Tell Me The Truth

The effect of being told the diagnosis of dementia

SUMMARY

There is a great deal of debate about whether people with dementia should be told what their diagnosis is. Arguments in favour of telling are that people have a ‘right to know’, and that knowing the diagnosis may enable them to make plans for the future. The most common argument made by professionals and carers against disclosing the diagnosis is that it will cause undue distress. This research by Dr. Heather Wilkinson and Rebekah Pratt of the University of Stirling, funded by The Mental Health Foundation as part of its Dementia Research Initiative, explores the views of people with dementia themselves. The research focuses on people’s views of the way they were told their diagnosis and the opportunities and limitations offered by receiving an early diagnosis.

Key findings of the research were:

- Participants experienced a range of feelings when first told the diagnosis, including shock, anger, depression, and fear. However the inappropriate withholding of the diagnosis also caused distress. Some participants felt that the diagnosis helped to explain and validate their own observations.

- Most participants identified a range of positive opportunities gained by knowing the diagnosis, including planning, accessing appropriate support, and making the most of one’s time. They identified few limitations from knowing the diagnosis.

- Social support was very important in enabling people to develop coping skills. The experience of diagnosis was also affected by medical practice, carer attitudes, availability of information, and social stigma.

- All participants who knew their diagnosis felt that in principle people with dementia should be told as soon as possible. However they also emphasised the person’s need to choose how much information they wished to receive at any given time.
BACKGROUND

The advantages and disadvantages of disclosing the diagnosis of dementia have been debated by health professionals and carers (Maguire et al 1996). Those arguing in favour of disclosing the diagnosis suggest that it reduces uncertainty, enables people to access support services, and empowers them to plan for future care. It is also claimed that people have a basic human ‘right to know’ (Fearnley, Weak & McLennan 1997). Arguments against disclosing the diagnosis focus on the uncertainty of the diagnostic process and on the distress caused to patients. Some people feel there is little point in disclosing a diagnosis if no treatment is available. However the development of new drugs, which may delay the progress of dementia if prescribed in the early stages, challenges this assumption. There have been few opportunities for people with dementia themselves to express their views about diagnosis disclosure, but in order to develop good practice it is important that their voice is heard.

THE RESEARCH

Twenty four people with dementia took part in the study. They were recruited through support agencies, day centres, memory clinics and a Community Psychiatric Nurse. The criteria for including participants in the study were that they had been diagnosed with dementia, and told their diagnosis, and that they were capable of describing their experience and giving free consent to participation. However it emerged that five of the twenty four were not currently aware of their diagnosis.

Participants were interviewed, starting with a discussion about memory problems. Those who revealed that they knew their diagnosis were asked about the way it was disclosed and the impact of the disclosure. No one was told his or her diagnosis during the interview. Eleven of the twenty four were interviewed a second time. This second interview provided further information, building on the researcher’s increased knowledge of the participants.

The interviews generated qualitative data which was analysed in two ways. Key themes which emerged across the interviews were identified through a process of open and theoretically driven coding. A case study approach was also used, to provide information on the context in which the process of psychological adjustment took place.

THE FINDINGS

- People were able to remember the immediate impact of diagnosis better then the process by which the diagnosis was disclosed. First reactions to the diagnosis included shock, fear, anger and depression. Some participants experienced a sense of relief and validation through understanding the reasons for their behaviour and memory difficulties.

- Participants emphasised the need to choose how much information they received, and when. Some wanted as much as possible, while others wanted it only one step at a time.
Most participants identified positive opportunities arising from disclosure of the diagnosis. These included opportunities to plan, make financial/legal arrangements, understand what was happening, develop memory aids (e.g. diaries, cards), access increased social support, and make the most of their time.

Participants identified very few disadvantages of disclosing the diagnosis. Some referred to loss of self-confidence and increased restrictions on daily life (e.g. loss of driving licence), which were largely due to the impact of the disease rather than the impact of diagnosis per se.

The process of accepting and adjusting to diagnosis included the following stages: noticing initial symptoms; the diagnostic process; disclosure; ‘crisis’; prognosis; distress; denial; maximising coping strategies.

Inappropriate withholding of the diagnosis had also been a source of distress to several participants, who reported feeling depressed when they did not know what was wrong with them.

The importance of information about prognosis and the need for follow-up support from medical staff were highlighted. Examples of poor practice included lack of information, conflicting information, and lack of follow-up.

All those participants who knew their own diagnosis said that people with dementia should be told their diagnosis. However they also noted that disclosure should be tailored to individual needs for information.

Social factors were important in influencing people’s experiences of adjusting to the diagnosis. Key social factors included: support services, medical practice, attitudes and stigma, information, and opportunities to talk to others. The stronger the support received, the better people were able to develop positive coping skills.

“I wish I’d been told earlier because ... we could have lived in a lot more harmony and we could have got access to those nice people (from Alzheimer’s Scotland) a lot earlier.”

THE IMPLICATIONS

This study indicates that for most people the opportunities from knowing the diagnosis outweigh the limitations. However people need appropriate support and information to help them through the time of crisis which can occur after disclosure.

The implications for services include the need for supportive environments (e.g. day centres where people can talk to each other and share experiences), and the urgent need to break down the stigma and lack of understanding around living with dementia.

There are implications for GPs, who play a pivotal role in the early diagnosis of dementia. Milne et al (2000) reported that 20% of GPs held negative attitudes towards early diagnosis, largely because of concerns about distress to people being informed of the diagnosis. The research reported here offers a contrasting perspective, emphasising the positive outcomes of diagnosis, and highlighting the fact that withholding the diagnosis can also have negative implications and cause distress.
REFERENCES


For further details contact Dr. Heather Wilkinson, Centre for Social Research on Dementia, Department of Applied Social Science, University of Stirling, Stirling FK9 4LA.

Series editor: Lisa Bird

*This Update was written by Dr. Jo Borrill, Clinical Research Manager, The Mental Health Foundation, in consultation with the research team.*