Association of Intellectual and Developmental Disabilities With Worse Outcomes After Surgical Treatment of Cancer

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Abstract

Background: Patients with intellectual and developmental disabilities (IDD) face unique challenges resulting in disparities in their health care. We sought to define the effect that IDD had on achievement of a "textbook outcome" (TO) following a cancer operation among a nationally representative cohort of patients. **Methods:** Data on patients who underwent surgery for a malignant indication, including lung, breast, liver, biliary tract, pancreas, and colorectal, between 2014 and 2020 were extracted from the 100% Medicare Standard Analytical Files database. The association of IDD with TO (defined as the absence of postoperative complications, extended length of stay, 90-day readmission, and 90-day mortality), expenditures, and discharge status was assessed using multivariable logistic regression. **Results:** Among 500,472 Medicare beneficiaries, 4,326 (0.9%) with IDD had a cancer diagnosis (breast, n=481; lung, n=419; hepatobiliary, n=194; pancreas, n=145; colorectal, n=3,087). Although overall incidence of TO was 50.5%, patients with IDD were less likely to achieve a TO than those without (37.1% vs 50.6%, respectively; odds ratio [OR], 0.50; 95% CI, 0.46–0.53; $P<.001$). On multivariable regression, patients with IDD had higher odds of a postoperative complication (OR, 1.53; 95% CI, 1.43–1.64), extended length of stay (OR, 2.06; 95% CI, 1.93–2.21), 90-day readmission (OR, 1.15; 95% CI, 1.07–1.24), 90-day mortality (OR, 1.90; 95% CI, 1.70–2.13), and discharge to a skilled nursing facility (OR, 4.28; 95% CI, 3.97–4.62) (all $P<.001$). **Conclusions:** Patients with IDD had a much lower chance of a postoperative TO, as well as discharge to a nonhome setting. The data highlight the need to improve the care of patients with IDD to assure equitable oncologic surgical care.

J Natl Compr Canc Netw 2024;22(9):610–616
doi:10.6004/jnccn.2024.7038

Background

Individuals with intellectual and developmental disability (IDD) constitute approximately 1.5% of the United States population, and the prevalence is increasing with the aging demographic.[1–5] Patients with IDD often have impairments in cognitive and social functioning that create barriers to equitable health care within a system designed primarily for individuals without disabilities.[4–6] Health care disparities may result in difficulties accessing medical care.[6,7] In turn, patients with IDD have a lower life expectancy and a higher mortality related to preventable causes.[4,6,8]

Accessibility and quality of cancer-related care among people with IDD has not been well-studied. Of note, people with IDD are at an increased risk of cancer.[9] This finding may be due to the fact that individuals with IDD experience greater difficulty identifying cancer-related symptoms and, consequently, present with later-stage disease.[8,10] Previous studies have also noted that social and cognitive manifestations of IDD may result in excessive difficulties in the identification of cancer symptoms, leading to lower rates of screening among this population.[11–13] Nonetheless, individuals with IDD generally rely on the same health care systems as patients without disabilities.[5,14] In turn, patients with IDD may face challenges navigating the complex, multidisciplinary care that is often needed during cancer treatment.[11] Patients with disabilities are required to navigate a system that is not patient-centered or designed to accommodate for certain health conditions, with underrepresentation of this patient population in clinical trials. Moreover, health care professionals may hold erroneous assumptions or implicit ableist attitudes that negatively impact the patient–provider relationship. Educating physicians about populations with disabilities, as well as accommodating for extra patient visit time and addressing alternative communication needs, may improve care for this patient population.[15–17] As a result of these systemic failures, patients with IDD may be especially vulnerable to disparate outcomes following surgical resection of cancer.

The association between IDD and postoperative outcomes among patients with cancer has not been comprehensively investigated. The current study sought to define the effect that IDD had on achievement of a "textbook outcome" (TO) following a cancer operation among a national cohort. Moreover, we sought to define differences in discharge disposition, cost of care, and long-term survival among patients undergoing a range of procedures for common cancer indications (eg, lung, breast, liver, biliary tract, pancreas, and colorectal) relative to IDD.

Methods

Data Source, Study Population, and Cohort Selection

Data on patients who underwent any type of surgery for a malignant indication, including lung, breast, liver, biliary tract, pancreas, and colorectal cancers, between 2014 and 2020 were extracted from Medicare Standard Analytical Files. Deidentified claims for inpatient and outpatient records were used alongside

Supplementary material is published online at https://doi.org/10.6004/jnccn.2024.7038

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the relevant ICD-9 and ICD-10 edition codes to identify patients with cancer who underwent surgery (see Table S1 in the supplementary materials, available online with this article). Patients who were not enrolled in Medicare Part A and B, and patients who were enrolled in a health maintenance organization during the index surgery were excluded, along with patients with multiple cancer sites. Adults with IDD were identified based on at least one encounter with ICD-9 or ICD-10 codes for intellectual disability (ICD-9: 317–319; ICD-10: F70–F79), pervasive developmental disorders (ICD-9: 299.×; ICD-10: F84.×), cerebral palsy (ICD-9: 343.×; ICD-10: G80.×), or Down syndrome (ICD-9: 758.0, ICD-10: Q90).[10,18] This retrospective cohort study was approved by the Institutional Review Board at the Ohio State University.

