“The Little Dance”: Delicate Deliveries of Dementia Diagnoses

Findings from the ShareD Study Focus Groups with Doctors

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ShareD Study:

- **Shared Decision Making in Mild to Moderate Dementia**
- How are diagnoses being delivered in current practice?
- What are persons with mild to moderate dementia and their family’s preferences for, and experiences of, involvement in decision making?
- What types of professional communication facilitate shared decision making with persons with dementia and carers?

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ShareD Study:

**Methods:**
- Cohort observation study using video of diagnosis feedback and follow up
- Semi-structured interviews and focus groups with people with dementia and family
- **Focus groups with clinicians**

Approval from Camden and Islington Research Ethics Service (13/LO/1309)
Background:

- PM’s challenge 2020
- Memory clinic referrals increasing (Hodge and Hailey, 2015)
- “Timely” diagnosis (Dhedi et al, 2014)
- Make decisions about future care, start medication, cognitive stimulation therapy (Leung, Finlay et al. 2011)
- Diagnoses are not adequately explained (Quinn, Clare et al, 2008)
- Voices of frontline clinicians missing from policy debates (Dhedhi et al, 2014)
Focus groups with doctors:

- **Methods:**
  - Four focus groups held in North London, East London, and Devon x 2 between October 2014 – March 2015, each lasting approximately 1.5 hours.
  - Further focus group with East London doctors in January 2016 to discuss and validate emerging findings.
Focus groups with doctors:

- Evolving semi-structured interview
- Topic guide reviewed by Alzheimer’s Society Research Network
- Participants:
  - 15 doctors: 13 old age psychiatrists and 2 geriatricians
  - Average 13.6 years of working with people with dementia
Focus groups with doctors:

- **Analysis:**
  - Verbatim transcription, line by line coding (NVIVO 11)
  - Thematic analysis following processes described by Braun & Clarke (2006) and Miles & Huberman (1994)

- **Results:**
  - 39 categories → 18 sub-themes → 8 overarching themes
  - Themes not mutually exclusive
1. Public awareness and the political agenda: service and individual responses

- Evolving remit of memory services: managing increasing referrals
  - “Ageless catch-all” (P15), loss of personalisation, continuity and follow up
- Media portrayals, stigma and dementia as a political agenda:
  - Increased profile generally positive, comparisons to cancer
    - “More people say “have I got dementia?” than maybe a few years ago. You’d have to skirt around it a bit.” – P7
  - But, catchy headlines might create false hope
    - “Every week in the mail or the express there’s a ‘X’ cures dementia. And you know I think they’ve built up beforehand. And what you’re doing is, is, being realistic.” – P9
2. Making and delivering a diagnosis: challenges, strategy and utility

- Making an accurate diagnosis with limited time and information
  - 85% of participants meeting patient for the first time in feedback “parachuted in” (P9)
    - “You’re at the mercy of the person who’s taken the history, and that can be variable at how skilled the person is at probing and sort of getting to the bottom of things.” – P4

- The utility of a dementia diagnosis
  - “The diagnosis, the label, and severities, and sharing that with all the right stakeholders.” – P10
3. Playing to two audiences

- Triadic dynamics: old patterns, new stresses
  - Triad contains both challenges and resources
- Doctors’ shifting alliances: balancing patient and companion needs and involvement
  - Potential for patient marginalisation, also needing to pick up on subtle cues for carer burden
    - “Sometimes the relative wants you to say something that they can’t say, or that they’ve been trying to say for some time. So there’s a lot of sort of picking up on, work to do before you get to the actual diagnosis.”- P4
- Complex, shifting role of family: insight, expectations and attributions
4. Breaking bad news: application and suitability of existing frameworks and training in memory clinics

- Limited training and support for the complex and emotional task:
  - Rare to receive dementia-specific training
  - Lack of supervision and opportunity to discuss emotional side of the work
    - “There is a lot of pain and angst. How do we deal with it? You know, the litany of the patients that have to be told they’ve got an incurable illness.” – P13

- Context and preparation: assessing insight and readiness:
  - “I think it depends on the signals you pick up from people. Some people will walk through the door and say, ‘Just tell me’.” – P3
  - “How do they want to know?” – P6

- The process of delivery: considered use of labels (‘D+A’ words), building personalised narratives
  - “It’s a little dance, isn’t it; using the language at the appropriate time.” – P7
5. The range of insight, engagement and emotional reactions to diagnosis

- The spectrum of insight and interest in the diagnosis
- Varying emotional responses to the diagnosis and its practical implications:
  - Occasional “hostility” (P3)
  - Driving discussions often create more distress than diagnosis itself
6. Balancing honesty, hope and uncertainty

- The uncertain efficacy of medication and the message of living well
  - Gentle and optimistic approaches might lead to further confusion
    - “It’s natural to try to ease the blow as much as you can but you don’t want people leaving without understanding.” – P3
  - Ambivalence about medication efficacy, but a metaphor for hope and a tool for ‘softening the blow’
    - “I think from the moment one starts talking about the treatment (donepezil), it already has a placebo effect on the actual adjustment or the sort of stress reaction of the patient.” – P15

- Practical implications and prognostic uncertainties
  - “I want them to understand, but not to understand too much.” – P1
7. Shared decision making: capacity, cognitive impairment and companion involvement

- Information provision and cognitive impairment
  - Utilising companion as an auxiliary memory
- Shared decision making: triadic communication within the context of existing relationships
  - Complicated by meeting for the first time and lack of follow up (and time to think it over)
  - Relational approach to best interest decisions
8. Providing continuity of personalised care within service constraints

- Service and individual strategies for continuity of care within memory clinic pathways
  - "There’s this tension with service provision versus quality of care. I think if you want genuine shared decision making and high quality care you’ve got to allow people to get to know to know people." – P5

- Balancing personalisation and flexibility with institutional agendas
Discussion:

- Double edged sword of raised political and public profile of dementia:
  - Increasing referrals on memory clinics (+ targets) → service adjustments to manage → meeting for the first time/loss of personalisation and continuity

- Delicate deliveries of complex information:
  - ‘D+A’ words – person centred approach, but the importance of saying ‘dementia’ (in most cases)
    - Shift from whether to disclose, rather to how, when to disclose (‘How do they want to know?’ – P6)
  - Breaking bad news as a ‘communicative dilemma’ of ‘truth telling vs. hope’ (Del Vento, Bavelas et al. 2009)(? Implicit understanding complicated by cognitive impairment)
Discussion:

- Training and supervision:
  - Emotionally challenging work, risk of disengagement
  - Does dementia fit into models of BBN training? (Kaye, 1997) (Baile, Buckman et al. 2000)

- Negotiating the triad and decision making:
  - Doctors and relatives are poor at predicting preferences of patients with dementia for participation in decision-making (Hamann, Bronner et al. 2011)
  - Personalisation and prior knowledge, family dynamics
(Inconclusive) conclusions:

- Huge pressure on services to make diagnoses, but frontline staff hesitant about efficacy of medical treatment and availability of support.
- Memory clinic pathways have the potential for loss of continuity, sensitivity, personalisation, and opportunities afforded from ‘early’ diagnosis.
- Emotional task – role of training in BBN in this setting, supervision to avoid emotional disengagement, burnout.
Future analyses and directions:

- Triangulating focus group findings with video data
- Best practice guidelines
- Evidence based training for doctors?
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References: