

CONFERENCE ABSTRACT

Embracing Client Engagement: A Strategy to Improve Services for Young Onset Dementia (YOD) at the Alzheimer Society of Brant, Haldimand Norfolk, Hamilton, Halton (ASBHNHH)

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Introduction

Receiving client feedback is crucial for providers to identify gaps and improve services. Surveys are typically used to collect client input for quality improvement (QI) consideration - but was this enough? We did not think so. The ASBHNHH conducted client surveys in 2019 and 2020 revealing that clients with YOD and their care partners have unique needs. Embracing client engagement as a framework allows clients to be empowered decision makers who direct what services they need. This paper will focus on our recent shift to empowerment through a co-design investigative project and outcomes for persons with YOD and care partners.

Aims Objectives Theory or Methods

With improved client engagement as a QI Plan indicator, the objectives of this project were to engage persons living with YOD and their care partners to identify gaps in service using co-designed, investigative strategies that promote people as partners in care. Qualitative research methods, including focus group discussions and semi-structured interviews, were used to examine the potential use of the co-design method in designing and delivering improved services. A YOD Advisory Group was assembled and meetings then took place through Zoom with the use of guiding questions, open dialogue, and Google Jam Board.

Highlights or Results or Key Findings

The YOD Advisory Group identified two service gaps to improve and increase: support needs for YOD in general, and resources at the time of receiving a diagnosis. The findings informed the subsequent development of a resource guide outlining “everything to know” when one is diagnosed; and a peer support group for persons with YOD and another for their care partners. Evaluation was also co-designed to better inform the success of these projects. The co-design process was reported to have been significantly empowering for the YOD Advisory Group and staff involved. All reported having benefited from the experience and contributing to the solutions from their own perspectives. Our client engagement efforts through co-design resulted in the development of new programs and resources that now fill the identified service gaps.

Conclusions

This work demonstrates the importance and value of establishing meaningful partnerships with YOD clients through engagement to ensure quality and relevance of services. Lived experience is viewed as a form of expertise and client engagement that is reflected in performance indicators related to the QI Plan for the ASBHNHH.

Implications for applicability/transferability sustainability and limitations

It was evident that client engagement contributed to enhanced quality improvement. Lessons learned from the experience of the ASBHNHH can inspire other service providers to engage their clients through co-design and QI projects. Anecdotal accounts of QI planning can be references to inform many other community service contexts.