

Evaluating Dementia Pathway Services: A Sussex-wide Patients and Carers' Perspective.

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Introduction

- The prevalence of dementia continues to increase across the UK¹.
- Understanding the lived experience of people living with dementia (PLWD) and their carers is paramount.
- There is an established dementia pathway in Sussex^{2,3}.
- To improve care and inform future commissioning priorities, the Brighton and Hove Health Watch (BHHW- a community interest company)⁴ surveyed the opinions of a group of PLWD and their carers around initial diagnosis and subsequent support.

Methods

PLWD and their carers receiving social support and willing to provide feedback were invited to this survey. Using a topic guide, BHHW volunteers conducted a telephone interview with participants exploring the experience with their general practitioner (GP), and the memory assessment service (MAS) in relation to diagnosis, and post-diagnosis support. Transcribed interviews were analysed using qualitative thematic analysis (inductively and deductively) using Braun and Clarke's method⁵.



Results

- Forty-five participants were interviewed, 6 PLWD (average age 78.2 range 64-95 years) and 37 carers between December 2022 and May 2023.
- Thirty-nine participants (86%) were of white-British ethnicity.
- Participants were generally satisfied with the initial GP care they received.
- Waiting time to access MAS was six weeks on average, an acceptable timeframe for the group.
- Some participants reported waiting as long as two years since the initial GP consultation before a dementia diagnosis was eventually made.
- Participants were generally satisfied by the thorough MAS review.
- Most participants felt that information received after dementia diagnosis was complex and overwhelming.
- Social support offered post-diagnosis was commendable.



Conclusion

The lived experience of PLWD and their carers in Sussex was generally positive. However, a tailored approach to post-diagnosis information provision is required.

References

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