# STIGMA, DEMENTIA AND MENTAL HEALTH
## Dr N Yoganathan & Dr J Willis
### MAC 16 September 2013
### Summary of feedback

## A. Workshop participants

There were 20 questionnaire returns, but some participants left without handing their questionnaire in. It is estimated that there were around 25 participants in total.

### Q.1 Age

The age of participants ranged from early twenties to sixties. The majority were in the ranges 41-50 years and 51-60 years, hence had considerable life experience which was likely to impact on their responses.

Figure 1



**Participants by age**

- <20
- 20-30
- 31-40
- 41-50
- 51-60
- 61-70
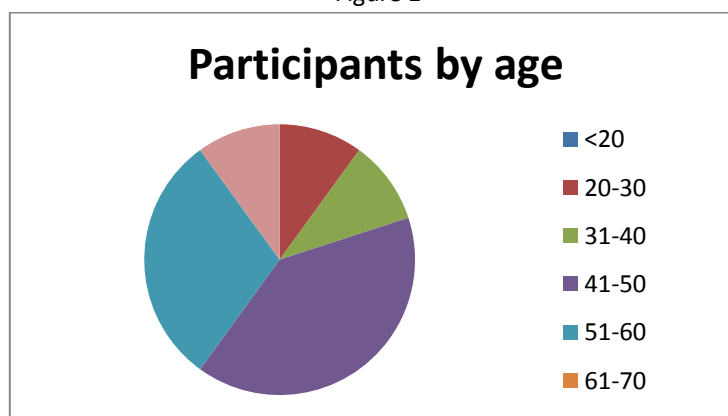
### Q.2 Gender

There was an imbalance between the genders, with 6 males, 12 females and 2 undeclared.

### Q.3 Ethnicity

Participants were predominantly British Caucasian.

Figure 2 Participants' ethnicity

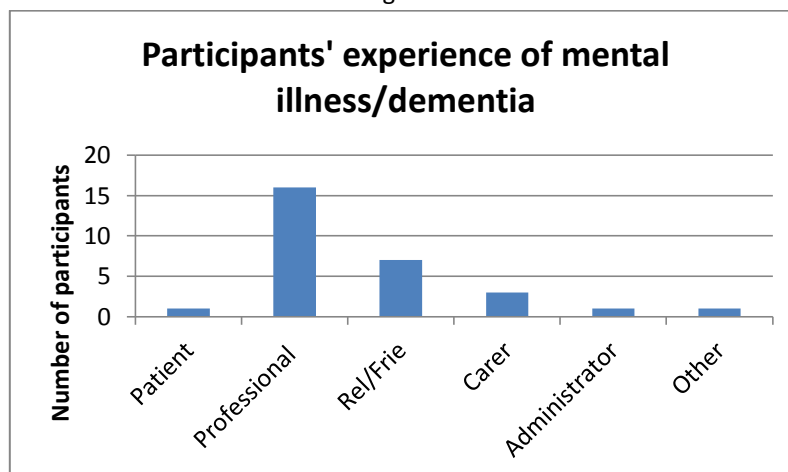| Ethnicity | Number |
|---|---|
| British White | 12 |
| British Asian | 1 |
| Northern Irish | 1 |
| Chinese | 1 |
| Asian | 1 |
| Undeclared | 4 |

### Q.4 Individual experience of mental illness/dementia

Individuals were asked to indicate the type(s) of experience they had and the number of years' experience in each domain.

The domain of greatest experience was that of professional (n=16). This included the roles of GP, nurse and support worker.

The length of professional experience ranged from 2 to 29 years.

