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Electronic Health Record Analysis of the Primary Care of Adults with Intellectual and Other Developmental Disabilities

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Abstract

Background and Aims—Adults with intellectual and other developmental disabilities (IDD) are at risk for sub-optimal primary health care. Electronic Health Record (EHR) analyses are an under-utilized resource for studying the health and primary care of this population.

Methods—This was a case-control EHR analysis of adults with IDD provided primary care through the Cleveland Clinic between 2005 and 2008. The IDD cohort was identified by relevant ICD-9 codes in problem list and encounter diagnoses. A comparison cohort matched by age, sex, race, and insurance was also specified. Demographic, health and health service characteristics of the two cohorts were compared.

Findings—The IDD cohort consisted of 1267 individuals, mean age 39 years, 54% male, 78% Caucasian. Age, sex, racial, and health insurance characteristics were similar in the 2534 individuals in the comparison cohort. Individuals with IDD were significantly more likely to carry diagnoses of epilepsy, constipation, osteoporosis, obesity, and hyperlipidemia; but were significantly less likely to bear diagnoses of hypertension, diabetes, osteoarthritis, heart failure, coronary heart disease, and COPD. Despite a lower mean BMI, individuals with IDD were more likely to be labeled obese. Only genetic consultation rates were higher in the IDD cohort.

Discussion—Health services research related to persons with IDD is becoming more feasible as large health systems adopt EHRs. Further analyses from this dataset will investigate whether variations in disease rates in adults with IDD represent true differences in disease prevalence versus disparities in health care.

Keywords

intellectual and other developmental disabilities; electronic health record; primary care; health service utilization

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An emerging body of literature is documenting disparities in the health care of adults with intellectual and other developmental disabilities (IDD) residing in the United States (Hayden, Kim, & DePaepe, 2005; Krahn, Hammond, & Turner, 2006; Parish & Saville, 2006; U.S. Public Health Service, 2001). To date, much of this research has been conducted through analysis of administrative databases including persons with disabilities (Hall, Wood, Hou, & Zhang, 2007; Havercamp, Scandlin, & Roth, 2004), comprehensive health care assessments of adults with IDD (Lewis, Lewis, Leake, King, & Lindemann, 2002), or painstaking chart reviews of limited clinical populations (Levy, Botuck, & Rimmerman, 2007). The increasing availability of electronic health records (EHRs) of large health system networks allows yet another means to identify differences and disparities in the health and health care of this population.

While the primary purpose of EHRs is to document and plan clinical care, they are also valuable sources of epidemiological data, and are increasingly utilized in health outcomes research (Dean, et al., 2009). As part of health information technologies, EHRs provide both a means for studying health services and a method for improving health care delivery. Linkage to an electronic health record allows incorporation of computerized prompts, specialized decision supports, and individualized clinician feedback reports; these have been associated with improved process and clinical outcome measures in chronic disease care (Dorr, et al., 2007).

Compared to claims data and many other administrative data sets, electronic health records contain richer clinical information, although some of that information is buried in unstructured narrative text, rather than in structured coded data, and requires additional work to retrieve and analyze (Schneeweiss & Avorn, 2005). The type of coded data that typically is directly extractable from the EMR includes pharmacotherapy, medical diagnoses, diagnostic laboratory and imaging tests ordered, referrals ordered, vital signs, and laboratory test results.

A systematic review of the scope and quality of electronic patient record data in primary care found that the overall positive predictive value of data was high, indicating good validity. However, the sensitivity of the primary care-EHR data was quite variable, with the highest sensitivity for prescribing and diagnostic data, and the lowest sensitivity for lifestyle and socioeconomic data (Thiru, Hassey, & Sullivan, 2003). In general, EHR systems appear to be conducive to more complete and accurate documentation by health professionals (Hayrinen, Saranto, & Nykanen, 2008).