Outcome of Interest and Correlated Variables

The primary outcome of interest was TO, a composite measurement of postoperative outcomes, which included the lack of postoperative complications, no prolonged length of stay (<75th percentile for each procedure), and lack of readmission or mortality within 90 days.[19] Secondary outcomes of interest included discharge to home (self-care), receipt of chemotherapy after surgery, and mortality.

Patient and hospital characteristics were used to describe the cohort. Patient-level characteristics included age, sex, race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, and other), and Charlson comorbidity index (CCI) score. Hospital characteristics included US census region (Northeast, Midwest, South, and West), and hospital teaching status (teaching vs nonteaching), metropolitan (metropolitan vs nonmetropolitan), and hospital volume.[20,21] Hospitals were categorized as low-, medium-, and high-volume hospitals based on tertiles. County-level social vulnerability index (SVI) was merged with the Medicare Standard Analytic Files. The SVI, developed jointly and maintained by the Centers for Disease Control and Prevention and the Agency for Toxic Substances and Disease Registry, is a validated measure of community vulnerability and resilience to external pressures.[22]

Statistical Analysis

Descriptive statistics were presented as median values (IQR) for continuous measures and frequency (percentage) for categorical measures. Univariate analysis of demographic and clinical characteristics between patients with and without IDD was performed using chi-square test for categorical variables and independent sample *t* test or Wilcoxon test for continuous variables. The statistical approach and the type of models used for this study were chosen based on the characteristics of the outcome variables. For binary outcomes, the multivariable mixed effects logistic regression model with a random effect for hospital was used. Hospitals were included as random effects to account for clustering at the hospital level (ie, patients treated at the same hospital may experience similar outcomes due to receiving care from providers in the same hospital). A multivariable generalized linear regression model with gamma distribution and log link was fitted to explore index hospitalization and postdischarge (90 days) health care expenditures. The methods used to choose the appropriate distribution for modeling the expenditure data are described in the Supplementary Methods. Models for TO, individual components of TO, discharge to home, discharge to a skilled nurse facility (SNF), and expenditure were adjusted for age, sex, race/ethnicity, CCI score, SVI, region, index year, rurality, teaching hospital status, cancer type, hospital volume, and type of admission for surgery (emergency vs elective). Models for chemotherapy, mortality, and type of admission for surgery were adjusted for all variables, except elective surgery. All calculated models were provided in the Supplementary Material. In addition, the log form of follow-up duration was included in the model for some postoperative outcomes to control for the effect of differences in follow-up duration. Risk-adjusted Cox proportional hazards models were used to investigate the association between IDD and survival time. Although survival analyses are generally designed to handle varying intervals of follow-up time, in mixed effect logistic models, the models do not account for censored observations. Hence, to account for variability in follow-up duration, follow-up duration was included in the mixed effect models for those postoperative outcomes affected by follow-up duration. Models for TO were further stratified by hospital volume and SVI to assess the effect of IDD in stratified groups. Statistical analyses were performed using SAS version 9.4 (SAS Institute Inc.), and a 2-sided significance level of $\alpha=0.05$ was used.

Results

Patient Clinical and Demographic Characteristics

Among 500,472 Medicare beneficiaries, 4,326 (0.9%) patients with IDD had a cancer diagnosis (breast, n=481; lung, n=419; hepatobiliary, n=194; pancreas, n=145; colorectal, n=3,087) (Table 1). Patients with IDD were more likely to be younger than those without (median age, 59 [IQR, 50–67] vs 70 [IQR, 65–76] years; $P<.001$). Overall, roughly one-half of patients with IDD were male (53.0%) and individuals with IDD were more likely than those without IDD to self-identify as Black (n=637 [14.7%] vs n=42,868 [8.6%]) or Hispanic (n=78 [1.8%] vs n=6,392 [1.3%]) ($P<.001$). Most patients with IDD resided in a metropolitan area (n=3,297 [76.5%]), with more than one-third of patients with IDD residing in a county characterized as having a high SVI (n=1,589 [36.9%]).

Patients with IDD were more likely than those without to have a breast or colorectal cancer diagnosis (11.1% vs 7.9% and 71.4% vs 52.6%, respectively; $P<.001$ for both), whereas lung, hepatobiliary, and pancreatic cancers were less common among individuals with IDD (9.7% vs 28.4%; 4.4% vs 5.0%; and 3.4% vs 6.1%, respectively; $P<.001$). Of note, patients with IDD more often had a surgical procedure performed in a low-volume hospital than those without IDD (46.7% vs 32.9%; $P<.001$).

