

Providing Primary Health Care for People with Physical Disabilities: A Survey of California Physicians

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Context: Beginning with the Americans with Disabilities Act of 1990 an awareness of the need for equal access to health care for people with disabilities was established. Moreover, the promotion of health for people with disabilities, the prevention of secondary conditions, and the elimination of disparities between people with and without disabilities have been ongoing goals of federal legislation. Critical to achieving these goals is quality health care by primary care providers.

Objectives: Two specific areas of focus were to document: (1) the scope of California primary care physician's knowledge, attitude, and behaviors regarding physical disabilities and (2) the extent of physician training in disability-related primary care.

Design and Participants: Mail survey using a stratified probability sample of 2000 primary care physicians in the state of California during 2003.

Main Outcome Measures: Physical disability, defined as a substantial functional limitation in the dimension of mobility: exposure to, awareness of, and treatment assessed with standardized questions.

Results: A total of 501 questionnaires were returned completed for a returned response rate of 26%. Almost 20% of the physicians responding were unaware of the Americans with Disabilities Act and 45% were not aware of its architectural requirements. Most common architectural problems cited were examination room accessibility (15.4 %) and examination table accessibility (49.1%). The majority of all physicians (61.5%) found it more difficult to examine individuals with a physical disability and spent more time in performing the examination (82.3%). In addition, those physicians who had some training on physical disability issues either in medical school (22.8%) or in residencies (34.1%) were in the minority. The majority (72.4%), however, acknowledged the need for such training.

Conclusion: The responses suggested that the majority of California primary care physicians have at least some difficulty in examining patients with physical disabilities and many are uncomfortable in managing their care. A lack of training in medical school and in residency programs was noted as contributing factors and suggests the need for disability awareness training for primary care physicians.

Primary health care is defined as first contact care that includes prevention, health maintenance, and treatment of minor medical problems. It has been described by some as "personal health services" and the physicians who provide such care as "personal physicians", regardless of specialty.¹ Certainly from both the patients perspective and actual practice patterns the dichotomy between generalists and specialists is artificial.² Primary health care also includes advocacy for persons and helping them access appropriate medical and financial resources.³ The concept of advocacy refers to a pathfinder concept, helping patients to navigate and use the human and financial resources available to them.

In today's health care environment the above mentioned advocacy necessarily includes those persons with physical disabilities. A national 2001 survey reported that the number of persons with limitations in usual activities due to chronic conditions was 30.9 million or 11.4% of the population;⁴ this study and others⁵ have reported that the percentage of adults with moderate to severe mobility difficulty is over 12%. Federal legislation, including the Americans with Disabilities Act of 1990 has mandated equal access to public services and health care for people with disabilities; the promotion of health for people with disabilities; the prevention of secondary conditions; and the elimination of disparities between people with and without disabilities. Moreover, a shift has occurred in this area to focus on health and function rather than impairment and disability.⁶ Health is now viewed as the ability to function effectively in particular environments and given this, persons must have architectural, equipment, and social/emotional accessibility.

One barrier to obtaining quality medical care is the lack of adequate physician training and experience in working with this population.^{7,8} In addition, the lack of disability-specific knowledge among primary care providers⁸ and a minimal awareness among most physicians on the difficulty that many persons with physical disabilities have in obtaining quality primary medical care⁹ has been documented. This may also be the reason why that there seems to be a lack of interest in providing health care to this patient population.¹⁰ Perhaps education of primary care physicians about the needs of person with disabilities in accessing primary medical care and an awareness of their specific problems could result in more interest, both in terms of providing care and being comfortable with the care they provide. This would suggest a need for additional education of primary care physicians on issues specific to people with common disabilities.

Research and service priorities in the area of primary health care for persons with physical disabilities have been topics of interest for many years.^{11,12} Areas of focus have been on access to primary care,^{13,14} health issues associated with aging,¹⁵ financing of service,¹⁶ coordinated health care management,^{17,18} and the training of primary care providers in disability-related primary care.^{19,20} These studies found that most primary care physicians are not comfortable with caring for people with physical disabilities and are not prepared adequately to deal with disability-specific issues.

To evaluate current knowledge and practices of primary care physicians in California on caring for persons with physical disabilities we initiated this study. We collected data on demographic characteristics, previous physical disability related education, current provision of care and perceived barriers and opinions regarding delivery of primary care. The results of this study can be used in identifying educational needs of practicing primary care physicians and designing medical school curriculums.

