**“One of the very lucky ones”: A critical realist case study of a woman with IDD’s experience of breast cancer treatment**

Rebecca Hansford (MA), Queen’s University, [8rlh3@queensu.ca](mailto:8rlh3@queensu.ca); Dr. Alyson Mahar (PhD), Queen’s University, [alyson.mahar@queensu.ca](mailto:alyson.mahar@queensu.ca); Dr Hélène Ouellette-Kuntz (PhD), Queen’s University, [helene.kuntz@queensu.ca](mailto:helene.kuntz@queensu.ca)

**Objectives:** Individuals with intellectual or developmental disabilities (IDD) experience worse cancer outcomes relative to persons without IDD. Our research team documented lower survival among people with IDD relative to without these disabilities across cancer stages, which highlights the need to consider cancer treatment specifically. It is important that the voices of individuals with IDD are highlighted when exploring their experience with breast cancer treatment. The objective of this component of a larger study was to explore the breast cancer treatment experience of one woman living with IDD.

**Method:** A critical realist case study was used. The single case included the breast cancer patient living with IDD, her support worker, and her surgeon. Semi-structured interviews were conducted. Interviews were transcribed and data were analyzed using critical realist thematic analysis. Advisors who are neurodiverse assisted with developing easy read and accessible study materials.

**Results:** Sandra (pseudonym) had stage II breast cancer and received treatment for her cancer five years earlier (lumpectomy, radiation, chemotherapy). Four themes were identified that could affect breast cancer treatment: relationships, access, decision making, and attitudes. Sandra had strong relationships with her support worker and surgeon, though tensions were present with her family. Sandra’s support worker ensured she had a constant presence during her treatment as “everyone but [support worker]… seems to run away”. Appropriate access to care was identified, including strategies to mitigate communication barriers, such as tailoring verbal information to Sandra. However, barriers were still noted as Sandra’s support worker “had to read” materials to Sandra. Sandra and her support worker also had to advocate for additional support overnight, so Sandra felt safe at night after her surgery. All three participants emphasized that Sandra was in charge of her treatment decisions. With the information provided by her doctor and reassurance from her support worker, Sandra was empowered to make choices about her own health. However, she had to stand up for herself with her family as they “weren’t too supportive” of her receiving chemotherapy and radiation. Attitudes were highlighted throughout the interviews. This included the attitudes of the surgeon that all people should receive appropriate breast cancer treatment, but also Sandra’s attitudes. Although Sandra was scared when she was diagnosed, she had a positive outlook and faith that she would get better, while noting that she enjoyed the extra “attention seeking”. Most importantly, Sandra emphasized how she is “just so happy that [she’s] well”.

**Conclusions:** Understanding the lived experience of breast cancer patients living with IDD is crucial to addressing gaps in breast cancer treatment care. This case study provides a mostly positive example of the type of care people with IDD diagnosed with breast cancer can receive though some gaps emerged, including the lack of accessible breast cancer treatment information materials. Not all individuals with IDD are this lucky, and many may lack positive support systems (support workers; unbiased clinicians, etc.) and access to care. Considering what occurs when these facilitators are absent is imperative for addressing breast cancer treatment gaps for people with IDD.