Textbook Outcome

The overall incidence of TO was 50.5% (breast, 53.5%; lung, 55.1%; hepatopancreatobiliary [HPB] tract, 41.0%; colorectal, 49.6%). Patients with IDD who underwent an operation for a malignant indication were less likely than those with IDD to achieve a TO (37.1% vs 50.6%; $P<.001$). Of note, after surgery, IDD status correlated with each individual component of TO (Figure 1). For example, patients with IDD were less likely to experience no complications (65% vs 75%), a standard length-of-stay (65% vs 78%), no 90-day mortality (89% vs 92%), and no 90-day readmission (71% vs 75%) ($P<.001$) than those without. Furthermore, after stratification by SVI and hospital volume, patients with high SVI and individuals treated in low-volume hospitals were less likely to achieve TO (SVI: 48.1% vs 52.0%; hospital volume: 48.0% vs 53.1%) (Figure 2).

On multivariable analysis, after controlling for clinical factors, IDD remained associated with TO. Specifically, individuals

Table 1. Demographic Characteristics of Patients With and Without IDD

Characteristic	Total n (%)	Without IDD n (%)	IDD n (%)	*P* Value[a]
Total, N	500,472	496,146	4,326	
Age, mean (IQR), y	70 (65–70)	70 (65–76)	59 (50–67)	<.001
Sex				<.001
Female	271,228 (54.2)	269,194 (54.3)	2,034 (47.0)	
Male	229,244 (45.8)	226,952 (45.7)	2,292 (53.0)	
Race/Ethnicity				<.001
White	425,973 (81.1)	422,494 (85.2)	3,479 (80.4)	
Black	43,505 (8.7)	42,868 (8.6)	637 (14.7)	
Hispanic	6,470 (1.3)	6,392 (1.3)	78 (1.8)	
Other	24,524 (4.9)	24,392 (4.9)	132 (3.1)	
Cancer type				<.001
Colorectal	264,295 (52.8)	261,208 (52.6)	3,087 (71.4)	
Breast	39,683 (7.9)	39,202 (7.9)	481 (11.1)	
Lung	141,439 (28.3)	141,020 (28.4)	419 (9.7)	
Hepatobiliary	25,194 (10.9)	25,000 (5.0)	194 (4.4)	
Pancreas	30,312 (6.1)	30,167 (6.1)	145 (3.4)	
CCI score				<.001
≤2	197,861 (39.5)	195,987 (39.5)	1,874 (43.3)	
>2	302,611 (60.5)	300,159 (60.5)	2,452 (56.7)	
Region				<.001
Midwest	120,313 (24.0)	119,145 (24.0)	1,168 (27.0)	
Northeast	98,427 (19.7)	97,414 (19.6)	1,013 (23.4)	
South	200,133 (40.0)	198,508 (40.0)	1,625 (37.6)	
West	81,598 (16.3)	81,078 (16.3)	520 (12.0)	
Metropolitan area				.006
Metropolitan	391,192 (78.5)	387,895 (78.6)	3,297 (76.5)	
Nonmetropolitan	106,845 (21.4)	105,835 (21.4)	1,010 (23.5)	
SVI (tertile)				<.001
Low	165,752 (33.3)	164,487 (33.3)	1,265 (29.4)	
Intermediate	165,975 (33.3)	164,522 (33.3)	1,453 (33.7)	
High	166,323 (33.4)	164,734 (33.4)	1,589 (36.9)	
Hospital volume, mean (IQR)	173 (88–301)	173 (89–301)	122 (60–230)	<.001
Hospital volume				<.001
Low	165,075 (33.0)	163,056 (32.9)	2,019 (46.7)	
Medium	165,568 (33.1)	164,248 (33.1)	1,320 (30.5)	
High	169,828 (33.9)	168,841 (34.0)	987 (22.8)	
Teaching hospital				<.001
No	202,905 (40.5)	201,040 (40.5)	1,865 (43.1)	
Yes	297,567 (59.5)	295,106 (59.5)	2,461 (56.9)	

Abbreviations: CCI, Charlson comorbidity index; IDD, intellectual and developmental disability; SVI, Social Vulnerability Index.
[a]Statistical significance: $P<.05$.

with IDD had 50% lower odds of achieving TO (odds ratio [OR], 0.50; 95% CI, 0.46–0.53; $P<.001$). During the postoperative period, the odds of no postoperative complication (OR, 0.65; 95% CI, 0.61–0.70), nonextended length of stay (OR, 0.49; 95% CI, 0.45–0.52), and subsequent nonurgent surgery (OR, 0.46; 95% CI, 0.43–0.49) were lower among patients with IDD (all $P<.001$). Furthermore, patients with IDD had lower odds of no 90-day readmission (OR, 0.86; 95% CI, 0.81–0.93) and no 90-day mortality (OR, 0.50; 95% CI, 0.45–0.56) (both $P<.001$). Notably, patients with IDD had markedly lower odds to be discharged to home (OR, 0.25; 95% CI, 0.23–0.27; $P<.001$), with a higher likelihood to be discharged to an SNF (OR, 4.34; 95% CI, 4.03–4.69; $P<.001$) (Table 2, Supplementary Table S2).