The Cleveland Clinic Health System is a non-profit, multispecialty clinic with 9 affiliated hospitals serving a population of 2.5 million patients through 1 million ambulatory clinical encounters annually (Cleveland Clinic). While some patients receive only specialty tertiary care services through the system, over 450,000 receive ongoing primary health care at the main campus located in Cleveland and at 14 community-based health centers positioned throughout northeastern Ohio. Between 2000 and 2002, Cleveland Clinic phased in the mandatory electronic health record (EHR) system EpicCare (Epic Systems Corp., Verona, WI) to all the primary care practice sites. The EHR required clinicians to perform computerized provider order entry (CPOE), electronic prescription writing, structured

documentation of vital signs, diagnoses and medical history, electronic results review and tracking, as well as messaging and progress note documentation. The electronic health record is most often populated during face-to-face encounters with patients in ambulatory health service or in-hospital settings, but documentation may also be added without the patient's physical presence to reflect telephone-based communication and health care or to add historical information to the medical record.

The eResearch service (comprised of clinical informatics, database specialists, analysts and report writers) was established in 2004 as part of eCleveland Clinic, an eHealth arm of the Cleveland Clinic Information Technology Division. Since its inception, eResearch has utilized data from EHR and other clinical information systems to allow investigators to conduct prospective clinical trials, retrospective outcomes research and quality improvement efforts. All services occur in a Health Insurance Portability and Accountability Act (HIPAA)-compliant manner within the scope of each study's Institutional Review Board (IRB) protocol. From 2004 to 2009, eResearch has assisted in recruitment for over 60 clinical trials, and in numerous other research projects that have resulted in over 100 abstracts and publications.

The primary research questions examined in this paper are: (1) What is the feasibility of identifying a cohort of adults with IDD through a large multi-site health system electronic health record? (2) What is the feasibility of similarly identifying a comparison cohort matched by age, sex, race, and health insurance? (3) How do differences in the rates of documented co-morbid chronic diseases in these two cohorts compare to those described in other studies utilizing other methodologies?

Methods

This electronic health record (EHR) abstraction and analysis was reviewed and approved by the Cleveland Clinic IRB. All data extracted from the EHR used in this project was devoid of any personally identifiable information in accordance with institutional privacy policies and was conducted in a HIPAA-compliant manner. The IDD cohort was defined as all Cleveland Clinic patients receiving ongoing health care during the years 2005–2008 inclusive, whose problem list or encounter-based diagnoses contained the following International Classification of Disease, Ninth Revision (ICD-9) codes: 317–319 (intellectual disability), 343 (cerebral palsy), 758 (chromosomal anomalies, including Down syndrome), 299 (pervasive developmental disorders, including autism), 315.8 and 315.9 (unspecified delay in development) and 742.4 (anomalies of the brain).

Through a one-to-one matching process, every index patient in the IDD cohort was paired by age, sex, race, and health insurance status with two other Cleveland Clinic patients similarly receiving ongoing care during the same study period, and whose records did not include any of the above ICD-9 codes; this comprised the comparison cohort.

In order to examine only those patients receiving primary care through the health system, all patients had at least one encounter with a primary care physician documented during the study period. All of the primary care physicians were attending physicians who may or may

not have worked in conjunction with resident physicians or other healthcare providers. For the purposes of this study, only structured, coded data was abstracted for subsequent analysis. Most of the clinical diagnoses referenced in this study were entered into the EHR by the physicians themselves, while the vital signs were most commonly obtained and recorded by nurses and medical assistants.

Analyses were limited to index patients with IDD and their matched "control" patients who were aged 18 years and older as of January 1, 2005. Verification of the cohort specification and the matching process was performed. Utilizing standard descriptive statistics, the two cohorts were compared in their documentation of selected disability-associated conditions, biophysical data, chronic diseases, and health service use.

Results

The final adult IDD cohort was comprised of 1,267 individuals, paired with 2,534 control patients. The average age of both groups was 39 years and 54% were male. Table 1 describes the demographic characteristics of the two cohorts. Matching was verified by Pearson's Chi-square analyses or by T-test.

