

# Long-term impact of disclosing amyloid PET results to individuals with Subjective Cognitive Decline

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## BACKGROUND

- **Amyloid PET assessments** increasingly inform diagnostic evaluation and treatment decisions in AD 
- Evidence on **impact of disclosing results** is mainly based on cognitively unimpaired trial participants and **short-term follow-up**
- **Long-term implications** for memory clinic patients with **subjective cognitive decline (SCD)** remain unknown.

## AIM

 We aimed to examine the psychosocial and behavioral impact **three years after amyloid PET disclosure** in memory clinic patients **with SCD**

## METHODS

- In-depth **semi-structured interviews**
- With 17 participants with SCD at time of imaging 
- **7 amyloid PET negative**, **10 positive**
- Interviews were conducted **35 ± 4 months after disclosure** 
- 1 had progressed to MCI at interview
- Transcripts analyzed inductively

## RESULTS

### Participants' characteristics

|                                   | all (n=17) | negative (n=7) | positive (n=10) | p-value |
|-----------------------------------|------------|----------------|-----------------|---------|
| Sex (n (%) female)                | 5 (29%)    | 3 (43%)        | 2 (20%)         | 0.59    |
| Education (mean±sd)               | 6±1        | 6±1            | 6±1             | 1.00    |
| Marital status                    |            |                |                 | 0.12    |
| Married                           | 10 (59%)   | 6 (86%)        | 4 (40%)         |         |
| Cohabiting                        | 1 (6%)     |                | 1 (10%)         |         |
| Unmarried                         | 2 (12%)    |                | 2 (20%)         |         |
| Widowed                           | 1 (6%)     | 1 (14%)        |                 |         |
| Missing                           | 3 (18%)    |                | 3 (30%)         |         |
| At time of amyloid PET disclosure |            |                |                 |         |
| Age (mean±sd years)               | 64±8       | 64±7           | 65±9            | 0.81    |
| MMSE (mean±sd)                    | 29±1       | 29±1           | 29±1            | 0.93    |
| Diagnosis                         |            |                |                 | 1.00    |
| SCD (n (%))                       | 17 (100%)  | 7 (100%)       | 10 (100%)       |         |
| At time of follow-up interview    |            |                |                 |         |
| Age (mean±sd years)               | 67±7       | 67±7           | 67±8            | 0.92    |
| MMSE (mean±sd)                    | 29±1       | 29±1           | 29±1            | 0.56    |
| Diagnosis                         |            |                |                 | 1.00    |
| SCD (n (%))                       | 16 (94%)   | 7 (100%)       | 9 (90%)         |         |
| MCI (n (%))                       | 1 (6%)     | 0 (0%)         | 1 (10%)         |         |

### Motivations for learning amyloid PET status

- Shaped by **family history** and experience with dementia
- Desire to understand brain health and cognitive concerns
- Preference for knowledge over uncertainty
- Half reported **no drawbacks**, others mentioned emotional impact, prognostic uncertainty, and limited clinical utility 

### Comprehension of amyloid PET status

- All showed **accurate understanding** of amyloid status
- **Amyloid-negative**: absence of detectable amyloid pathology
  - Reassuring, but understood as a **snapshot**
- **Amyloid-positive**: elevated amyloid pathology
  - “Bad news”: **high risk** of progression over time 

## RESULTS

### Emotional impact of amyloid PET result

- **Amyloid-negative**: relief, happiness, and peace of mind
  - Memory lapses often **reattributed to ageing**
- **Amyloid-positive**: initial shock, disappointment, and fear
  - Distress often **attenuated in absence of rapid decline**



### Actionability of amyloid PET status

- **Amyloid-positive**: shifting priorities, sometimes lifestyle changes
- **Regardless of result**: reflection on remaining life span,
  - preparation for possible future cognitive decline,
  - 14/17 spontaneously mentioned **self-determined end-of-life options**



### Sharing amyloid PET status with others

- **Regardless of result**: **most shared results** with relatives and friends,
  - some also informed colleagues or acquaintances,
  - others were more cautious in sharing “**sensitive information**” to avoid stigma or burdening others



### Perceived significance of amyloid PET testing

- **Regardless of result**: personal meaning sometimes shifted over time,
  - more urgency, greater awareness of mortality,
  - or life with cognitive decline considered “still worth living”,
  - **no regret**, all would choose biomarker testing again



## CONCLUSION

- Three years after disclosure, participants had generally **adjusted** to living with their amyloid PET result.
- They found **personal meaning and practical engagement**, without reporting ongoing psychological harm.
- Residual **concerns and uncertainty remained** for some participants, irrespective of amyloid status.
- Findings offer **guidance for clinicians and patients** as biomarker disclosure becomes common in routine care. 