Figure 3

**Participants' experience of mental illness/dementia**

Number of participants

20
15
10
5
0

Patient | Professional | Rel/Frie | Carer | Administrator | Other

6 participants had experience in more than one domain. These were:

Figure 4, participant with experience in more than one domain
(shaded cells indicate domain of experience)

|  | Patient | Professional | Relative/friend | Carer |
|---|---|---|---|---|
| 2 participants |  | ▓ | ▓ |  |
| 2 participants | ▓ | ▓ | ▓ |  |
| 1 participant |  | ▓ |  | ▓ |
| 1 participant |  | ▓ | ▓ | ▓ |

One person had personal experience of mental illness as a patient; this was for a period of 5 years.

3 participants had experience as a carer. This ranged for up to 15 years.

This combined experience was also likely to impact on individual response to the workshop.

**B.  Perceptions of Stigma and mental health**

**Q.5 Impact of the UK anti-stigma campaign**

Figure 5 Assumed impact of campaign

| Worse | 7 |
|---|---|
| No change | 13 |
| Better | 0 |

No-one thought that the campaign had a positive impact on public opinion. 7 respondents correctly said that attitudes had actually worsened.

Significantly, one person, with 29 years' experience as a GP, actually noted "I don't remember it happening."

***Q.6 Points raised in relation to article A, Word Power***

- Worse when technical terms are used to describe someone
- Technical terms are harmful
- PC gone too far
- Too big an issue to resolve by just not using wrong terms
- Big problem, will take years/generations to solve
- Words are embedded in our culture
- Certain words widely accepted in society
- 'Nutter' does not mean mentally ill – just not necessarily sharing your opinion
- Words used in wrong context
- Anxiety about difference
- Fear/anxiety/lack of understanding regarding mental health
- People are frightened of mental health – lack of understanding
- Insightful
- Provocative
- Generic
- Misdirected
- Lack of education
- Lack of sensitivity
- More considerate use of language
- Refrain from making psychiatric diagnosis without professional knowledge
- Use of technical language can be more harmful if no professional knowledge
- Medical vs social use of terms
- Anti-stigma campaign forgotten
- Celebrities' language not picked up
- Only people with mental health problems do bad things according to language used by politicians/press!
- Identifying/ addressing issues
- Need for awareness and education around sensitivity of these terms
- Political ignorance
- Education, schools should include mental health
- Education of children > more tolerant adults
- Need a famous person to destigmatise mental health

***Q.7 Points raised in relation to article B, Defining Moment***

- The article was not clear in whether she felt it was a positive or negative experience
- Mixed messages – happy or sad?
- Ambiguity regarding institutions
- Huge number of 'mental health problems'
- Confusion
- Negative
- Institutionalised – not good
- The feelings of a patient

- Good to see from patient's perspective
- Labelling
- Stigma
- Holistic
- Divided
- Very poignant account
- Losing individuality
- Removing independence
- People quickly become institutionalised
- Hard to get out of the system
- Place of accurate diagnosis
- How helpful is a diagnosis?
- Diagnosis as a tool for us/label for patient
- Is mental health a social concept?
- Fear labelling
- Relapse
- No one size fits all
- Impact on family
- No statistics or test to prove a mental illness
- May not have to be admitted if social worker found her earlier
- Lack of insight –'tears in her mother's eyes'
- Just how bad was she initially?
- Could she have been as creative if on medication?

### Q.8 and Q.9 perceived value of each article in illustrating aspects of stigma related to mental illness

Perceptions were expected to vary according to individual experience and awareness. Figure 6 indicates that article A, Word Power, was felt to be more useful.