Characteristics of the IDD cohort are summarized in Table 2. Of the entire IDD cohort, 597 (47.1%) were identified with intellectual disability; of these, less than half were further specified according to severity (mild, moderate, severe, profound intellectual disability). Documented sensory impairments included 3.5% with moderate or severe visual impairment and 9.7% with hearing impairment.

Table 3 compares the documentation of disability-associated conditions and chronic diseases in the two cohorts. Adults with IDD were significantly more likely than those in the control cohort to carry diagnoses of epilepsy ($p<0.001$), constipation ($p<0.001$), osteoporosis ($p=0.006$), obesity ($p=0.022$), and hyperlipidemia ($p=0.036$); but were significantly less likely to carry diagnoses of hypertension ($p<0.001$), diabetes ($p<0.001$), osteoarthritis ($p=0.046$), heart failure ($p<0.001$), coronary heart disease ($p<0.001$), and chronic obstructive pulmonary disease ($p<0.001$).

Table 4 compares mean height, weight, body mass index, and blood pressure of the two cohorts. During the four-year study period, height was documented in 77% of the IDD cohort, compared to 80% of the comparison cohort; weight in 96% vs. 98%; and BMI in 76% vs. 78%.

Selected health care utilization measures are summarized in Table 5. Consultation rates in orthopedics ($p=0.040$), gastroenterology ($p<0.001$), pulmonology ($p<0.001$), cardiology ($p=0.004$), obstetrics and gynecology ($p=0.020$), general surgery ($p<0.001$), and pain management ($p<0.001$) were more frequent in the comparison group; there were no significant group differences in consultation rates in neurology, ophthalmology, dermatology, and geriatrics. Only genetic consultation rates were greater in the IDD cohort ($p=0.015$). Rates of primary care encounters were 54% higher in individuals with IDD, while rates of emergency room use ($p=0.013$) and hospitalization ($p<0.001$) were significantly higher in the comparison group.

Discussion

This study demonstrates the feasibility and potential utility of a large health system EHR abstraction to examine the health and health care of individuals with IDD. The ability to assemble a comparison cohort of a matched patient population within the same geographic location, receiving care by the same cadre of health care providers, allowed further insight into potential disparities in health care. Congruent with other studies, our initial analyses suggest adults with IDD may be at risk for under-diagnosis and/or under-documentation of major co-morbid chronic diseases, including hypertension, diabetes, and osteoarthritis. While there was significant reliance on primary care services, there appeared to be disproportionate underutilization of specialty consultations. These initial findings identify potential targets to anchor institutional quality improvement initiatives, and to plan for future health service needs.

The characteristics of this IDD cohort are congruent with that expected for a community-based sample of adults with IDD, with a mean age in the late 30's, for whom data are solely derived from administrative and clinical electronic health records (McDermott, Platt, & Krishnaswami, 1997). There was a preponderance of males; racial composition approximated that of the geographic region, as referenced in Northeast Ohio Community and Neighborhood Data for Organizing, a free and publicly accessible social and economic data system (NEO CANDO); and governmental health insurance was the most common payor. While intellectual disability was the most frequent disability identified, less than half of this subgroup was further characterized by severity of that impairment. Frequencies of identified sub-groups, including persons with chromosomal anomalies (most frequently, Down syndrome), cerebral palsy, and autism spectrum disorders, appeared congruent with those for an unselected primary care population (van Schrojenstein Lantman-de Valk, Metsemakers, Soomers-Turlings, Haveman, & Crebolder, 1997). The substantial rates of non-Down syndrome chromosomal anomalies may have reflected the health network access to a tertiary care center with comprehensive clinical genetic services. There was likely under-reporting of sensory impairments (Evenhuis, Mul, Lemaire, & de Wijs, 1997; Meuwese-Jongejeugd, et al., 2006; van Splunder, Stilma, Bernsen, & Evenhuis, 2006; Warburg, 2001). Low rates of documented sensory impairments likely reflect a number of processes and biases, including low rates of screening, hearing and vision services provided by out-of-network providers, and poor documentation in the EHR.

