How can we make breast cancer treatment (and other cancer treatments) more accessible and inclusive: Lessons from mixed methods research

Breaking Barriers: Enhancing Cancer Care for Individuals with Intellectual Disabilities May 14, 2025

Dr Rebecca Hansford



# Thank you to the team

### Manitoba

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lanitoba

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## Outline



We will discuss regarding cancer generally, but also specific to breast cancer

- 1. What do we know so far across cancer milestones, including cancer clinical trials?
- 2. How can we address differences, disparities, and inequities to improve treatment and other cancer care outcomes for adults with intellectual and/or developmental disabilities

# Cancer-related care among adults with intellectual and/or developmental disabilities



## Incidence



- Adults with intellectual and/or developmental disabilities may be less likely to experience cancer compared to those without disabilities overall
- But among certain cancers/younger age groups, cancer risk is higher relative to those without disabilities
- More work needed to understand cancer incidence

Ward et al. (2024)

## Screening





Adults with intellectual and/or developmental disabilities are less likely to be screened for breast, colorectal, and cervical cancer.

Breast: OR= 0.46 (95% CI 0.43-0.49)

Colorectal: OR= 0.54 (95% CI 0.52-0.56)

Cervical: OR= 0.62 (95% CI 0.58-0.65)

# Diagnosis

Relative to those without disabilities



Retrieved from: https://www.mesothelioma.com/mesothelioma/metastasis/

Adults with intellectual and/or developmental disabilities are more likely to be diagnosed with metastatic breast and colorectal cancer

Breast: RR= 1.66 (95% CI 1.16-2.20)

Colorectal: RR= 1.44 (95% CI 1.24-1.67)

Adults with intellectual and/or developmental disabilities are also more likely to be diagnosed with an unknown stage at diagnosis (breast, colorectal, lung).

Our team is in the process of trying to understand why these differences are occurring.

### Survival

Relative to those without disabilities

Adults with intellectual and/or developmental disabilities are more likely to die from breast, colorectal and lung cancer. Breast: HR= 2.74 (95% CI 2.41–3.12)

Colorectal: HR= 2.42 (95% CI 2.18-2.68)

Lung: HR= 1.49 (95% CI 1.34-1.66)

They are also 1.53 times more likely to die from any cancer (95% Cl 1.38-1.71).



(Hansford et al., 2024; Hansford et al. 2024)

# What might cause these differences in survival?

What about treatment?

### **Treatment: Scoping review**

> Lancet Oncol. 2022 Apr;23(4):e174-e183. doi: 10.1016/S1470-2045(21)00694-X.

### Cancer treatment and decision making in individuals with intellectual disabilities: a scoping literature review

Anne J Boonman<sup>1</sup>, Maarten Cuypers<sup>2</sup>, Geraline L Leusink<sup>2</sup>, Jenneken Naaldenberg<sup>2</sup>, Haiko J Bloemendal<sup>3</sup>

### **Breast cancer treatment study: PhD research**

### Quantitative objective:

 Examine the relationship between intellectual and/or developmental disabilities and receipt of breast cancer treatment.

### Qualitative objective:

 Explore how one breast cancer patient with intellectual and/or developmental disabilities received breast cancer treatment.

### Breast cancer treatment study: PhD research

### Quantitative objective:

- Population-based retrospective cohort study
- Female breast cancer (stage I-III)
- ICES

### Qualitative objective:

- Critical realist case study
- Thematic analysis

### **Treatment: Quantitative research**

Adults with intellectual and/or developmental disabilities were significantly less likely to receive:

- Surgical resection (HR= 0.84; 95% CI 0.76-0.94)
- Breast conserving surgery (HR= 0.69; 95% CI 0.60-0.80),
- Adjuvant chemotherapy (HR= 0.49; 95% CI 0.32-0.74)
- Radiation (stage I-II) (HR= 0.58; 95% CI 0.46-0.73)

Adults with intellectual and/or developmental disabilities were **as likely to** receive

• Mastectomy (HR=1.13; 95% CI 0.97-1.33)

### **Treatment: Qualitative research**

Sandra received the breast cancer treatment she wanted

What affected her care?

- Contextual factors
- Attitudes
- Relationships
- Opportunities for shared decision-making and accommodations
- Advocacy

### **Treatment: Qualitative research**



### Advocacy

"I pulled up for myself. I didn't get upset or anything or bad anxious. I just told them, you know, I just say, hey, that's the way I want, I want it [treatment]"

Sandra



"But I was thinking about how...my dad was right and how sick he was and...I said, Sandra, I don't think you should do this [chemotherapy and radiation]."

Sister

## **Outcomes following treatment?**

### Relative to those without disabilities

Adults with intellectual and/or developmental disabilities after surgery are more likely to experience:

- Postoperative complication
- Extended length of stay
- 90-day mortality
- 90-day readmission
- Discharge to skilled nursing facility



# Cancer-related care among adults with intellectual or developmental disabilities



### What about inclusion in cancer clinical trials?

## Inclusion in clinical trials

"74.6% of NIH-funded clinical trials had eligibility criteria that could exclude adults with intellectual disability"

"About one-third of studies directly excluded adults with intellectual disability. 64.5% of studies may have indirectly excluded adults with intellectual disability"



Disability and Health Journal 15 (2022) 101368



Original Article

Eligibility criteria in NIH-funded clinical trials: Can adults with intellectual disability get in?



