The Person with Dementia:
*The personal impact of diagnosis disclosure.*

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58% of carers surveyed across Europe identified dementia as part of the normal ageing process (Bond et al, 2005).

“it is far more than simply memory loss... it is a real disease, not a normal part of ageing” (Bryden, 2005)

Dementia does not consistently remain person-centred.
In Brazil only 58% of carers of people with dementia believed diagnosis should be disclosed (Shimizu et al, 2008).

In Taiwan this number was 76% (Lin et al, 2005), Finland 97% (Laakkonen et al, 2008), Belgium 43% (Bouckaert and van den Bosch, 2005) and Italy 39% (Pucci et al, 2003).

Widespread differences in perspectives of carers.
Van Hoult et al (2007) 58% of GP’s in a study in the Netherlands felt confident in making a diagnosis.

Turner et al (2004) 33% of those surveyed in a Scottish study felt a diagnosis should be made by a specialist.

In Brazil, Raicher et al (2008) found that only 45% of patients were informed of diagnosis.

Teel (2004) in Kansas, USA a physician stated: “No-one wanted a diagnosis of Alzheimer’s disease”.

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* Diagnosis is the gateway to living-well with any condition.
* Widespread disparity in the disclosure of diagnosis across the world (Bamford et al, 2004).
Two separate themed searches were undertaken for literature review:

A. The patient’s attitude to disclosure of diagnosis.  
   (4 studies identified from 1996)

B. The patient’s experience of a diagnosis.  
   (12 studies identified from 2006)
Theme A: Patient Attitude

* Four studies in conclusion that participants generally wish to know diagnosis.

* Dautzenberg et al (2003) 96% felt it was important to know their diagnosis.

* Pinner and Bouman (2003) report 92% wished to be informed.
Elson (2006) found that 86% of participants favoured disclosure of a disease relating to memory problems. **HOWEVER** this fell to 69% with disclosure of Alzheimer’s disease specifically (Elson, 2006).

Marzanski (2000) reported 70% of people were in favour of diagnosis disclosure.
Theme A: Patient Attitude (3)

* Few studies in the literature conducted in relation to what people with dementia want with regards to diagnosis disclosure.

* Plethora of research concerning views of carers and physicians.
* In Stark contrast to Theme A, many studies have been conducted regarding the experiences of a person receiving a diagnosis of dementia.

* 12 studies were identified since 2006 that sought to establish the person’s feelings after diagnosis.
The feeling of “shock” and “denial” pervaded the primary literature.

- “It’s a lot of information; it’s painful information... the brain shuts down and says I can’t take any more bad news” (Aminzadeh et al, 2007).
- “It’s old age and not Alzheimer’s, its just the memory isn’t there” (Frank et al, 2006).
The term “Alzheimer’s disease” was found to be much more likely to cause a negative emotional response as opposed to “dementia” or “mild cognitive impairment”.

“It’s a frightful name, it just makes you want to curl up... when you think of Alzheimer’s disease” (Langdon et al, 2006)
* Shame and Stigma appear synonymous with some experiences of diagnosis. Langdon et al (2006) state participants felt they would be perceived as: “gaga... crackers... screw loose... need to be locked up”.

* “I still have enough intelligence, you know to be a person, and not just someone you pat on the head as you go by... its devastating”. (Beard and Fox, 2008).
Theme B: Patient Experience (5)

* Stigma extended to deprivation of liberties: “You can’t do what you want, you have to do what someone else wants, and they have to do it for you” (Beard and Fox, 2008).

* Surprisingly the feeling of guilt was also prevalent: “I just want to stay a grandmother for my grandchildren” and “I can see the hardest part of this will be for my wife” (Derksen et al 2006).
Beneficial to diagnosis, more than half of the studies identified participants who adopted coping strategies such as undertaking new hobbies and joining support groups.

“I’m still the same person I’ve always been... I think the more you know... the better you are going to be able to make a decision when issues start” (Beard and Fox, 2008).
The enabling of “future-planning” was an often cited as a benefit with people able to “get your house in order” and “enjoy dancing once a week” (Moinz-Cook et al 2006).

Lingler et al (2006) found for some people it was “a great relief, I haven’t worried since” regarding formal diagnosis.
Disempowerment:
“socially demoted” (Beard and Fox, 2008), “I had to hand my financial affairs to others” (Derksen et al, 2006) and “they drugged her up” (Moniz-Cook et al, 2006)
* **Infantilisation**
  Through relatives and physicians shielding the person from their diagnosis.

* **Labelling, Withholding and Invalidation**
  The person should remain a person in spite of diagnosis. Society is becoming more hyper-cognitive and people with dementia should not be re-categorized to a passive role.
“The voice of the relative is, in general, much more powerful than the voice of the person with dementia” (Cox, 2003).

- Non-maleficence vs. Autonomy

- Advanced Directives.

- No evidence of advanced depression or suicidal tendencies following diagnosis.
* Terminology of “Alzheimer’s disease” appears to draw more fear from population.

* Negative feelings in the literature appear more to do with how the person is treated following diagnosis as opposed to the illness itself:

  vis-à-vis: WE MUST ALWAYS CONSIDER THE PERSON WITH DEMENTIA AND NOT THE DISEASE.
References

Theme A:


Theme B:


Theme B:
References

References