METHODS

Participants

At the time of this study the total number of physicians practicing in the state of California was 80,000. Our population of interest was primary care physicians defined for this study as those who provide medical diagnosis, treatment, and guidance for an individual or family on a long-term, continuing basis and include family physicians, internists, pediatricians, and obstetricians/gynecologists. Thus, to ensure a representative sample population, a random sample of active primary care physicians was stratified by the following variables: primary specialty (family practice, internal medicine, obstetrics/gynecology, and pediatrics), gender, and geographical region.

The sampling frames of physicians were obtained from a medical marketing service list representing the American Medical Association (AMA). The set included a stratified random sample of: 500 internal medicine, 500 family practice, 500 pediatric, and 500 obstetric/ gynecology physicians selected for a total of 2000 California physicians. Since our population of interest was primary care physicians in practice in California who have some exposure to patients with physical disabilities those physicians who did not have any exposure to this patient population were asked not to complete the questionnaire.

Questionnaire Design

In a previous study, osteopathic physicians were surveyed on their awareness and knowledge base on caring for persons with physical disability.²¹ The questionnaire used in that study was modified here. In addition, an advisory committee was formed to assist with the development of the survey instrument. The committee consisted of several individuals with disabilities, physicians, an individual with a medical legal background, and a research expert. Based on input from the advisory group an initial survey instrument was developed. This instrument was tested with members of the advisory group and was then revised. In a small pilot study, this prototype questionnaire was given to 40 physicians at several medical centers in southern California. The physicians were asked to complete and return the questionnaire and provide comments on its administration and suggestions for improvement. Modifications were made as deemed appropriate. The average time required to complete the questionnaire was 15 minutes.

The 41-item, six-page questionnaire asked respondents to provide information on the following: demographic information; the number and type of physically disabling conditions seen in their medical practice; the architectural environment of their medical practice; the degree of comfort in examining and treating patients with a variety of physical disabilities; the knowledge of community resources available for people with physical disabilities, and the need for continuing medical education. Person with a disability was defined as both children (0-17 years) and adults (18 years+) with physical and functional limitations. Specifically, the survey content included demographic information on the gender, medical school attended, year of graduation, present employment status, size of practice, number of patients seen daily, and location of practice.

Physicians' were only asked to complete the questionnaire if they had some contact with patients who had physically disabling conditions that specifically impaired mobility. These conditions included stroke, traumatic brain injury, neuromuscular diseases, spinal cord injury, poliomyelitis, amputations, arthritis, and developmental disabilities. In connection with this the respondents were asked whether they were aware of the Americans with Disabilities Act (ADA) in general and specifically in regards to their office. Questions asked were those on architectural features that allowed or prevented accessed by those patients with physical disabilities including ramps, parking spaces, office/examination room maneuverability and examination table.

In addition questions were asked on established protocols for office staff in managing patients with physical disabilities; on the physician's difficulty, and the specific reasons for the difficulties. Also, questions were asked on whether for the same chief complaint more time is spent in examining a patient with a physical disability.

Questions on referral patterns to other health care providers and health care programs. Health care providers included physiatrist, physical therapist, occupational therapist, speech therapist, psychologist, social worker, nurse, and vocational/rehabilitation counselor. Health care services included those most common in California including California Department of Rehabilitation, California children services, public transit services for the Disabled, and disability specific organizations. Specific questions dealt with the respondent's awareness of the provider or program and the services they provided and whether or not they had referred any patient to the particular provider/program.

Lastly, respondents were asked questions on whether they had received any education in medical school education or residency training on caring for people with physical disability. In addition, questions were asked on their specific education needs were and how best to deliver that information

Data Collection

Questionnaires were sent by mail. In addition to the six-page questionnaire, each 9 x 12 mail envelope contained a cover letter from the principle investigator explaining the purpose of the study, a letter of support from an active California disability-advocate, and a stamped envelope for use in returning the completed questionnaire. Follow-up reminders were sent one month following the initial mailing with the goal of obtaining a 30% response rate.

Statistical Analysis

Descriptive statistics were used to summarize all responses. For quantitative responses means and standard deviations were calculated. For categorical data the frequency of responses to each question and the percentage of the total sample were calculated. A chi-square test was used to examine relations between two or more sets of responses.