Long-Term Survival

Median overall survival was 49.7 months (95% CI, 49.5–50.0 months) in the cohort. Patients with IDD had a lower median survival (45.6 months; 95% CI, 42.8–48.0 months) versus patients without IDD (49.8 months; 95% CI, 49.5–50.1 months). Of note, patients with IDD had a higher risk of 1-, 3- and 5-year mortality following surgery than individuals without IDD (hazard ratio [HR], 1.72 [95% CI, 1.61–1.84]; 1.59 [95% CI, 1.51–1.67]; 1.57 [95% CI, 1.50–1.64], respectively) (Supplementary Table S3).

Discussion

IDD is often present at birth and can affect the entire life trajectory of an individual's physical, intellectual, and/or emotional development.[23] Over the past several decades, people with IDD have experienced longer life spans.[24] In turn, there is a growing population of patients with IDD who are suffering from chronic conditions, including cancer.[3,25,26] Unfortunately, the American Association on Intellectual and Developmental Disabilities (AAIDD) has noted that "there is a marked disparity of health between persons with IDD and the general population."[27] Patients with

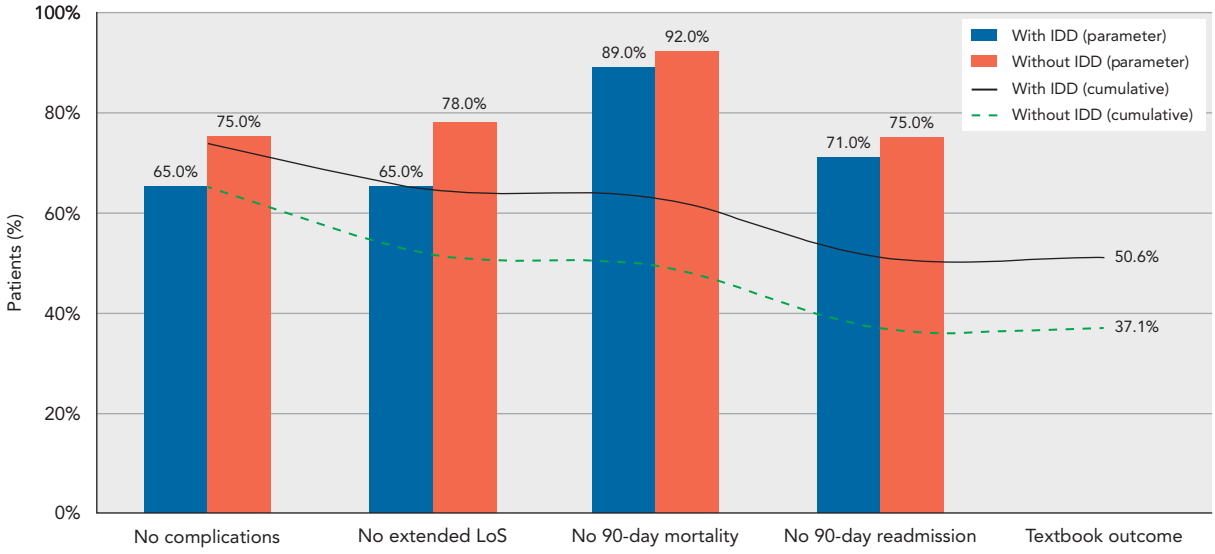

Figure 1. Proportion of patients achieving textbook outcome and individual components of textbook outcome stratified by intellectual and development disability status.
Abbreviations: IDD, intellectual and developmental disability; LoS, length of stay.

IDD and cancer may be particularly at risk for disparate care within multimodal, multidisciplinary oncological treatment. The lack of integrated delivery systems to link health care providers in a coordinated, vertical continuum of services may place the IDD community at particular risk.[28] To date, despite calls for increased research and education to address care for this vulnerable population, the association between cancer treatment and outcomes among patients with IDD remains ill-defined.[29–31] The current study was important because we specifically used a national database to define the association between IDD and postoperative outcomes after surgical resection of cancer. Notably, a TO was achieved in only 37.1% of IDD patients who underwent surgical resection. Moreover, patients with IDD had worse short- (ie, postoperative complications, length of stay, readmission rates, 90-day mortality, discharge to SNF), as well as long-term outcomes.

In the current study, patients with IDD were more likely to self-identify as Black or Hispanic (Table 1). Newacheck et al[32] noted that the prevalence of disability is higher among Black children than White children. In turn, as these individuals aged, differences in child-related IDD persisted into adulthood and impacted the natural history and treatment of chronic disease. Moreover, individuals with IDD have more barriers to engaging in preventive care and healthy behaviors, such as physical activity.[25,26] Often the health care system focuses on acute medical conditions and is poorly equipped to interact with health care needs of people with IDD who have chronic conditions.[24] In turn, individuals with IDD are more likely to be hospitalized for ambulatory care conditions and are less likely to have their needs met during admission, and have more inpatient medical complications.[33,34] In particular, people with IDD, their caregivers, and their families often have challenges navigating complex health care delivery systems and accessing health care systems. Although little attention has been focused on the evaluation of surgical outcomes, such data are important to target efforts to improve cancer care among patients with IDD.[8,10,35]