Co-morbidities common in persons with developmental disabilities, including epilepsy, spasticity, gastroesophageal reflux disease, constipation, and osteoporosis, were frequently documented, at rates consistent with published literature (Jansen, Krol, Groothoff, & Post, 2004; Jones & Kerr, 1997; Kerr, et al., 2003). Given the functionality of EpicCare, in which clinicians are prompted to associate all medications with a specific diagnosis, it was likely that most co-morbid conditions treated with a medication were entered into the electronic health record, and thus captured on data abstraction.

In contrast, this analysis suggested probable under-diagnosis of chronic diseases. Community-based studies of adults with IDD report rates of cardiovascular risk factors (hypertension, hyperlipidemia, etc.) similar to those of the general population (Baxter, et al.,

2006; de Winter, Magilsen, van Alfen, Penning, & Evenhuis, 2009; Draheim, 2006). Yet, compared to the control group, the relative odds of documented hypertension in the IDD cohort was just 0.66 (95% Confidence Interval: 0.57, 0.77). Similarly, the relative odds of documented diabetes were suspiciously low. Since spasticity, cerebral palsy, and obesity increase risk for degenerative joint disease, the low relative odds for osteoarthritis in the IDD cohort likely represented under-diagnosis. Future analyses will help elucidate whether there are indeed systematic biases in the screening, identification, and treatment of major chronic diseases in the community-based care of adults with IDD.

Interestingly, despite a lower mean BMI, the IDD cohort was significantly *more* likely to bear a diagnosis of obesity. Further analyses can clarify whether indeed individuals with IDD carry increased risk for the “label” of obesity.

Despite a high rate of epilepsy specifically identified in this IDD cohort, and a relatively high prevalence of orthopedic, ophthalmologic, pulmonary and dermatologic conditions generally found in adults with IDD (Straetmans, van Schrojenstein Lantman-de Valk, Schellevis, & Dinant, 2007; van Schrojenstein Lantman-de Valk & Walsh, 2008), only genetic consultations were more frequent in the IDD cohort. In particular, given the complexities inherent with identifying and treating pain in persons with IDD, the low rate of pain management consultation was disconcerting (Symons, et al., 2008).

Decisions around specialty consultations are complex phenomena influenced by the knowledge, attitudes, and expectations of patients, residential service providers, and primary care physicians. Multi-method research approaches will likely be necessary to understand the origins of low specialty consultation rates documented in this study.

Limitations of this study include those generic to the use of secondary administrative and clinical databases, as exemplified by EHRs, as well as those more specific to the study of persons with IDD. As articulated by Terris, Litaker, and Kououkian (2007), there are multiple dynamic and interacting sources of bias in administrative and clinical databases, including patient, clinician, encounter, community, and system-based factors. Patient-based factors influence an individual’s propensity to seek health care, to report health state attributes, and to adhere to diagnostic and treatment recommendations (Andersen, 1995). Clinician-based factors influence the clinician’s propensity to detect, treat, and document health status and health care. Encounter-based factors include the focus of the visit, the venue, and the intensity of services provided. Community and system-based factors include the availability of trained clinicians, reimbursement mechanisms, and the general state of medical knowledge relevant to the population or condition under study. Finally, there are many factors which influence the processing and storage of information in EHRs, including its origin, purpose, and input structure.

