



Advocacy for colorectal cancer screening and awareness in people with intellectual disability

Daniel Satgé^{1,2^}, Sarah Habib-Hadef¹, Amaëlle Otandault¹, Emmanuelle Samalin³, Brigitte Trétarre^{4,5}

¹Oncodéfi, Parc Euromédecine, Montpellier, France; ²Desbrest Institute of Epidemiology and Public Health, INSERM, Univ., Montpellier, Montpellier, France; ³Montpellier Cancer Institute (ICM), Digestive Oncology, Montpellier, France; ⁴Hérault Tumor Registry, Montpellier, France; ⁵UMR 1295, Université Toulouse III, Inserm, Team EQUITY, CERPOP Constitutive Team, Toulouse, France

Correspondence to: Daniel Satgé, MD, PhD. ONCODEFI Director, 209 Avenue des Apothicaires, 34090 Montpellier, France.

Email: danielsatge@orange.fr; daniel.satge@oncodefi.org.

Submitted Oct 11, 2022. Accepted for publication Apr 04, 2023. Published online Apr 25, 2023.

doi: 10.21037/jgo-22-998

View this article at: <https://dx.doi.org/10.21037/jgo-22-998>

Individuals with intellectual disability (ID) develop cancers as frequently as individuals in the general population, but those with ID develop an excess of digestive tract tumors, particularly colon and rectal cancers (1-3). Unfortunately, cancers are poorly documented in this group of individuals, which account for nearly 2% of the population. Of note, individuals with ID are less likely to receive a fecal occult blood test (FOBT), compared to individuals in the general population. For example, in Canada (4) and France, FOBT screening is practiced 29% less frequently in people with ID than in the general population (34% vs. 24%) (5). In France, colorectal cancer screening is practiced with FOBT every two years, from age 50 to age 74 years. This retrospective study aimed to examine colorectal cancer outcomes among adults with ID and compare them to the outcomes observed in the general population.

We retrieved data from the Hérault Tumor Registry on all patients with colon and rectum cancer diagnosed between 01/01/2012 and 31/12/2020. This registry comprehensively included all cancers from the southern France region, which included nearly 1,160,000 inhabitants. We cross-linked all colon and rectum cancers in the registry (n=7,023) with a list of 3,764 individuals with ID that lived in Hérault. This list was built in the context of the Cancer Hérault Adult Intellectual Disability (CHAID) study, and it was approved by the National Commission on Informatics and Liberty (No. 913052). This list included all individuals 20 years of age and older with ID that were either connected to an institution in

Hérault, where he/she lived or worked, or lived with their families and had consulted with physicians in hospitals and private clinics. For each person that entered one of the institutions, the disability and its level (mild, moderate, severe, or profound) was established by a physician. For individuals that lived with their families, the general practitioner was contacted for more information. The registry included data on biological characteristics, disease stage at diagnosis, treatment modalities, and outcomes. Those data were compared to corresponding data from the general population with the Chi-square statistical test.

During this 9-year period, 14 patients (5 men, 9 women) with ID were diagnosed with colorectal carcinoma. The median age was 66.5 (range, 32–85) years vs. 72.3 in the Hérault Tumor Registry. For 12 patients, the carcinoma was symptomatic. No tumor was found by screening. One tumor was discovered by systematic surveillance in a family with a genetic predisposition for colon cancer.

In 13 patients (93%), a positive lymph node was found at the time of diagnosis. Only one patient had a stage I/II carcinoma (7.1% vs. 48.7% in the general population; $P < 0.0001$), four patients had stage III tumors (28.6% vs. 21.2% in the general population; $P = 0.29$), and 9 patients had stage IV tumors with peritoneal carcinomatosis and visceral metastases in the liver and lung (64.3% vs. 26% in the general population; $P < 0.0001$).

Among 10 patients with colon cancers, 3 received only surgical treatment and 3 received chemotherapy as a first-

[^] ORCID: 0000-0002-0293-8081.



Figure 1 Images show a French booklet (*Monique passe une mammographie, Gilles fait un test du côlon, Leila fait un frottis*) that explains cancer screening for individuals with intellectual disability. (A) Estelle helps Gilles put feces on the sample stick. (B) Gilles and Estelle send the blue envelope by post to the laboratory.

line treatment without a primary tumor resection. Among four patients with rectal cancers, one was treated with preoperative chemo-radiotherapy, followed by primary tumor surgery, and 3 received palliative chemotherapy as the first-line treatment. Of the 14 patients included, only 3 are currently alive. The median overall survival was 2 months (range, 1–96 months).