In the present study, we sought to characterize how IDD was associated with the likelihood of achieving TO after cancer surgery. Traditional "siloed" postoperative surgical outcomes have been criticized as inefficient to assess overall quality of care.[36] In turn, an emerging concept of overall quality has been defined as "textbook outcome" (TO): a single composite outcome globally representing ideal surgical care.[37–39] Of note, individuals with IDD had a decreased likelihood of experiencing an "optimal" postoperative course. In fact, individuals with IDD had markedly lower odds of achieving a TO, and lower odds of achieving each of the components of TO. Although the reasons for these findings were undoubtedly multifactorial, patients with IDD face barriers to in-hospital care, with increased challenges related to patient–provider communication and a higher dependence on caretakers.[34,40,41] Moreover, misunderstandings and implicit biases by health care providers may further contribute to poor outcomes due to a lack of formal training and experience in providing care to individuals with IDD.[26,41] The vast majority of residency programs provide minimal curricular programs on the care of patients with developmental challenges. Of note, some medical schools are beginning to offer content in IDD, including the Ohio State University, University of Iowa, and Tufts University School of Medicine.[24] Moreover, patients with IDD who resided in areas with high SVI were even less likely to achieve a TO. Social factors, such as economic status, race and/or ethnicity, and residential area, have increasingly been demonstrated to be intrinsically linked with access to accessible, affordable, and high-quality surgical care for patients with IDD.[10,42–45] These social determinants of health may also play a role in cancer treatment disparities among patients with IDD.

Results from our study can serve to guide efforts to enhance provision of high-quality health care among patients with IDD undergoing surgical resection of cancer. Our findings highlight the need for tailored perioperative planning and support to mitigate the higher risk of complications in this patient population. The increased complications and reduced likelihood of discharge to home for patients with IDD underscore the importance of comprehensive discharge planning and postoperative support, rather than advocating for premature discharge that may