Figure 6, Individual perceptions
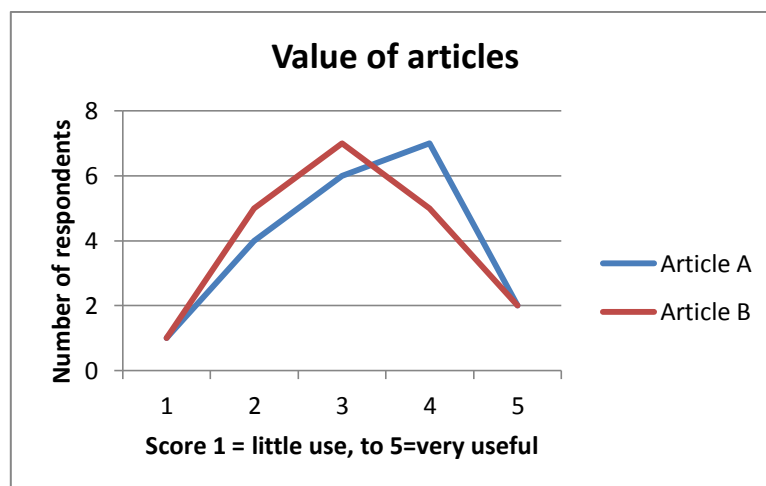
## C. Stigma and dementia

### Q.10 Well-known people diagnosed with dementia

The following names were suggested (number indicates citations)

| | | |
|---|---|---|
| Terry Pratchett x 5 | Margaret Thatcher x 5 | Ronald Reagan x 3 |
| Muhammed Ali x 3 | Jeremy Hunt | Glen Campbell |
| Iris Murdoch | | |

It is interesting that so many people made the same associations. The higher profile individuals are the people who have registered most with participants, a point of significance for those wishing to destigmatise dementia.

### Q.11 Number of people diagnosed as suffering from dementia in 2010.

The correct answer was 36 million. 6 participants gave the correct answer, the rest were spread across the alternatives. This suggests that the question provided new information.

Figure 7, Dementia sufferers globally in 2010

| | 12 million | 24 million | 36 million | 48 million |
|---|---|---|---|---|
| **Votes** | 3 | 6 | 6 | 5 |

### Q.12 How many people will be suffering with dementia worldwide in 2050?

Most participants anticipated an increase, though one person proposed 1.7 million. Other figures ranged from 24 million to 736 million. We conclude that this was a valuable question in raising awareness of the scale of the illness(es).

### Q.13 Proportion who have concealed their diagnosis of dementia.

The correct answer was 24%. 6 participants gave this answer. With one exception, the remainder overestimated the number of people who have concealed their diagnosis. Again, the question contributed to greater awareness amongst participants.

Figure 8, Concealment of personal diagnosis of dementia

| | 3% | 24% | 47% | 59% |
|---|---|---|---|---|
| **Votes** | 1 | 6 | 8 | 5 |

### Q.14 Who may have treated those diagnosed with dementia differently since their diagnosis?

| | | | | |
|---|---|---|---|---|
| Family | Friends | Carers | Health care professionals | Doctors |
| People who have been diagnosed early and treated | | | | Strangers |
| The world! | Everyone | Neighbours | Their partner | GP |

The above people were proposed. There was a sense that everyone/anyone potentially was involved in discrimination.

***Q.15 How may they have been treated differently since diagnosis?***

Most suggestions are negative, and relate to a degradation in the way the person is treated:

- Lack of understanding
- Being ignored
- Decision making/ not consulted on things affecting them
- Less in control of future
- Future very different from imagined
- Opinion disregarded
- Talking over them
- Information kept from them
- Paternalism/ patronising/ condescending
- Treated like a young child
- Overprotection
- Disrespect
- Derogatory
- People become frustrated
- Different racial/cultural backgrounds
- Can't do anything for themselves or think for themselves, need to have everything done for them
- Fear (others feel it)
- Lack of understanding so stopped seeing them regularly, inviting them out
- People take over
- Feel they can't live safely / independently

However, a few suggestions indicate an improvement in the way in which the person is treated:

- Empathy increased
- Increased help
- Talking therapy
- Drugs
- More consideration

It is salutary to consider both sides of this issue.