Limitations specific to the study of persons with IDD originate with the failure of clinicians to recognize and document the presence of IDD in their patients (van Schrojenstein Lantman-de Valk, et al., 1997). It is likely that some adults with IDD receiving primary care services at Cleveland Clinic during the study period were not captured in our abstraction process. Case-finding or prospective study designs would enable characterization of those

individuals with IDD at greatest risk for "invisibility." Since the disability-associated conditions and chronic disease analyses were based on diagnoses entered into the electronic health record as discrete data, e.g., problem list or encounter diagnoses, additional diagnoses entered as text only would have been missed. Templates are available for use in the EHR, but they are not mandatory and the system does not require corroborating studies to be conducted before a diagnosis is added to the EHR. For example, a documented hearing test is not required in the medical record before a diagnosis of hearing impairment can be added to the medical record, but this is no less reliable than analyses based on other kinds of secondary data sets. Lastly, health services data captured only those services provided by network-affiliated hospitals, clinics, and physicians; out-of-network health care was not captured.

Future analyses, based on laboratory data and medications typically associated with specific chronic diseases, will help confirm the reliability of documented diagnoses and allow an estimate of the extent to which clinicians failed to document prevalent diagnoses. Additionally, future analyses of this dataset will focus on identifying disparities in process and outcome measures related to the management of specific chronic diseases in adults with IDD. Patient, provider, and specific encounter data retrievable through the EHR will allow multivariate and multi-level analysis of differences and disparities in health care.

As an increasing number of health systems convert to electronic health records, new methodologies to examine and improve the health care provided to persons with IDD will emerge. Substantive progress will be slow, without strategic collaborations of researchers and clinicians with expertise in EHR-based research, clinical informatics, practice-based quality improvement, primary care, and developmental medicine.

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Table 1

Demographic Characteristics of IDD Cohort and Matched Control Cohort.

		IDD Cohort		Control Cohort	
Demographic Characteristic		**N**	**Mean(SD) or %**	**N**	**Mean(SD) or %**
Age		1267	38.8(14.3)	2534	38.9(14.5)
Gender	Male	681	53.8	1355	53.5
	Female	586	46.3	1179	46.5
Race	Caucasian	983	77.7	1995	78.7
	African American	213	16.8	417	16.5
	Hispanic	12	0.95	22	0.87
	Other	58	4.6	100	4.0
Payor	Private Insurance	337	26.6	727	28.7
	Medicaid	229	18.1	446	17.6
	Medicare	658	51.9	1276	50.4
	Self-Pay	43	3.4	85	3.4

Table 2

Characteristics of the IDD Cohort.

Condition (ICD-9 Code)	**N**	**%**
Intellectual Disabilities		
Mild Intellectual Disability (317)	94	7.4
Moderate Intellectual Disability (318.0)	87	6.9
Severe Intellectual Disability (318.1)	42	3.3
Profound Intellectual Disability (318.2)	30	2.4
Other Intellectual Disability (318)	172	13.6
Intellectual Disability NOS (319)	452	35.7
Cerebral Palsy (343)	378	29.8
Chromosomal Anomalies, Including Down Syndrome (758)	229	18.1
Down Syndrome (758.0)	149	11.8
Pervasive Developmental Disorders, Including Autism (299)	108	8.5
Unspecified Delay in Development (315.9)	73	5.8
Other Specified Delays in Development (315.8)	36	2.8
Other Congenital Anomalies of the CNS (742)	94	7.4
Other Specified Anomalies of the Brain (742.4)	62	4.9

Table 3

Prevalence of Disability-Associated Conditions and Chronic Diseases for IDD and Control Cohorts.