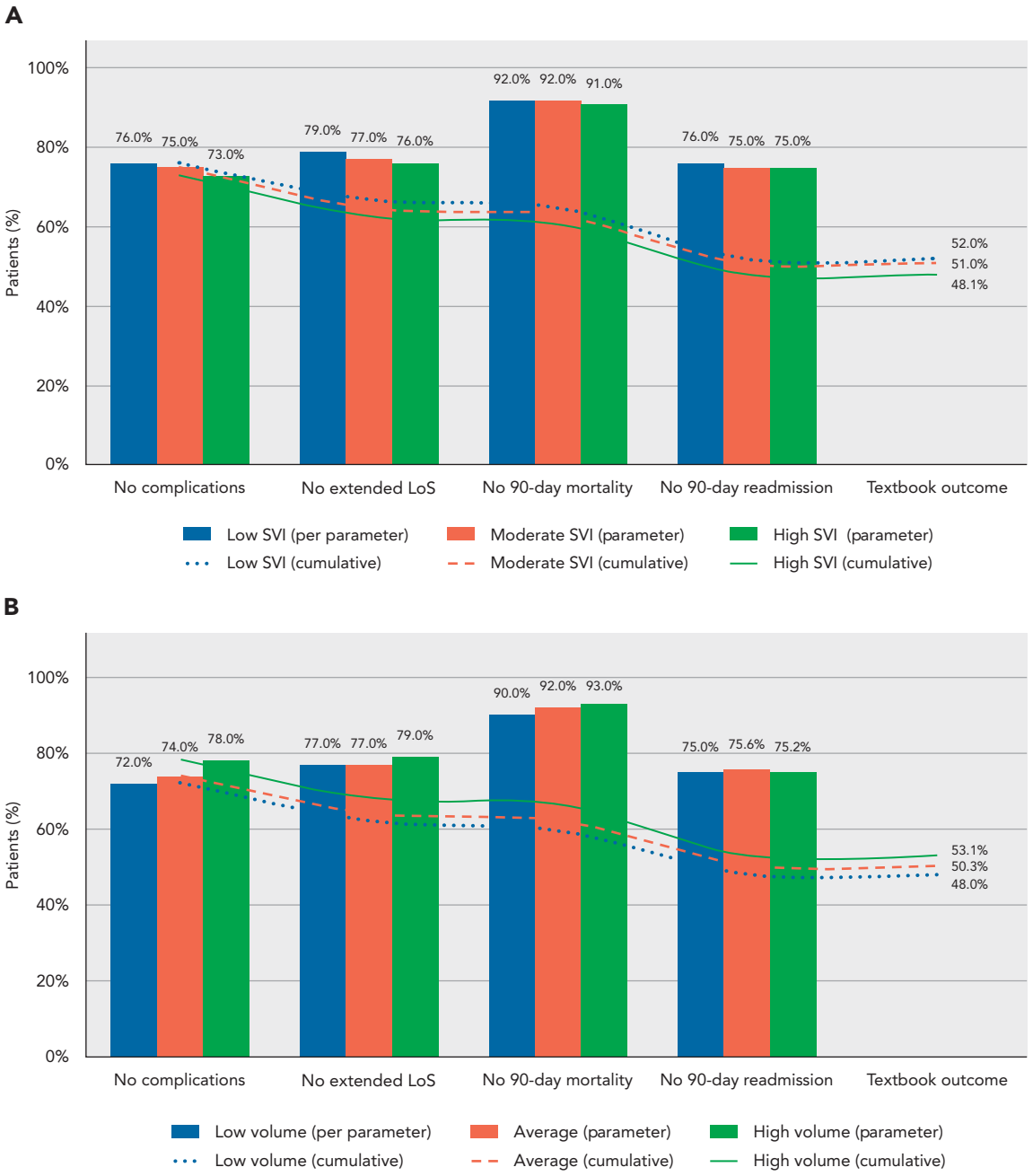

Figure 2. Proportion of patients achieving textbook outcome and individual components of textbook outcome stratified by **(A)** social vulnerability index and **(B)** hospital volume.
Abbreviations: LoS, length of stay; SVI, social vulnerability index.

not serve the best interests of individuals with disabilities. Moreover, there is a need for a multidisciplinary approach in the surgical care of patients with IDD, ensuring that decisions are patient-centered and account for the broader social and medical contexts influencing health outcomes. For instance, it is crucial to include patients with IDD in the treatment consent and decision-making process, as well as support self-management wherever possible to increase the effectiveness of clinical interventions in this patient population.[16,46] Implicit bias training for clinicians is also important to ensure equitable care for patients with disabilities, addressing the concern that adaptations in treatment based on behavioral issues may not always align with best practices or may be influenced by organizational constraints. In particular, physicians need to be aware that a patient's behavior or social skills during consultation should not bias treatment decisions nor exclude them from research and trial participation.[16] Policies and practice guidelines should seek to facilitate secure, safe, local surgical care to accommodate unique patient needs while delivering complex surgical care at specialized centers.[47,48] Although the current study identified disparities in outcomes for patients with IDD, it is crucial to consider how unmeasured factors, such as differences in cancer stage or aggressiveness, which could not be

Table 2. Multivariable Analysis of Surgical Outcomes for Patients With IDD, Adjusted for Competing Risk Factors

Outcome	OR (95% CI)	*P* Value[a]
Textbook outcome		
Without IDD	Ref	
IDD	0.50 (0.46–0.53)	**<.001**
No complications		
Without IDD	Ref	
IDD	0.65 (0.61–0.70)	**<.001**
No extended LoS		
Without IDD	Ref	
IDD	0.49 (0.45–0.52)	**<.001**
No 90-day mortality		
Without IDD	Ref	
IDD	0.50 (0.45–0.56)	**<.001**
No 90-day readmission		
Without IDD	Ref	
IDD	0.86 (0.81–0.93)	**<.001**
Nonurgent surgery		
Without IDD	Ref	
IDD	0.46 (0.43–0.49)	**<.001**
Discharge to home		
Without IDD	Ref	
IDD	0.25 (0.23–0.27)	**<.001**
Discharge to SNF		
Without IDD	Ref	
IDD	4.34 (4.03–4.69)	**<.001**

Abbreviations: IDD, intellectual and developmental disability, LoS, length of stay; OR, odds ratio; SNF, skilled nursing facility.
[a]Bold indicates statistical significance: $P<.05$.

accounted for due to data limitations, may have contributed to observed differences. Given the observed disparities, there is a pressing need for research that specifically addresses barriers to optimal surgical outcomes for patients with IDD, including prospective studies to identify tailored outcome measures, as well as define how best to adapt surgical care protocols and postoperative support to meet the unique needs of this patient population.

Findings of the present study should be interpreted while considering several limitations. Given the retrospective nature of the study, reporting and misclassification biases, including incomplete or inaccurate coding, were possible. Moreover, the dataset was restricted to Medicare claims, which may not be generalizable to the remainder of the population, including individuals with other insurance statuses. Due to database restrictions, clinicopathologic data on tumor burden and disease stage were not available, thus limiting the ability to adjust for potential clinical confounders in the analyses. Additionally, discharge disposition may have been affected by the patient's preoperative living status, given that patients with IDD are more likely to live in an assisted-living facility at baseline. A composite endpoint for surgical quality (ie, TO) was used, which has not been validated among people with disabilities. Given the low incidence of IDD in the study cohort, different IDD diagnoses were grouped and analyzed together.

Conclusions

Individuals with IDD have unique challenges and disparate outcomes after surgical treatment of cancer compared with individuals without IDD. In particular, patients with IDD were much less likely to experience a TO. In addition, patients with IDD had higher expenditures and were less likely to be discharged home. These data highlight the need to improve the care of patients with IDD to assure equitable, oncologic surgical care.

Submitted September 8, 2023; final revision received May 10, 2024; accepted for publication May 10, 2024. Published online October 22, 2024.

