Research Update

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Dementia: public knowledge and attitudes

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Introduction

Dementia is the term which is used to describe a group of conditions that affect the brain and cause a progressive decline in the ability to think, remember and learn. It is an issue of global, national and regional concern, since it is estimated that there are 36 million people worldwide living with dementia, and that this will double every twenty years to 66 million by 2030 (ADI, 2011). There are approximately 750,000 people living with dementia in the United Kingdom (UK) in 2011 and this is set to increase to over a million by 2021 (Alzheimer's Research Trust, 2010).

Closer to home, there are approximately 19,000 people living with dementia in Northern Ireland. This is estimated to be 60,000 by 2051, which is the fastest expected rate of increase in the UK (DHSSPSNI, 2010). Significantly, Northern Ireland is awaiting the outcome of Ministerial decision in relation to the draft dementia strategy, *Improving Dementia Services in Northern Ireland*, which was the subject of public consultation in 2010.

It was very timely, therefore, that the 2010 **Northern Ireland Life and Times (NILT) Survey** included a module of questions exploring attitudes and knowledge of dementia. This Research Update is based on these survey results.

Knowledge of dementia

Given the statistics highlighted above, it is not surprising that nearly one half of NILT respondents (45%) said that they knew someone with dementia. This varied by age, with just under one quarter of those aged 18-24, knowing someone with dementia (23%), compared with one half of those aged 65 years or over. The figures shown in Table 1 indicate that the public has a wide range of understanding of what dementia is. The vast majority of NILT respondents (94%) thought that dementia is a disease of the brain, whilst much lower proportions thought that dementia was another term for Alzheimer's disease (58%) or that it was a mental illness (54%). Just over one quarter (28%) thought that dementia was part of the normal process of ageing, including 42 per cent of those aged 65 years or over, but only 16 per cent of those aged 18-24 years.

Table 1: Knowledge of dementia

	% saying 'True'
Dementia is a disease of the brain	94
Dementia is a mental illness	54
Dementia is part of the normal process of ageing	28
Dementia is another term for Alzheimer's disease	58
People who eat healthily and exercise are less likely to get dementia	29
There are drug treatments that help with dementia	75
There are many different kinds of dementia	72
Dementia can be cured	6

In relation to treatment, three quarters of respondents (75%) thought that there are drug treatments that help with dementia, but only six per cent thought that it could be cured. Three out of ten respondents (29%) said that people who eat healthily and exercise are less likely to get dementia.

Describing dementia

When asked to identify which words they would use to describe the way that someone who has had dementia for a long time appears, nearly all respondents said 'confused' (90%), followed by 'frightened' (62%) and 'lost' (58%). More positive words – such as 'happy' – were selected much less often by respondents (see Table 2). This suggests that the general public often has a narrow, and quite negative, way of thinking about people with dementia.

Table 2: Describing dementia

	%
Confused	90
Frightened	62
Lost	58
Unpredictable	52
Trapped	44
Sad	38
Angry	36
Dangerous	16
Pathetic	16
Happy	7
Gentle	6
Kind	4
Fun	3
None of these	<1
Other answer	1

* Respondents could identify more than one word

Living with dementia

The reality of how society thinks about, and cares for people with dementia was explored in the survey. There was wide support among respondents (83%) for the idea that 'there comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe' – see Table 3. However, there was less agreement about where a person with dementia should live. Around one third of respondents thought that it is better for a person with dementia – and their families – if they were cared for in a nursing home or residential unit. However, similar proportions disagreed with this statement, or said that they neither agreed nor disagreed. Of course, the particular stage or type of dementia may influence respondents' attitudes to this particular statement.

Table 3: Living with dementia

	% agreeing or strongly agreeing
There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe	83
Other people take over making decisions for people with dementia far too much	48
Once they have dementia the person you knew eventually disappears	75
As soon as someone is diagnosed with dementia they are not treated like a thinking human being anymore	46
For people with really bad dementia I don't think life is worth living	27
People with dementia are like children and need cared for as you would a child	73
People with dementia should be involved in activities in the community	87
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home	34
There is little or no benefit to be gained from telling someone they have dementia	36
People who have just been diagnosed with dementia are unable to make decisions about their own care	29
There is no point talking to someone with dementia, as they won't be able to understand	14

Around three quarters of respondents (73%) thought that people with dementia are like children and need cared for as you would a child, suggesting that many people hold a very paternalistic opinion about those with dementia and their care. A similar proportion (75%) agreed that that once they have dementia the person you knew eventually disappears. Differences by age were strong, with 81 per cent of the oldest age group (65 years or older) agreeing, compared with 43 per cent of the youngest age group (18-24 years).

There appeared to be a general acceptance that a recent diagnosis of dementia resulted in a negative change by society: around one half respondents (46%) agreed as soon as someone is diagnosed with dementia, they are not treated like a thinking human being anymore. Furthermore, a similar proportion (48%) acknowledged that other people can take over decision making for people with dementia far too much. Less than one third (29%) thought that people who have just been diagnosed with dementia are unable to make decisions about their own care.

