

Physician Attitudes and Practices on Providing Care to Individuals with Intellectual Disabilities: An Exploratory Study

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ABSTRACT—A dearth of literature exists regarding barriers to physicians providing medical care to patients with intellectual disabilities. Using an exploratory study, we assessed current physician practice for this population of patients. We mailed a 17-question anonymous survey to primary care physicians (PCPs) in Connecticut. Results showed that many physicians care for patients with intellectual disabilities, but approximately 62% of physicians believed caring for this group to be more difficult compared to other groups. Lack of training and education pertaining to patients with intellectual disabilities, issues of communication, and interruptions in continuity of patient care affect physicians' ability to care for this population. Future research should establish best practices and examine nationwide practices in providing care to patients with intellectual disabilities.

Background

INDIVIDUALS with intellectual disabilities are living longer, fuller lives¹⁻⁴ but are at increased risk of poor health.^{2,5} Intellectual disability is defined by the International Classification of Diseases as “a condition of arrested and incomplete development of the mind, which is especially characterized by impairment of skills manifested during the development period, which contribute to the overall level of intelligence.”^{1,6} As individuals with intellectual disabilities age, they risk acquiring illnesses associated with older age making the need for medical care essential to health maintenance.^{2,7} When managing the care of patients with intellectual disabilities, it is important that physicians determine the cause of illness in relation to the patient's disability.⁸ Education and training are required to conduct the etiological assessments that will lead to this determination, especially since the presentation of illnesses may be nonspecific, atypical, or absent for adults with intellectual disabilities.⁹

Physicians may be unprepared to assess the medical status of individuals with intellectual disabilities. Physicians may possess inadequate medical information¹⁰ due to fewer or no opportunities to gather sufficient medical information or to receive training in the provision of adequate medical care to this group of individuals.⁴ As patient-load increases, physicians may be hardpressed to keep pace with current research efforts surrounding the care of patients with intellectual disabilities. Little is known about training for physicians with regard to individuals with intellectual disabilities. Minihan and colleagues in 1993¹⁰ found that physicians expressed interest in continuing educational topics surrounding the care of individuals with intellectual disabilities. The paucity

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of literature addressing continuing education for physicians in this manner, however, suggests that few advances have occurred since 1993.

Another concern with providing adequate health services to this population is adequate time to accurately diagnose and treat patients. More time for examinations may be needed by physicians to treat adequately this special population of patients as compared to patients who have no known disabilities.^{4,11} A question remains as to whether physicians believe that caring for patients with intellectual disabilities is too time-consuming, especially based on a time-conscious health-care system governed by Health Maintenance Organizations (HMOs), precarious health insurance reimbursement rates, and other systems of reimbursement. Furthermore, patients with intellectual disabilities tend to be overly represented among those eligible for Medicaid benefits,⁴ making adequate reimbursement for physician services difficult. Limited amounts of time for medical visits may then contribute to ineffective communication between physicians and their patients with intellectual disabilities.

Issues regarding the continuity of medical care for this population also exist. Individuals with intellectual disabilities may depend upon family and friends for transportation to physician appointments. If individuals with intellectual disabilities have little or no contact with family and friends,¹² then continuity of medical care may be interrupted. Individuals with intellectual disabilities may not possess the capacity to make medical decisions,¹³ relying instead on caregivers to make such decisions; this includes the ability of individuals with intellectual disabilities to make decisions regarding health-care advanced directives and end-of-life care.

In an effort to expand the literature base on healthy aging for individuals with intellectual disabilities, an exploratory study was proposed using physicians in the state of Connecticut.

Purpose

The purpose of this study was to examine the attitudes and practices of physicians in providing medical care to individuals with intellectual disabilities. The study that we conducted was exploratory in nature. Not since 1993¹⁰ has an attempt been made at surveying physicians in a manner similar to that which we have presented here. The study that we have conducted in Connecticut may serve as the basis for a national survey in which physicians across the United States are surveyed regarding their ability to provide medical care to patients with intellectual disabilities and any barriers encountered in providing medical care to this special population.

Objectives

The objectives of the study presented here are twofold. First, we sought to assess current physician practice with regard to individuals with intellectual disabilities. Second, we focused on factors that impact the ability of physicians to provide care to individuals with intellectual disabilities.