Author contributions: *Study concept & design:* Resende, Woldesenbet, Katayama, Rawicz-Pruszyński, Khan, Waqar, Mavani, Endo, Pawlik. *Data curation & formal analysis:* Woldesenbet, Katayama, Munir, Lima, Endo, Pawlik. *Methodology:* Resende, Woldesenbet, Lima, Rawicz-Pruszyński, Khan, Waqar, Mavani, Endo. *Project administration:* Resende, Woldesenbet, Katayama, Khalil, Pawlik. *Supervision:* Pawlik. *Visualization:* Woldesenbet, Katayama, Munir, Lima. *Writing—original draft:* Resende, Katayama, Rawicz-Pruszyński, Khan, Waqar, Mavani, Endo. *Writing—review & editing:* Munir, Lima, Khalil, Pawlik.
Data availability statement: The data for this study were obtained from the Medicare Standard Analytic Files. There are restrictions to the availability of this data, which is used under license for this study. Data can be accessed with permission from the Centers for Medicare and Medicaid Services.
Disclosures: The authors have disclosed that they have not received any financial consideration from any person or organization to support the preparation, analysis, results, or discussion of this article.
Funding: This study was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - Brasil (CAPES) - Finance Code 001.
Supplementary material: Supplementary material associated with this article is available online at https://doi.org/10.6004/jnccn.2024.7038. The supplementary material has been supplied by the author(s) and appears in its originally submitted form. It has not been edited or vetted by *JNCCN*. All contents and opinions are solely those of the author. Any comments or questions related to the supplementary materials should be directed to the corresponding author.
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References

1. Maulik PK, Mascarenhas MN, Mathers CD, et al. Prevalence of intellectual disability: a meta-analysis of population-based studies. Res Dev Disabil 2011;32:419–436.
2. McMahon M, Hatton C. A comparison of the prevalence of health problems among adults with and without intellectual disability: a total administrative population study. J Appl Res Intellect Disabil 2021;34:316–325.
3. Coppus AMW. People with intellectual disability: what do we know about adulthood and life expectancy? Dev Disabil Res Rev 2013;18:6–16.
4. Cuypers M, Koks-Leensen MCJ, Schalk BWM, et al. All-cause and cause-specific mortality among people with and without intellectual disabilities during the COVID-19 pandemic in the Netherlands: a population-based cohort study. Lancet Public Health 2023;8:e356–363.
5. Cuypers M, Schalk BWM, Boonman AJN, et al. Cancer-related mortality among people with intellectual disabilities: a nationwide population-based cohort study. Cancer 2022;128:1267–1274.
6. Hirvikoski T, Boman M, Tideman M, et al. Association of intellectual disability with all-cause and cause-specific mortality in Sweden. JAMA Netw Open 2021;4:e2113014.
7. Armin JS, Williamson HJ, Begay A, et al. Adapting a cancer screening education program for Native American women with disabilities. Int J Environ Res Public Health 2022;19:9280.
8. 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.
9. Liu Q, Adami HO, Reichenberg A, et al. Cancer risk in individuals with intellectual disability in Sweden: a population-based cohort study. PLoS Med 2021;18:e1003840.