RESULTS

Out of the 2000 questionnaires sent out a total of 1959 questionnaires were received and of these 501 were returned completed. This represented a response rate of 26%. Specific demographic data on gender, medical specialty, year of graduation from medical school, type of employment, and size of practice are presented in Table 1. Those least represented in our sample were obstetrician/gynecologists (17.2%, n=86), pediatrics (32%, n=164), family practice (26%, n=132), and internal medicine (23%, n=118) were fairly equally represented. We also asked for the respondents to indicate the medical school attended. Of the 379 responses to this question, 28.4% (n=108) had attended a medical school within California. In addition, 10.2% (n=39) attended a medical school outside the United States.

Table 1: Demographics of Respondents

Demographics of Respondents	Percentage
Gender:	
Male	57.0
Female	43.0
Year of Graduation (Medical School):	
1960's	06.2
1970's	23.2
1980's	34.5
1990's	36.1
Specialty:	
Pediatrician	32.8
Family Practice	26.0
Internist	23.6
Obstetrician/Gynecologist	17.2
Present employment:	
Full-time, salaried	41.9
Full-time, self-employed	38.2
Part-time, salaried	10.2
Part-time, self-employed	06.9

Only those primary care physicians having contact with patients with some type of physical disability were asked to complete the questionnaire. The percentages of physicians having contact with a variety of physical disabilities are presented in Table 2 (below). Clearly, the most frequently occurring diagnosis was developmental disabilities, arthritis, and stroke. Other frequently reported disabilities included: Parkinson disease, traumatic brain injury, spinal cord injury, amputation, and poliomyelitis.

Table 2: Type of physical disability and frequencies

Type of physical disability and frequencies	Percentage
Disability:	
Developmental disabilities	66.8
Arthritis	66.6
Stroke	63.9
Neuromuscular diseases	55.8
Parkinson Disease	46.7
Traumatic Brain Injury	44.5
Amputation	40.5
Spinal cord injury	36.6
Poliomyelitis	25.1
Other	03.5

Whereas 80% of all the primary care physicians sampled were aware of the ADA and its requirements, almost 20% of the physicians sampled were unaware of the ADA and 45% were not aware of the architectural requirements of this federal law (see Table 3 below). As far as the office areas that were most inaccessible to a patient with a disability 51% of the physicians reported that an examination table was not available to accommodate someone in a wheelchair and 15% indicated that the examination room itself interfered with accessibility.

Table 3: Americans with Disabilities Act (ADA) related data

Americans with Disabilities Act (ADA) related data	Percentage	
	Yes	No
respondents who were aware of the ADA	81.3	18.7
respondents aware of the accessibility guidelines of the ADA	54.9	45.1
<u>Office areas accessible to a person using a wheelchair:</u>		
▪ outside ramps/curve cuts	98.0	02.0
▪ parking	96.8	03.2
▪ waiting room	93.3	06.7
▪ rest room	88.1	11.9
▪ examination room	85.6	14.4
▪ examination table	50.9	49.1
▪ written guidelines for office staff (eg safe transfers)	20.6	79.4

When questions were asked regarding whether the physician found it difficult to examine individuals with disabilities 62% reported that they did find it difficult (Table 4 below). The reasons varied but for many (77%) patient weakness and patient balance (49%) were the primary contributors to the difficulty. Also, given were environmental barriers (45%) and obesity (10%). In addition, 48% of the physicians reported feeling uneasy in caring for individuals with physical disabilities. The reasons given for this uneasiness were multiple medical problems (72%), lack of cure for the medical condition (46%), because it is depressing (24%), and because of the lack of knowledge and inadequate medical school training (17%). When asked if for the same chief complaint more time was spent on the examination of a patient with a physical disability 82% of the respondents answered in the affirmative. Again, the majority (88%) of the respondents gave multiple medical problems as the reason for the increase in time needed.

Table 4: Percentage of respondents who found it difficult to examine patients with physical disabilities and spent increase amount of time

Percentage of respondents who found it difficult to examine patients with physical disabilities and spent increase amount of time.					
Totals		Pediatrics	Family Practice	Internist	Ob/Gyn
	n=501	n=164	n=132	n=118	n=86
Difficult to examine	61.5	50.4	68.8	59.6	79.4
Increased time to examine	81.4	84.5	81.7	70.5	92.2

Table 5: Patient Care Data

Patient Care Data	Percentage
Reasons for increase examination time	
multiple medical problems	87.3
limb weakness	58.3
limb paralysis	50.0
environmental barriers	31.8
Reasons for increased difficulty in examination	
limb weakness	77.1
limb paralysis	55.4
related impairments	50.0
poor balance	48.6
environmental barriers	44.6
orthotics/braces	10.8