Methods

Participants.—Family physicians and internists in the state of Connecticut were surveyed for this exploratory study. A list of primary care physicians in Connecticut was obtained from a statewide agency which contracts with the University of Connecticut for purposes of conducting research and providing education regarding issues pertinent to primary care. The list contained the names and addresses of a network of community-based primary care physicians involved in private practice. These physicians are engaged in the practice of internal medicine, pediatrics, and family medicine. Excluded from the list are physicians who are hospital-based, community health center-based, or practicing within a subspecialty. The list contained contact information for 1,469 physicians. Approximately 1,000 surveys were mailed to the primary care physicians; surveys were not mailed to the pediatricians. Fifty-two surveys were returned due to incorrect addresses, “no such recipient” labels, or the lack of a forwarding address. Two hundred and six surveys (22%) were returned and used for analysis.

Survey.—A 17-question anonymous mail survey was developed for the study. Thirteen of the questions were either forced choice (i.e., yes/no answers) or multiple choice in nature. Based on a previous study¹⁰ and the observations and experiences of the research team, elements were included in the survey which were perceived to be important, easily answered, and nonintrusive. The survey elicited responses regarding physicians’ experiences, feelings, education, and interest in current research efforts concerning patients with intellectual disabilities. In an open-ended format, the survey also provided physicians the opportunity to state opinions regarding beliefs about the most important factor affecting physicians’ ability to provide care to patients with intellectual disabilities and how care could be improved for this population. Physicians were also given the opportunity to include any other comments regarding the provision of medical services to patients with intellectual disabilities.

Statistical Analysis.—Since our study was exploratory in nature, descriptive statistics were tabulated for the survey responses. Data were entered and analyzed using version 10.0 of the Statistical Package for Social Sciences (SPSS) software. Reliability of the data entry was checked for 100% of the data; any errors were corrected. Frequency

data were used to provide further insight into the current care provided by physicians to adult patients with intellectual disabilities. Comparisons were conducted to examine relationships between and among the number of patients with intellectual disabilities in the respondent's practice, the amount of time respondents spent with patients with intellectual disabilities, the comfort level of respondents in caring for patients with intellectual disabilities, and the respondents' interest in learning more about current research efforts regarding intellectual disabilities. Relationships between physician specialty, physicians' comfort level with patients with intellectual disabilities, and the amount of training received by physicians with regard to intellectual disabilities were also examined.

Reliability analysis was conducted for the qualitative responses. Statements made by physicians were placed into categories by two raters. The categories were created by individual responses made by physicians. The two raters then individually placed each statement into its category to determine the percent agreement that the statement fit into the category. For the question regarding what physicians believe is the most important factor affecting the ability to provide care to patients with intellectual disabilities, raters attained 94% agreement. For the question regarding how to improve care of patients with intellectual disabilities, raters attained 99% agreement. For those statements in which the raters did not agree, consensus coding was conducted and the statement was placed into a category.

Characteristic	N	% of cases
Internal medicine	107	51.9
Family physician/family practice	54	26.2
No response	26	12.6
Geriatrics	5	2.4
Rheumatology	3	1.5
Endocrinology	3	1.5
Urgent care	2	1.0
Surgery	1	<1
Hospital board	1	<1
Pulmonary	1	<1
Occupational health	1	<1
General medicine	1	<1
Allergy and immunology	1	<1
Women's health	1	<1
Med/peds	1	<1
GI/IM	1	<1
Long-term care	1	<1

Note: Discrepancy in sample size due to multiple responses provided.

Results

Descriptive statistics.—Although only family physicians and internists were targeted, responses were received from those practicing in a range of specialty areas. As seen by Table 1, the majority of the physicians surveyed are primary care physicians (PCPs), having specialized in either internal (51.9%) or family medicine (26.2%). While most PCPs provide ongoing outpatient care to five or fewer adult patients with intellectual disabilities, at least 17.0% provide care to more than five adult patients with intellectual disabilities. The most common conditions for which physicians provided treatment were reported as infections (20.9%), neurological conditions (20.4%), endocrine conditions (19.5%), and cardiac conditions (18.3%). Less common, ongoing problems such as dementia and/or behavioral issues (15.4%) were also reported.

Most physicians surveyed reported caring for the following age groups of patients with intellectual disabilities: ages 22–34 (25.0%); ages 35–49 (48%); ages 50–65 (18.0%); and, age 75 or older (7.5%). Eighty-two percent of respondents stated that they see at least one patient with intellectual disabilities monthly on an outpatient basis. Twenty-six percent indicated that they see at least one patient monthly with intellectual disabilities on an inpatient basis. The majority of respondents (49.5%) reported spending zero to 20 minutes per visit with patients with intellectual disabilities. Approximately 41.3% of respondents reported spending 21 to 40 minutes per visit, and 9.2% reported spending more than 41 minutes per visit with patients with intellectual disabilities. Eighty-six percent of physicians stated that their patients with intellectual disabilities did not possess health-care advanced directives.