10. Zondlak AN, Oh EJ, Neiman PU, et al. Association of intellectual disability with delayed presentation and worse outcomes in emergency general surgery. Ann Surg 2023;278:e1118–1122.
11. Kiani R, Vahabzadeh A, Hepplewhite EA, et al. Overcoming challenges in diagnosing and treating cancers in people with intellectual disability: a case analysis. Tizard Learn Disabil Rev 2014;19:51–58.
12. Mason J, Scior K. 'Diagnostic overshadowing' amongst clinicians working with people with intellectual disabilities in the UK. J Appl Res Intellect Disabil 2004;17:85–90.
13. Merten JW, Pomeranz JL, King JL, et al. Barriers to cancer screening for people with disabilities: a literature review. Disabil Health J 2015; 8:9–16.
14. Mansell J, Ericsson K, eds. Deinstitutionalization and Community Living. Springer; 1996.
15. Iezzoni LI. Cancer detection, diagnosis, and treatment for adults with disabilities. Lancet Oncol 2022;23:e164–173.
16. Boonman AJ, Cuypers M, Leusink GL, et al. Cancer treatment and decision making in individuals with intellectual disabilities: a scoping literature review. Lancet Oncol 2022;23:e174–183.
17. Witham G, Haigh C. A narrative literature review examining cancer treatment issues for patients living with intellectual disabilities. Eur J Oncol Nurs 2018;36:9–15.
18. Reichard A, Haile E, Morris A. Characteristics of Medicare beneficiaries with intellectual or developmental disabilities. Intellect Dev Disabil 2019; 57:405–420.
19. Kolfschoten NE, Kievit J, Gooiker GA, et al. Focusing on desired outcomes of care after colon cancer resections; hospital variations in 'textbook outcome'. Eur J Surg Oncol 2013;39:156–163.
20. United States Census Bureau. ZIP Code Tabulation Areas (ZCTAs). Accessed June 26, 2023. Available at: https://www.census.gov/programs-surveys/geography/guidance/geo-areas/zctas.html
21. Franks JA, Davis ES, Bhatia S, et al. Defining rurality: an evaluation of rural definitions and the impact on survival estimates. J Natl Cancer Inst 2023; 115:530–538.
22. CDC/ATSDR Social Vulnerability Index (SVI): Overview. Accessed June 13, 2023. Available at: https://www.atsdr.cdc.gov/placeandhealth/svi/index.html
23. Jansen DEMC, Krol B, Groothoff JW, et al. People with intellectual disability and their health problems: a review of comparative studies. J Intellect Disabil Res 2004;48:93–102.
24. Ervin DA, Hennen B, Merrick J, et al. Healthcare for persons with intellectual and developmental disability in the community. Front Public Health 2014;2:83.
25. Krahn GL, Fox MH. Health disparities of adults with intellectual disabilities: what do we know? What do we do? J Appl Res Intellect Disabil 2014;27:431–446.
26. Anderson LL, Humphries K, McDermott S, et al. The state of the science of health and wellness for adults with intellectual and developmental disabilities. Intellect Dev Disabil 2013;51:385–398.
27. American Association on Intellectual and Developmental Disabilities. Declaration on Health Parity for Persons with Intellectual and Developmental Disabilities. American Association on Intellectual and Developmental Disabilities; 2006.
28. Enthoven AC. Integrated delivery systems: the cure for fragmentation. Am J Manag Care 2009;15(10 Suppl):S284–290.
29. WHO global disability action plan 2014-2021. Accessed June 12, 2023. Available at: https://www.who.int/publications-detail-redirect/who-global-disability-action-plan-2014-2021
30. Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. Am J Public Health 2015; 105(Suppl 2):S198–206.
31. Mitra M, Long-Bellil L, Moura I, et al. Advancing health equity and reducing health disparities for people with disabilities in the United States. Health Aff (Millwood) 2022;41:1379–1386.
32. Newacheck PW, Stein REK, Bauman L, et al. Disparities in the prevalence of disability between black and white children. Arch Pediatr Adolesc Med 2003;157:244–248.
33. Walsh S, O'Mahony M, Lehane E, et al. Cancer and breast cancer awareness interventions in an intellectual disability context: a review of the literature. J Intellect Disabil 2021;25:131–145.
34. Iacono T, Davis R. The experiences of people with developmental disability in emergency departments and hospital wards. Res Dev Disabil 2003; 24:247–264.
35. Dhiman N, Chi A, Pawlik TM, et al. Increased complications after appendectomy in patients with cerebral palsy: are special needs patients at risk for disparities in outcomes? Surgery 2013;154:479–485.
36. Etzioni DA, Wasif N, Dueck AC, et al. Association of hospital participation in a surgical outcomes monitoring program with inpatient complications and mortality. JAMA 2015;313:505–511.
37. Karthaus EG, Lijftogt N, Busweiler LAD, et al. Textbook outcome: a composite measure for quality of elective aneurysm surgery. Ann Surg 2017; 266:898–904.
38. Sweigert PJ, Eguia E, Baker MS, et al. Assessment of textbook oncologic outcomes following pancreaticoduodenectomy for pancreatic adenocarcinoma. J Surg Oncol 2020;121:936–944.
39. Sweigert PJ, Ramia JM, Villodre C, et al. Textbook outcomes in liver surgery: a systematic review. J Gastrointest Surg 2023;27:1277–1289.
40. Lee MS, Diaz M, Bassford T, et al. Providing equitable access to health care for individuals with disabilities: an important challenge for medical education. Harv Public Health Rev (Camb) 2021;44.
41. Sowney M, Barr OG. Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units. J Adv Nurs 2006;55:36–45.
42. Lin JA, Liao CC, Chang CC, et al. Postoperative adverse outcomes in intellectually disabled surgical patients: a nationwide population-based study. PLoS One 2011;6:e26977.
43. Stirling M, Linton J, Ouellette-Kuntz H, et al. Scoping review protocol documenting cancer outcomes and inequalities for adults living with intellectual and/or developmental disabilities. BMJ Open 2019;9: e032772.
44. Huang SY, Chang CC, Lin CS, et al. Adverse outcomes after major surgery in children with intellectual disability. Dev Med Child Neurol 2021; 63:211–217.
45. Diaz A, Hyer JM, Barmash E, et al. County-level social vulnerability is associated with worse surgical outcomes especially among minority patients. Ann Surg 2021;274:881–891.
46. Friedman C, Rizzolo MC, Spassiani NA. Self-management of health by people with intellectual and developmental disabilities. J Appl Res Intellect Disabil 2019;32:600–609.
47. Lansing SS, Diaz A, Hyer M, et al. Rural hospitals are not associated with worse postoperative outcomes for colon cancer surgery. J Rural Health 2022;38:650–659.
48. Diaz A, Pawlik TM. Rural surgery and status of the rural workplace: hospital survival and economics. Surg Clin North Am 2020;100:835–847.