

Brain Health Navigation in an Integrated Health System: Initial Experience



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Background

Alzheimer’s Disease and related dementias are leading causes of disability across the world. However, care in the United States is often disjointed, leaving many patients and their families to struggle filling the many gaps in care. Navigation has been shown to improve overall care, addressing the many gaps in routine care, though there is limited experience with navigation in neurology and particularly within the field of dementia. We report here our initial experience with a brain health navigation (BHN) program with particular attention to the perspectives and experiences of providers, patients and caregivers.

Methods

- Brain Health Navigation (BHN) Services were begun at Norton Neuroscience Institute (NNI) in March 2025.
- Referrals were accepted from both Primary Care and the Memory Center.
- We examined basic data such as number of referrals, number of enrollees in navigation services and referral to amyloid-targeting therapies of those enrolled since inception.
- We also designed and utilized brief questionnaires for clinicians, patients and caregivers.
- Surveys focused on satisfaction and usability of the BHN program.
- Two open ended questions complete the survey to provide more detailed feedback on the benefits of the BHN program.
- All clinicians associated with our BHN program completed surveys.
- A sample of 50 patients and caregivers were invited to complete surveys.

Results

Institutional Experience

- In the first 15 months of operation
 - 198 referrals received
 - 160 patients enrolled
- Principal Care Management (PCM) codes were used in essentially all cases
- Principal Illness Navigation (PIN) codes were used in 5 cases

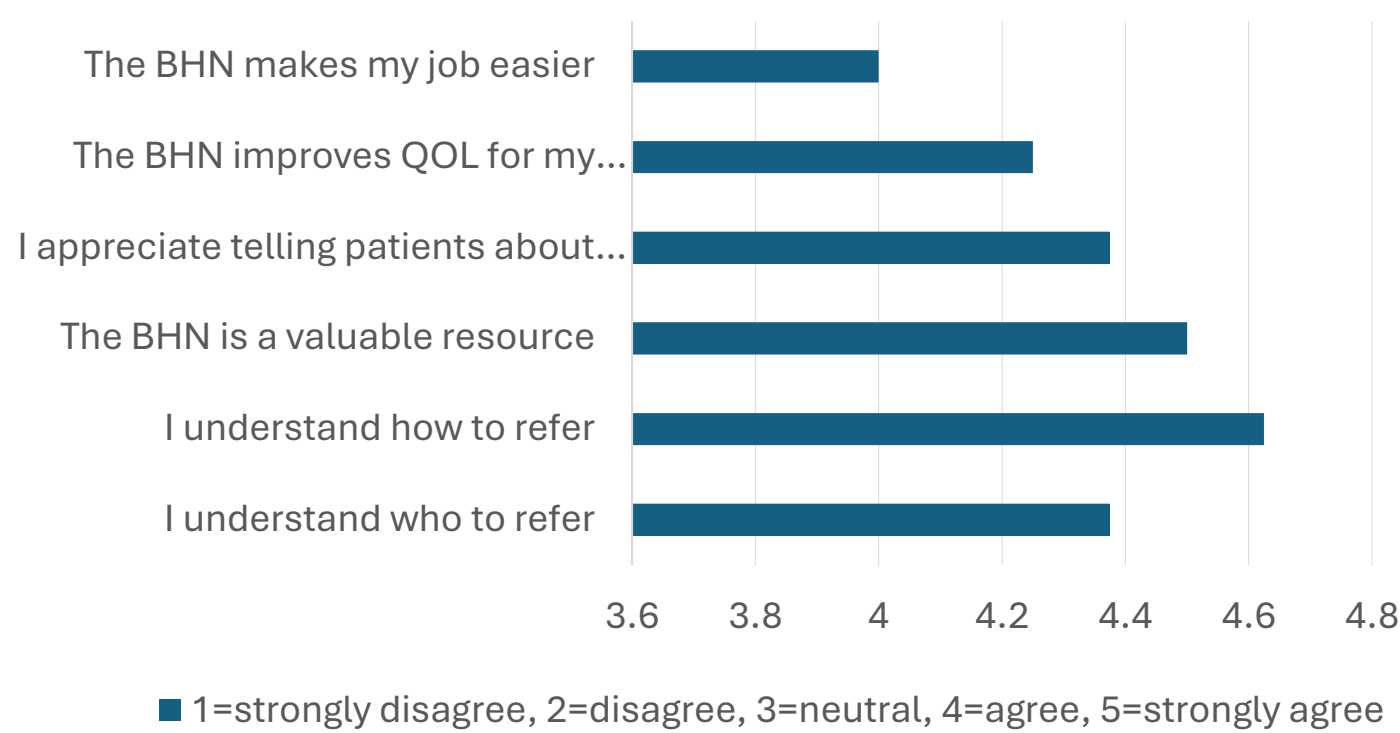
Patient/Caregiver Experience

- Patient/Caregiver ratings are generally high
 - No scores lower than 3
- Highest scores
 - Improved care overall (4.78)
 - Improved communication with medical team (4.72)
 - Improved QOL (4.62)
- Lowest scores
 - Understanding of services
 - Cost
- Sample quotes
 - “I can’t tell you how much relief I felt just talking to you”
 - “We were in crisis mode before”
 - “I would have been lost without the BHN”
 - “Reassuring to have someone help me”

Provider Experience

- Provider ratings are generally high
 - No scores lower than 3
- Highest scores
 - BHN is a valuable resource (4.5)
 - I appreciate the BHN service (4.4)
 - The BHN improves the quality of life for patients and caregivers (4.25)
- Most commonly reported benefits
 - Increased support for patients/caregivers
 - More efficient diagnostic process
- Most commonly reported critique
 - Need clarification of role

Provider Experience



Summary

- Brain Health Navigation was quickly adopted
- Nearly all referrals resulted in enrollment
 - Some initial referrals were not appropriate for BHN services; this improved within 2-3 months
- Caregiver experience has been very strong
 - Strong need for navigation services, and absence in routine care noted
- Provider experience was positive, though lagging behind caregiver experience
 - Providers may underestimate the value of BHN services to caregivers
- Responses from both caregivers and providers indicate a need for improved definition of program and communication of value

Conclusion

Brain Health Navigation (BHN) can significantly improve overall satisfaction among clinicians, patients with dementia and caregivers by addressing the many gaps in current care and decreasing overall friction within the healthcare system. As clinicians and healthcare systems are increasingly overwhelmed by the increasing numbers of those needing care, BHN offers one potential solution to elevate care, efficiency and overall satisfaction. Future work should be focused on opportunities to build upon BHN, with strategies to aid early diagnosis and coordination with primary care.

Acknowledgments

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