dementia in the first instance. From this, we conclude that it is vital that there is wide understanding amongst the population at large of how to respond if someone close to them is looking for help. The reaction which
is given in the first instance may be influential in determining whether the individual makes contact with services that could provide appropriate help.

There is a strong indication that people wish to see more ‘dementia friendly’ communities and are prepared to play a part in this

There is a great deal of willingness to help those with dementia. Around 9 in 10 (89%) said they would be willing to help a neighbour with mild dementia while around 8 in 10 (80%) would be willing to help a neighbour with a more severe form of dementia. There was also broad support for the idea that there should be a legal obligation for businesses to support people with dementia in a range of different situations, with 6 in 10 (59%) agreeing that ‘employers should have a legal duty to help people with dementia keep working for as long as possible’, 7 in 10 (72%) agreeing that ‘shopkeepers should have a legal duty to train their staff to help people with dementia’ and almost 9 in 10 (88%) agreeing that ‘banks should have a legal duty to make sure people with dementia get help in managing their finances’.

People in Scotland think that dementia is a high priority for more government spending on care and support and also on prevention

Two-thirds of people (66%) chose dementia as their highest or second highest priority for more government spending on care and support; this was a higher figure than for any of the other conditions listed (cancer, depression, stroke, heart disease and obesity). As far as prevention was concerned, 38% chose dementia as their highest or second highest priority, second only to cancer (68%).

A ‘mixed economy’ for funding and giving of care is thought to be appropriate

A majority of people in Scotland are of the view that care for people with dementia – whether that care is provided in their home or whether it is in a residential home – should be paid for by the government. Means testing was thought to be appropriate by a third of people (32%) in relation to residential care and by 42% of people in relation to paid care at home. In terms of who should be responsible for giving the care, around two-thirds of people (65%-69%) thought that in the case of mild dementia, the person’s family and friends should provide most of the care, whereas only a small proportion (5%-22%) thought that this was appropriate for someone with severe dementia. This suggests that a ‘mixed economy’ for funding and giving of care is preferred with a strong leaning towards the government taking responsibility for both funding
and giving of care where someone has severe dementia, but with much more financial and practical input from families (and friends) being expected where someone has mild dementia. This implies a strong social expectation on families to provide care regardless of their own individual circumstances.

Conclusions

In addition to the conclusions discussed above, the findings from SSA 2014 have highlighted a range of specific areas where further work is required:

- More needs to be done to inform and educate the public about how to minimise the risk of developing dementia or delay the onset of dementia.
- There is a particular requirement to focus on educating people about the importance of maintaining a healthy blood pressure.
- Any educational initiatives should be targeted at the whole population rather than focussing on specific subgroups.
- The widespread reluctance to tell an employer about a diagnosis of dementia suggests that there is more to be done to build confidence that employers would act fairly in this situation.
- Given that many people would talk to their friends and family in the first instance if they thought they were showing the first signs of dementia, it is vital to build greater understanding amongst the population at large of how to respond if someone close to them is looking for help.

Methodology

The Scottish Social Attitudes survey involves c. 1,200 to 1,500 interviews annually, with respondents selected using random probability sampling to ensure that the results are robust and representative of the Scottish population. The 2014 survey, which was conducted between May and September 2014, involved 1,501 face-to-face interviews.