Seventy-five percent of respondents stated that for patients with intellectual disabilities whom they treat, Medicaid/Title XIX is the primary source of insurance, followed by Medicare, with 36% of respondents. Approximately 62% of respondents indicated that they felt caring for persons with intellectual disabilities was more difficult compared to other groups. Respondents also indicated that they anticipate caring for about the same or more patients with intellectual disabilities in the future, 81.4% and 11.7% respectively. Only 7% indicated that they would care for fewer patients with intellectual disabilities.

When asked if any formal training regarding the care of adults with intellectual disabilities was received during undergraduate or graduate medical education, 91% indicated none was received. Approximately 71% of respondents indicated that they would benefit from education that focused on the special health-care needs of patients with intellectual disabilities.

Qualitative responses to survey questions were coded and placed into categories. Eleven categories were identified for the question asking what was the most important factor that affects the respondent's ability to provide care to patients with intellectual disabilities. *Communication and understanding* was identified as the most frequent factor, indicated by 40% of respondents. *Continuity of care* made up the second highest category, approximately 33% of responses (Table 2).

Twelve categories were identified for responses to the question regarding how respondents would like to improve care to their patients with intellectual disabilities. *Continuity of care*, followed by *research and training/education* (approximately 20% and 21% respectively) were found to be the most frequent responses among the list of categories (Table 3).

Comparison statistics.—Of the comparisons examined for this exploratory pilot study, one comparison yielded a significant difference. A Mann-Whitney U Test was conducted to examine differences in the interest of learning more about current research efforts for adults with intellectual disabilities based on the number of patients seen monthly on an outpatient basis. It was found that respondents indicating an interest in learning more about current research efforts treat a significantly higher number of patients monthly on an outpatient basis than those respondents indicating a lack of interest in learning more about current research efforts $U(76,105) = 3152.5$, $P > 0.014$. Results indicate that the more patients with developmental disabilities a physician treats, the more interested he or she will be in learning more about current research efforts for adults with intellectual disabilities.

Discussion

The results of our study may help to dispel some common misconceptions within the field of medicine regarding individuals with intellectual disabilities. Two such assumptions are discussed here. The first assumption involves the idea that relatively few physicians provide the vast majority of medical care to patients with intellectual disabilities. The second assumption suggests that individuals with intellectual disabilities suffer from psychiatric illnesses that hinder the ability of this special population to receive adequate medical care.

An unexpected finding of our study is that many physicians provide care to patients with intellectual disabilities. As seen by the results of our study, dedicated physicians exist who provide medical care to patients with intellectual disabilities. Rather than a small number of physicians providing the majority of medical care to this special population, many physicians *each* provide care to a smaller group of patients with intellectual disabilities.

Table 2.—Most Important Factor Affecting Ability to Provide Care to Patients with ID (N=206)

Characteristic	N	% of cases
Communication/understanding	62	40.0
Continuity of care	51	32.9
Time constraints*	28	18.1
Insurance/coverage/access	26	16.8
Miscellaneous	24	15.5
Supports/services	21	13.5
Research and training/education	7	4.5
Forms/documentation	5	3.2
Patience	5	3.2
Healthcare directives/DNR status	3	1.9
State policy/oversight/regulation	3	1.9

*Study results show that MD visits with patients with intellectual disabilities average 20 minutes.
Note: Discrepancy in sample size due to multiple responses provided.

Furthermore, the idea that persons with intellectual disabilities have overriding psychiatric issues in relation to other health-care concerns is *not* well supported by the data. One explanation may be that known psychiatric concerns are routinely managed by psychiatrists rather than by PCPs.

Additionally, issues of communication are raised. Relevant processes and practices of exchanging information appear to create a definite barrier to improving efficiency and quality of care for this special population. Related to the issue of communication is that of the amount of time a physician spends with a patient with an intellectual disability. An interesting finding is that the average time spent by the physician in examining the patient with an intel-

Table 3.—How to Improve Care of Patients with ID (N=206)

Characteristic	N	% of cases
Continuity of care	21	21.4
Research and training/education	20	20.4
Communication/understanding	13	13.3
Insurance/coverage/access	13	13.3
Time constraints	12	12.2
Miscellaneous	12	12.2
Forms/documentation	12	12.2
No issues	12	12.2
Supports/services	11	11.2
Don't know/unsure	8	8.2
Healthcare directives/DNR status	4	4.1
State policy/oversight/regulation	4	4.1

Note: Discrepancy in sample size due to multiple responses provided.

lectual disability is approximately 20 minutes. This would not appear to be a markedly prolonged period of time when compared to the general population. Yet, despite the complex medical needs of patients with intellectual disabilities and the communication barriers that these patients may experience, physicians are not spending more time with these patients during a typical clinic encounter.