We found important delays in colorectal cancer diagnoses among adults with ID. Half of these patients could not be treated, mainly due to the advanced tumor stages. Ten patients rapidly died of their malignancy, and one patient died after 4 years. A recent study on cancer in deceased adults conducted in England reported similar findings (6). In that study, among 865 cancers in 771 individuals with ID, 147 (19%) were located in the colon, rectum, or anus. Digestive tract cancers were diagnosed at stage IV in 57% of the patients. Less than three in 147 (2%) colorectal cancers were discovered by screening. The unexpectedly low participation in colon cancer screening among adults with ID was probably related to the screening policy. Screening for colorectal cancer began at age 60 years during the study period in the UK. However, this may have been too late, because 43% of individuals with ID died of lower digestive-tract cancer at ages 18–59 years. In contrast, at Ehime University hospital in Japan, regular screening, including FOBT, is currently performed in individuals with severe motor and intellectual disabilities. This practice led to the early discovery of 7 out of 9 reported malignancies,

and 7 of these patients, including three with colorectal cancer, underwent surgery. Moreover, all 7 patients were alive at the time of that publication (7).

Diagnostic delays are responsible for late tumor stages at diagnosis and poor outcomes (8). It is well established that cancer screening makes it possible to detect cancers at stages where they are accessible to treatment and easier to cure, which leads to less emotional and physical costs to the patient. Screening is likely to be even more advantageous for individuals with ID, because they have difficulty expressing pain and symptoms (9). Moreover, because cancer symptoms are exactly like symptoms of common chronic or minor abdominal diseases (10), objective testing is even more important for detecting cancers of the lower gastrointestinal tract. Studies have shown that the main barriers to cancer screening for individuals with ID included a lack of recommendations from physicians and professional caregivers, a lack of accessible information, reduced accessibility to screening procedures, and the need for support to complete the test (3,4).

In conclusion, this study suggested that, among individuals with ID, colorectal cancers were frequently discovered at an advanced stage. Moreover, this population participated less in screening with fecal occult tests (hemoccult) than the general population. Therefore, it is critical to strongly encourage and promote colorectal cancer screening for individuals with ID (*Figure 1*), because they are at higher risk of developing this malignancy. Moreover,

it is important to make these individuals aware of the abdominal symptoms that are indicative of gastrointestinal cancers.

Acknowledgments

Funding: This work was supported by the French National Cancer Institute (grant No. 2012-016); the Fondation Obélisque, and the Association Française de l'Épargne Retraite (AFER).

Footnote

Provenance and Peer Review: This article was a standard submission to the journal. The article has undergone external peer review.

Peer Review File: Available at <https://jgo.amegroups.com/article/view/10.21037/jgo-22-998/prf>

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at <https://jgo.amegroups.com/article/view/10.21037/jgo-22-998/coif>). ES reports that she received payment for lectures and presentations from Pierre Favre Oncology, Servier, AMGEN and MSD; received support for travel and meetings from Pierre Favre Oncology, MSD and Merck; and participated on data safety monitoring board of Pierre Favre Oncology, Servier, Daichi and Astellas. The other authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Open Access Statement: This is an Open Access article distributed in accordance with the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the non-commercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>.

References

1. Satgé D. Cancers des personnes déficientes intellectuelles. Chapitre dans l'ouvrage d'expertise collective INSERM: Déficiences intellectuelles 2016:1115-32.
2. Glover G, Christie A, Hatton C. Access to cancer screening by people with learning disabilities in England 2012/13: information from the Joint Health and Social Care Assessment Framework. *Tizard Learning Disability Review* 2014;19:194-8.
3. Willis D, Samalin E, Satgé D. Colorectal Cancer in People with Intellectual Disabilities. *Oncology* 2018;95:323-36.
4. Ouellette-Kuntz H, Coo H, Cobigo V, et al. Uptake of colorectal cancer screening among Ontarians with intellectual and developmental disabilities. *PLoS One* 2015;10:e0118023.
5. Bourgarel S, Trétarre B, Satgé D, et al. Le cancer colorectal et son dépistage chez les personnes déficientes intellectuelles vivant en institution en France. *Oncologie* 2016;18:265-70.
6. Heslop P, Cook A, Sullivan B, et al. Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources. *BMJ Open* 2022;12:e056974.
7. Ishimaru K, Akita S, Matsuda S, et al. Tumor Screening, Incidence, and Treatment for Patients with Severe Motor and Intellectual Disabilities. *J Nippon Med Sch* 2022;89:212-4.
8. Neal RD, Tharmanathan P, France B, et al. Is increased time to diagnosis and treatment in symptomatic cancer associated with poorer outcomes? Systematic review. *Br J Cancer* 2015;112 Suppl 1:S92-107.
9. Chew KL, Iacono T, Tracy J. Overcoming communication barriers - working with patients with intellectual disabilities. *Aust Fam Physician* 2009;38:10-4.
10. Neal RD. Do diagnostic delays in cancer matter? *Br J Cancer* 2009;101 Suppl 2:S9-S12.

Cite this article as: Satgé D, Habib-Hadef S, Otandault A, Samalin E, Trétarre B. Advocacy for colorectal cancer screening and awareness in people with intellectual disability. *J Gastrointest Oncol* 2023;14(3):1650-1652. doi: 10.21037/jgo-22-998