***Q.16 What can be done to support people with dementia?***

Participants made a very wide range of suggestions. They include interpersonal attitudes and behaviour, professional diagnosis and treatment, education, training, practical and affective support for carers, family etc., and address the whole person by looking at their diet, physical wellbeing etc. Suggestions were:

- Give them more time
- More resources
- More time from younger generation
- Support and training for family, partner, carers and professionals
- More information available
- Media information
- Tolerance
- Acceptance e.g. by discussing how common this is
- Listen to them
- Respect them
- MDM approach
- Early diagnosis
- Eliminate organic issues
- Continued monitoring
- Medications
- One-stop-shop
- Advocacy
- Empower them e.g. through peer support
- Recognise the rights of the person with dementia and their carers
- Educate
- Sign post
- Stable environment
- Routine
- Visual prompts (memory boxes)
- Home visits
- Groups after diagnosis
- Social support
- Involve them in their communities
- Memory clinics
- Occupational therapy
- Retain independence as much as possible
- Concentrate on what the person can do and not on what they can't do
- Appropriate exercise
- Healthy diet

## D. Evaluation of the workshop

*Q.17 Gained greater understanding of stigma related to dementia/mental illness.*

*Q.18 Workshop has changed my perception of stigma.*

The workshop is designed to increase awareness and change perceptions. Responses will vary according to the existing experience and understanding of participants. This is clearly reflected in the scores awarded for these two questions (figure 9).

Figure 9
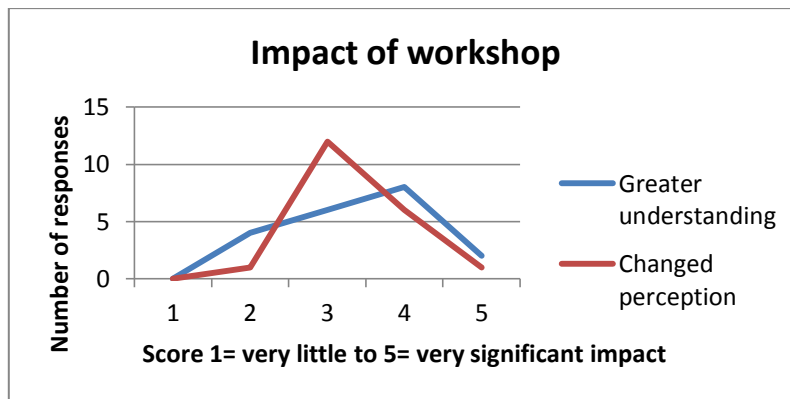


The workshop was more successful in increasing understanding than in changing perceptions.

***Q.19 What was most useful?***

Some respondents made comments related to the whole day, whereas this section was intended to relate only to the stigma sessions. The generic comments are not included here, but will be captured in MAC's feedback.

- The two articles
- Discussion
- Group work
- Positive steps to address stigma, particularly education from an early age
- Exploring the use of language used in mental health and analysing this
- The quotes
- Understanding the fact that stigma is not easy to remove – it takes time and effort and education

***Q.20 What was least useful?***

Some participants were satisfied with the whole day:

- All useful
- All relevant

Reflecting the subjectivity of responses, there was some overlap between issues of most and least value. Comments included:

- Not long enough – would have been god to have more time to discuss with other attendees ideas to carry out locally
- Group discussions
- Some slides a little repetitive
- As an administrator/secretary, very clinical biased, but helpful
- Challenging thoughts and processes questioning current practices and views
- Part C of the questionnaire
- Not enough knowledge of local policy

*Other comments*

- All presentations were good
- Would have liked an update from the local MAS service and how it is working locally.
- Strategies locally for how to stop medications when they no longer work/no longer have a benefit
- Rep from local services would be good
- Needs to be more directly linked to dementia care – it was challenging to decipher how
- Was more directed at GPs, not so relevant for nurses

THANK YOU TO ALL WHO HAVE CONTRIBUTED YOUR VIEWS. THESE ARE VERY VALUABLE AND WILL HELP US TO IMPROVE ON FUTURE WORKSHOP.

If you have any further comments, please do email us. The report will be made available on our website, no2stigma.weebly.com.

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