On other issues relating to living with dementia, opinions were more mixed. For example, while just over one half of respondents disagreed that 'for people with really bad dementia I don't think life is worth living', a sizeable minority (27%) agreed. Public opinion was split over the benefit of telling someone that they have dementia – 36 per cent thought there was little or no benefit, whilst 41 per cent thought the opposite.

On a more positive note, however, there was overwhelming agreement (87%) that people with dementia should be involved in activities in the community. The idea that there is no point talking to someone with dementia, as they won't be able to understand was dismissed by 71 per cent of respondents.

The effect of time

All types of dementia are progressive, meaning that the person's ability to remember, understand, communicate and reason declines over time. How quickly this happens depends on the individual person. However, public attitudes and stereotypes often view people with dementia as one group, without acknowledging the different stages and types of dementia. In order to explore if this was the case, the survey included four scenarios (continuing to live alone, manage their own medication, drive, or have an electronic device fitted so that they can be located if they wander). Respondents were asked if they thought that in most cases, someone who has just been diagnosed with dementia should carry out these. There was limited support for the first three of these, and in fact, there was a fairly high proportion of respondents saying 'it depends', especially in relation to living alone and managing their own medication – see Table 4. However, nearly two thirds of respondents (64%) thought that someone just diagnosed with dementia definitely or probably should have an electronic device fitted so that they can be located if they wander.

Next, the same set of scenarios was presented in relation to someone who has had dementia for a long time. Two patterns emerge in comparison with the previous set of responses. Firstly, respondents were more definite in their views, in that the proportion of respondents saying 'it depends' decreased considerably. Secondly, the level of support for living alone, managing medication and driving also fell dramatically, with few respondents thinking that these activities are appropriate. In contrast, the proportion of respondents thinking that an electronic tag is appropriate remained fairly constant, regardless of the length of time since diagnosis.

Table 4: Scenarios by time since diagnosis

	%			
	Live alone	Manage medication	Drive	Electronic tag
Just diagnosed Definitely/probably	18	12	4	64
It depends	35	24	15	20
Probably/definitely not	46	63	80	15
Diagnosed a long time Definitely/probably	3	2	1	69
It depends	16	11	6	15
Probably/definitely not	81	87	93	16

Conclusion

Critically, this survey has enquired about perceptions, attitudes and awareness of dementia. We know that just under 50 per cent of those who partook in the survey had direct experience of knowing someone who is living with dementia, of which half are a family member. The views reflected by the survey confirm much of what needs to be challenged about attitudes, care and services for people with dementia and the need to address this in public policies and research, as well as in practice through the provision of services.

Some of the outcomes of the survey are encouraging, for example the majority of respondents understand that dementias are diseases of the brain (94%). Further, it is encouraging that a significant cohort (87%) agrees that participation in activities in the community is a something that people with dementia should be involved in. That said, the issue of stigma about dementia is significant. The World Alzheimer Report (ADI, 2011) states 'Unfortunately, the main barriers to access to care – the stigma of dementia that prevents open discussion, the false belief that nothing can be done for people with dementia and their families – are too prevalent.' Dementia must therefore be lifted out of the shadows.

The results tell us that there is greater need for clear, accessible information that gives the public an accurate understanding about dementia and how it impacts on the person with dementia. Responses suggest paternalistic views of the person as shown by the results that indicate that people with dementia need to be kept clean and safe, that they are perceived as being child-like, or in need of electronic tags.

There is a need, therefore, to raise public awareness about modifiable risk factors such as diet, obesity and alcohol consumption. Correspondingly the public need to be informed of the benefits of early diagnosis, a good diet, engagement in activities, maintenance of social networks and, in general, the things which can prevent or delay dementia and which also maintain or add quality of life (DHSSPSNI, 2010).

This survey indicates the need for further research to explore the views of people with dementia themselves and this is backed by the *Listening Well* report (Alzheimer's Society, 2009). The views of people with dementia are vital to understanding their needs, as well as ensuring that there is also an increase in the expectation that higher quality of life can be achieved by, and for, people with dementia.

Key points

- 45% of NILT respondents knew someone with dementia, around half of which were family members.
- Nearly all respondents (90%) would describe someone with dementia for a long time as confused, and few would say they were happy (7%).
- Most NILT respondents (83%) agreed that there comes a time when all you can do for someone with dementia is keep them clean, health and safe.
- A similar proportion (87%) thought that people with dementia should be involved in activities in the community.
- Nearly half of respondents agreed that once someone is diagnosed with dementia, they are not treated like a thinking human being.
- The views of people with dementia are vital if we are to understand their needs and raise expectations about how to live well with dementia.

References

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The ***Northern Ireland Life and Times survey*** is carried out annually and documents public opinion on a wide range of social issues. In 2010, 1205 adults were interviewed in their own homes. Fieldwork was carried out by Central Survey Unit.

The survey is a joint project of the two Northern Ireland universities and aims to provide an independent source of information on what the public thinks about the social issues of the day. Check the web site for more information on the survey findings (**www.ark.ac.uk/nilt**) or call the survey director on 028 9097 3034 with any queries.

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