Possible explanations for this finding are numerous. Four such explanations are considered here. First, the quality of the communication during a visit between the physician and the patient with an intellectual disability may be poor. This special population of patients may be unable to express medical concerns; as a result, the physician is unable to spend time in addressing potential medical problems. Second, consideration should be given to the manner in which the time allotted for the medical visit is arranged. Does the patient spend the entire 20 minutes with the physician? Or is much of the visit's time spent in completing forms, having vital signs taken by the nursing staff, and the like? Next, low reimbursement rates for physicians' services rendered may dictate that no more than 20 minutes is allotted for visits with this special population of patients. A fourth explanation simply may be that no additional time is needed; all issues are sufficiently addressed within the 20-minute time frame.

Issues of communication with patients and caregivers effect a physician's ability to provide care to patients with intellectual disabilities. The need for systems of care that improve communication and initiate the exchange of information is evident. For example, the majority of physicians who responded state that most of their patients with intellectual disabilities do not possess advance directives of any kind. Reasons for this need to be further evaluated and explained, as the establishment of health-care advanced directives for this special population may be particularly complicated.

No significant relationship was found with regard to the physician's discipline and prior training received at the undergraduate or graduate level in the care of individuals with intellectual disabilities. In fact, the overwhelming majority of physicians had no formal training of any kind in working with patients with intellectual disabilities. The need and desire for such training appears to be fairly consistent across most survey respondents. This indicates that the process of medical school education needs to include training with regard to individuals with intellectual disabilities. One statistically significant finding involves the difference between the physician's need to learn more about current research efforts and the number of patients with intellectual disabilities in the physician practice. Physician interest in learning more about

research related to intellectual disabilities increases as the number of patients with intellectual disabilities in the physician practice increases. This group of physicians that cares for large numbers of patients with intellectual disabilities may also be the group most interested in research results or possibly enrolling patients in research studies. As research efforts improve for those with intellectual disabilities, physicians whose practices consist of large numbers of these patients may be looked to as sources of recruitment as potential research participants.

Medicaid/Title XIX is identified by physicians surveyed as the main payer source for approximately 75.0% of patients with intellectual disabilities. Despite the lack of financial incentives, the overwhelming majority of respondents in our study fully expect to care for patients with intellectual disabilities. This is similar to the finding of Minihan and colleagues¹⁰ that inadequate financial compensation, though a realistic concern for physicians, does not appear to act as a primary barrier to care.

This exploratory study possesses several limitations that should be taken into consideration with regard to the interpretation of results. First, the sample size of this study is relatively small. Second, all of the physicians surveyed in this study are located within a single state. Both of these limitations affect our ability to generalize the results to other populations of physicians. Physicians in other states will need to be surveyed in order to determine if responses are similar to those of physicians in Connecticut. Next, because we did not request demographic information other than the age range of patients, no generalization can be made according to the patients' age, gender, race, socioeconomic status, or the like. Additionally, the findings of our study cannot be analyzed according to demographic (e.g., age, gender, race) or other mitigating factors of either patients or physicians. As part of a pilot study, our survey was used to gather preliminary information. Therefore, the findings of our study may serve as the basis for similar studies that include broader geographic distributions of physicians.

Conclusion

Most physicians surveyed are willing to provide care for patients with intellectual disabilities. Clearly, however, known systems of care must be improved so as to foster more effective communication between physicians and patients with intellectual disabilities and their caregivers, more appropriate exchanges of information, and improved mechanisms of reimbursement. Research into the clinical care of patients with intellectual disabilities must increase in order to serve as the basis for improved clinical outcomes. Future research includes an examination of nationwide practices of providing care to

patients with intellectual disabilities. This type of research may prove to be a worthwhile step in more fully understanding such care and in establishing best practices to be used with patients who have intellectual disabilities. Finally, of immediacy is the need for increased training and education for physicians with regard to patients with intellectual disabilities. Increased training and education are keys to eliminating a significant barrier encountered by physicians in providing care to this special population.

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