		IDD Cohort		Control Cohort			
	Condition (ICD-9 Code)	**N**	**%**	**N**	**%**	**Odds Ratio (95% CI)**	**P-value***
Disability-Associated Conditions	Blindness and Low Vision (369)	44	3.5	29	1.1	3.1 (1.9,5.0)	**<0.001**
	Hearing Loss (389/744.0)	123	9.7	86	3.4	3.1 (2.3,4.1)	**<0.001**
	Epilepsy (345/780.39)	290	22.9	132	5.2	5.4 (4.3,6.7)	**<0.001**
	GERD (530.8/530.1)	291	23.0	518	20.4	1.2 (0.99,1.4)	0.073
	Constipation (564)	239	18.9	250	9.9	2.1 (1.8,2.6)	**<0.001**
	Osteoporosis (733)	161	12.7	247	9.8	1.3 (1.09,1.7)	**0.006**
	Spasticity (343)	378	29.8	0	0.0	--	**<0.001**
Chronic Diseases	Hypertension (401)	313	24.7	841	33.2	0.66 (0.57,0.77)	**<0.001**
	Diabetes (250/357.2/362.0/366.41)	131	10.3	384	15.2	0.65 (0.52,0.80)	**<0.001**
	Obesity (278.0–278.8)	232	18.3	390	15.4	1.2 (1.03,1.5)	**0.022**
	Osteoarthritis (715)	148	11.7	355	14.0	0.81 (0.66,1.00)	**0.046**
	Hyperlipidemia (272.0–272.4)	443	35.0	800	31.6	1.2 (1.01,1.3)	**0.036**
	Congestive Heart Failure (428)	20	1.6	100	4.0	0.39 (0.24,0.63)	**<0.001**
	Coronary Heart Disease (414/429.2)	44	3.5	196	7.7	0.43 (0.31,0.60)	**<0.001**
	Chronic Obstructive Pulmonary Disease (491/492/494/496)	41	3.2	145	5.7	0.55 (0.39,0.78)	**<0.001**
	Asthma (493)	151	11.9	34	13.5	0.86 (0.70,1.06)	0.16

*Pearson's Chi-square

Table 4

Mean Height, Weight, BMI, and Blood Pressure of IDD and Control Cohorts.

	IDD Cohort		Control Cohort		
	N	**Mean (SD)**	**N**	**Mean (SD)**	**P-Value***
Height (Inches)	978	64.5(5.0)	2029	67.3(4.1)	**<0.001**
Weight (Pounds)	1222	169.8(53.7)	2491	191.9(60.4)	**<0.001**
BMI	964	28.5(7.6)	1981	29.4(8.1)	**0.005**
BP-Systolic	1243	118.0(13.8)	2522	123.6(16.3)	**<0.001**
BP-Diastolic	1243	74.0(9.2)	2522	76.1(9.9)	**<0.001**

*T-test

Table 5

Select Health Care Utilization Measures for IDD (n=1266) & Control Cohorts (n=2534).

		IDD Cohort	Control Cohort	
Type of Health Service	**Encounter Type**	**Mean Rate (SD)***	**Mean Rate (SD)***	**P-Value****
Primary Care	Primary Care Physician	1.88(1.93)	1.22(1.89)	**<0.001**
	Internal Medicine	1.29(1.84)	0.80(1.31)	**<0.001**
	Family Medicine	0.48(1.10)	0.37(1.44)	**0.009**
	Internal Medicine/Pediatrics	0.05(0.33)	0.04(0.25)	0.37
	Pediatrics	0.07(0.32)	0.01(0.30)	**<0.001**
Specialty Consultations	Neurology	0.35(1.09)	0.27(1.81)	0.083
	Orthopedic	0.20(0.61)	0.24(0.76)	**0.040**
	Gastroenterology	0.08(0.26)	0.12(0.57)	**<0.001**
	Pulmonary	0.05(0.28)	0.14(1.02)	**<0.001**
	Cardiology	0.13(0.63)	0.21(0.91)	**0.004**
	Genetics	0.060(0.247)	0.107(0.369)	**0.015**
	Ophthalmology	0.28(1.18)	0.27(1.25)	0.82
	OB/GYN	0.15(0.78)	0.22(1.00)	**0.020**
	General Surgery	0.06(0.25)	0.11(0.37)	**<0.001**
	Dermatology	0.13(0.60)	0.10(0.40)	0.095
	Pain Management	0.03(0.38)	0.15(1.02)	**<0.001**
	Geriatrics	0.012(0.164)	0.009(0.102)	0.65
Emergency Room		0.53(3.09)	0.82(4.10)	**0.013**
Hospitalizations		0.51(1.76)	1.06(2.77)	**<0.001**

* Mean rate of visits per patient per year.

** T-test