Capturing the diagnostic narrative of dementia through a qualitative longitudinal study

Older people’s experiences

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Study Sites

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The ‘Transitions’ Project

- Aim: To understand the experiences, expectations and service needs of the person who is becoming the person with dementia, from the perspectives of the older person and their supporter.

- Qualitative interview methodology in 3 sites

- 3 sites
  - London: inner London Borough; relatively younger population (11% over 65); multi-cultural with over 100 languages spoken.
  - North East: 2 sites – one urban and one rural:
    - Urban site: 270,000 population, low proportion of Black and Minority Ethnic groups within the population.
    - Rural site: 200,000 population with dementia in 2008
  - Greater Manchester: 200,000 population; 20% over 65; significantly worse health than national average

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Literature Review – Method

- Update of systematic review on disclosing a diagnosis of dementia (Bamford et al., 2004)
- 926 abstracts screened; majority failed inclusion criteria
- 129 full papers screened = 57 papers included in final review
Literature Review – Themes

- Most people wish to know their diagnosis, although majority can not accurately recall it
- ‘Alzheimer’s Disease’ appeared to have more negative connotations than ‘dementia’
- Lack of information before and after diagnosis; but type and nature of information preferred not identified
- Triggers for help-seeking not identified
- Short-term distress at diagnosis not always result long-term
- Most people with dementia come to terms with the condition
- Family carers commonly become decision-maker and adjust to responsibility
- **Implications of review: diagnosis should be a process with follow-up; planning for future should be discussed**

Qualitative longitudinal study methods

- Ethical approval was granted by Newcastle and North Tyneside REC 1.
- Purposive sampling
- Interviews conducted Retrospectively (dementia diagnosis already disclosed) and Prospectively (at the time of first assessment).
- Semi Structured interviews (using a topic guide) were held with people with memory problems and their carer/supporters in their own homes. Where possible follow up interviews (after minimum of 3 months) were held to explore how things had changed.
- Analysis was based on the constant comparative method. A thematic table was developed according to early analysis and revised iteratively as analysis went on.

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Participants

There were 53 Participants:

- 27 people with memory problems
- 26 carers;
- 20 were matched pairs
- 14 women and 13 men with memory problems
- 20 female carers and 6 male carers
- 8 people with memory problems lived alone with no carers
Interview Schedule Topics

- Triggers for help-seeking
- Experience of assessment and support at pre-diagnosis stage
- Experience of diagnostic process and support at post-diagnosis stage
- Experience of receiving a diagnosis
- Expectations, feelings, experience of medication
- Other support from services (medical, psychosocial, emotional) and gaps in service provision

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Emerging Findings

- Multi-layered narratives
- Poorly managed diagnostic disclosure
- Information and communication within the dementia pathway

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Internal narratives

- ‘Internalising dialogue’
  - Gradual self awareness that something may be wrong
  - Almost always in relation to memory problems; some in relation to living independently
  - Inability to sustain hobbies, lifestyle that they used to have

I felt as though I should be at home and that’s why I retired. And I suppose in a way when you’ve always worked like that and then you’re at home, I suppose you can go into freefall a little bit can’t you because although we keep busy don’t we X, we’re either in the garden or doing in the house but it’s a different … it’s an entirely different thing than leaving the house at seven in the morning to go to your daily job and what have you.

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Intimate narratives

• ‘Confirming positions’
  – Seeking confirmation and reassurance from those closest to the person with memory problems that help is needed

He’s been, he went to his GP – he kept me out of it quite a bit at first – he was just trying to make enquiries himself and really he was non-stop reading about it and going on the internet and things like that which I used to get annoyed about, I have to say, because I felt he was talking himself into this problem. I said “why don’t you just leave it and see how you go” but no, he wants to know what’s to be expected and this type of thing ... I felt he was being paranoid, I suppose, at the time and I just felt he was reading too much about these problems and talking himself into this condition. Maybe I should have been a bit more sympathetic at the time, I don’t know, or maybe it was just a case of not wanting to face up to it really.

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External narratives

- "Seeking expert advice": disclosing position to professionals (usually GP).

  "Yes, reluctantly, right, so when I kept saying, ‘I’m having memory problems’, it went on over a year I would say, it was February before I was referred anyway, and it wasn’t his fault, he’s an excellent doctor, I could see he was getting slightly annoyed with me but unfortunately my approach is, I have no intention of giving up when I want something done and I’m very polite". (Person with memory problems)

- ‘Being tested’: undergoing diagnostic investigations and receiving results

  “my score was something like, was it 13 out of 18, I think. It wasn’t a bad score”

- ‘Seeking understanding’: from professionals and other sources.
Clinical narrative

- Participants described long wait between appointments, and being given very little information about process of assessment and follow up
  - High levels of confusion & anxiety reported regarding what to expect and when

- Participants wished to be kept informed about what is going on at every stage of assessment and intervention
  
  “It would help for some clarity at the beginning before the diagnosis is done, and explanations and clarity and where you go from there, you know, what sort of course of actions should be taken, I think that would help so that you see a chain of something progress through the business”.

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Clinical narrative

- Limited time given to patients and carers for processing information or for asking questions
- Participants were keen to understand what is wrong, in order that they can plan for their future better
  - Written information about different types of dementia was welcome by some, but not all

“What I need is advice. I need to talk to somebody to see what the outcome could possibly be. I want to know what I am up against.”

“But to be able to have it explained in... how I put ease in... Because sometimes you get medical letters and you just don’t understand a word that they’re trying to explain to you. Just to be told clearly what’s going to happen, or what could happen.”

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Poorly managed diagnosis disclosure

- Most described feeling unsupported at this time and none had received referral to further emotional or counselling support
- Diagnosis disclosure should be developed as an ongoing process, rather than one-off event

“They did ask if we’d got any questions, but it is not then that you have the questions, is it? It’s when you come home and you sit and you think .....that’s when you have your questions.”

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More tailored approaches welcomed

- Some keen to help themselves and wanted appropriate information
- Merely giving information not enough for busy carers, who would prefer a more tailored approach to address specific needs

“The thing is I was told that I should get some sort of papers signed, erm, but as I said, somebody said go to the website and download it, I haven’t really done that, I mean I e-mailed back the lady who told me to do this in the first place, and just said ‘what exactly do you want me to do? which one’, you know, because I know she has told me to go to that web site and have a look at dementia and stuff like that. I need somebody to help me to fill the forms in, because that is what I need... it doesn’t help if I know what dementia is, I am able to manage my father and his condition. I need more help with these forms. And that isn’t there. And there are so many different forms.”

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Recommendations and Conclusions

- Qualitative narratives identify how individuals come to recognise their memory problems as a first step towards help-seeking.
- Decision to seek help is last in long stream of dialogues that individuals with memory problems may have with themselves, with loved ones, with others.
- Diagnosis disclosure needs to be managed sensitively with due importance given to this process.
- Seeking qualitative narratives through in-depth interviews and analysis can be a valuable technique to reach the parts that other methods might not, i.e. subconscious internalised processes of meaning-making.

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Disclaimer: The views and opinions expressed here are those of the research team and do not necessarily reflect those of the NIHR SDO programme or the Department of Health.

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