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# What about cancer trials specifically?

- We see that adults with intellectual and/or developmental disabilities are often excluded from this research
- And subsequently, these findings are not always directly transferable to this patient group
- Could exacerbate assumptions that adults with intellectual and/or developmental disabilities may not "handle" cancer treatments in the same way as those without disabilities



# What about cancer trials specifically?

Adults with intellectual and/or developmental disabilities have diverse experiences, and there could be individuals who would choose to pursue treatment via clinical trials

Need to work with people with lived experience and clinicians to help us better understand eligibility criteria



### Ways to Improve? Ways to Accommodate?

## **Next Steps**



### Inclusive research to inform next steps

System-level:

- Training, education, and resources for healthcare professionals and caregivers
  - How to best support and resources for addressing ableism, stigma, and bias across settings
- Patient navigation?
- Support for getting to and from cancer centres? Overnight support?
- Ethics committees for patients with additional considerations

Patient-level:

• Resources: Self-advocacy guides, plain language resources, resources in other formats (digital storytelling, podcasts, etc.),

### **Examples of Training and Resources**

### **Prepare to Communicate CARE**

Know your patient <sup>[i]</sup>	<ul> <li>Review available patient information and plan to accommodate needs (eg, physical, cognitive, communication).</li> <li>Involve the patient as much as possible.</li> </ul>	Cancer-specific resources needed though	
Create a safe and comfortable space [i, ii]	<ul> <li>Modify possible stressors that can make the patient feel uncomfortable or unsafe (eg, commotion, lights, smells).</li> </ul>		
Accommodate needs	<ul> <li>Book preferred appointment times.</li> <li>Plan for longer and several appointments.</li> </ul>	trials?	

Determine and adapt to how the patient communicates (verbal, non-verbal, devices).

https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/03/1.1CommunicateCare.pdf

### **Examples of Training and Resources**

Identifying and addressing ableism in healthcare settings **Am I Ableist?** Disability Awareness in Healthcare

https://sites.google.com/view/amiableist/



# **Patient navigation**

Trained in working with people with differences in understanding and communicating  $\rightarrow$  support with reaching clinical trials as well?

# Supports for overnight support, transport, parking, etc.?







# **Ethics committees for more complex patient experiences**

# What is ethically required to adapt to intellectual disability in cancer care? A case study of testicular cancer management

### C. Delany<sup>a,b</sup>, M. Diocera<sup>a</sup> and J. Lewin<sup>a,c,d,e</sup>

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### **Evaluate accessibility of existing patientdecision-aids**

### Breast Cancer: Should I Have Breast-Conserving Surgery or a Mastectomy?

You may want to have a say in this decision, or you may simply want to follow your doctor's recommendation. Either way, this information will help you understand what your choices are so that you can talk to your doctor about them.

Breast Cancer: Should I Have Breast-Conserving Surgery or a Mastectomy?							
<b>1</b> Get the Facts	2 Compare Options	<b>3</b> Your Feelings	4 Your Decision	<b>5</b> Quiz Yourself	6 Your Summary		
Cat the facto							

#### Get the facts

Your options

- Have surgery to remove the breast (mastectomy).
- Have surgery to remove just the cancer from the breast (breast-conserving surgery), followed by radiation treatments.

#### Key points to remember

 For early-stage breast cancer, studies show that women who have breast-conserving surgery followed by radiation treatments live just as long as women who have mastectomy.

https://www.healthwise.net/ohridecisionaid/Content/Std Document.aspx?DOCHWID=tv6530 Are existing patient decisionaids accessible for individuals with intellectual and/or developmental disabilities?

Need to work with people with lived experience to evaluate and develop accessible materials

## Easy read language, self-advocacy guides

In partnership with



https://www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14 c45b2a629/14209-10061/Breast%20care%20and%20screening

### Self-Advocacy Guide for Cancer Patients on the Autism Spectrum

Co-created by Paula Holmes-Rodman, PhD and Lindsey Holmes, ovarian cancer survivor, and an adult with autism, with input from the autism community.

https://www.autismcanada.ca/advocacyguide

Other ways we can communicate information should be considered: digital storytelling, podcasts, etc.

Considerations for cancer clinical trials as well

### **Community-engaged research**

Current Developmental Disorders Reports (2025) 12:15 https://doi.org/10.1007/s40474-025-00326-1

#### REVIEW

Narrowing the Gap in Cancer Care for Individuals with Intellectual and/or Developmental Disabilities: The Need to Prioritize Advocacy and Inclusion in Research for All People Diagnosed with Cancer

Rebecca L. W. Hansford<sup>1,2</sup>

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Check for updates

# How can we make sure cancer treatment accessible?

- Make tools that can help doctors speak in plain language
- Improve things that make treatment hard. For example, having more help at night and getting to and from the hospital
- Make easy read tools that can help people with intellectual disability understand
- Most important: Work with people with lived experience to understand what they want and need!



https://www.peoplefirstltd.com/

# Thank you. Questions?

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