In looking at community resource knowledge the physicians were asked ten questions. The data from these questions are presented in Table 6. As far as their knowledge of when to refer to another health professional the majority of the respondents indicated that they knew when to refer a patient to physical therapy, occupational therapy, speech therapy, and social worker. Less than 50% were familiar with when to refer their patients to physiatrist and community nurse. Similar percentage was seen when asked if they have and if they do refer to these professionals. When asked about their awareness of different programs for the disabled the majority were aware of pediatric programs but were less aware of adult programs for physical and vocational rehabilitation.

Table 6: Respondents knowledge regarding referral resources and community resources

Respondents knowledge regarding referral resources and community resources	Percentage
Knowledge of Health Professional:	
Psychiatrist	43.2
Physical therapist	92.8
Occupational therapist	83.1
Speech therapist	71.3
Social Worker	71.3
Vocational Counselor	40.2
Knowledge of Community Resources:	
California children services (CCS)	69.6
Disability-specific organizations	61.6
Public transit services	53.6
California Department of Rehabilitation	35.2

The final area of interest to us in this study was whether these physicians viewed their medical education as sufficient in regards to disability issues both in general terms and specifically as to the different medical conditions (see Table 7 below).

Table 7: Percentage of respondents who received disability-related education in medical school or residency

Percentage of respondents who received disability-related education in medical school or residency.					
	Totals	Pediatrics	Family Practice	Internist	Ob/Gyn
Training in medical school	22.8	22.9	25.0	20.8	19.4
Training in residency	34.1	47.3	28.1	28.7	20.3
Would have been helpful	76.0	84.0	54.0	56.0	31.0
Current need for training	72.0	78.0	74.3	77.9	50.8

In addition, we were interested in knowing whether these medial providers presently feel a need for education on issues related to caring for people with physical disabilities. For all respondents, 68% did not receive education/training in medical school on physical disability issues and the majority of these physicians would have found it advantageous to have had received education/training on such issues. In addition, 54% did not receive education/training during an internship/residency on physical disability issues. When asked whether they felt the need to receive continuing medical education on caring for people with physical disabilities 73% responded that they did indeed have the need. A majority of them indicated that they would attend a continuing medical education course and many provided specific recommendations as to the topics needed. These included issues related to safe transfers, community resources, and information on specific disabilities.

COMMENTS

The results of the survey raise important questions about the adequacy of training of primary care physicians on a variety of disability-related issues. These issues include the care and treatment of people with disabilities, architectural barriers that exist and interfere with medical access, and community resources available that would facilitate and promote healthy lives for these individuals. These results are consistent with previous reports on physician understanding of disability-specific problems; ²²ADA compliance of medical offices²³ and experiences of those with disabilities in getting quality health care. With advanced medical research and public health interventions people are living longer ²⁴and those living with a disability have substantially increased.²⁵ Activities to promote the health of people who are born with or acquire activity limitations are limited.²⁶

Few prevention efforts have targeted the unique needs of people who already experience a disability. There are many impediments to promoting the health of people with disability. One of these is access to quality primary health care. Since the passage of the Americans with Disabilities Act medical offices have been included as places of accommodation that must be made accessible and usable by persons with disabilities.²⁷ Our data suggests that physical barriers and inaccessible equipment still exist and interfere with access to medical care. Previous studies have reported that one factor affecting satisfaction with primary care among people with a disability is the accessibility of the physician's office²⁸ even to the degree that could be interpreted as noncompliant with the ADA.

Likewise other studies have demonstrated that additional barriers to effective primary health care include a lack of disability specific knowledge, providers' limited time and the amount of effort related to care. Our results are consistent with these previous findings. Oshima et al²⁹ evaluated the knowledge base and comfort level of "potential physician gatekeepers" when treating women with spinal cord injury. They found significant deficits in knowledge about physical accessibility, spasticity management, and potential disability-related problems.

Early studies of practice patterns of obstetrician-gynecologists suggested a dual role for these physicians serving both as primary physicians to woman and that of specialist.³⁰ In today's health care environment these physicians are frequently seeing women with physical disabilities. Therefore, training programs and educational content must reflect these changes. It has been suggested that present educational policy provide more generalist expertise.³¹

Our data suggest what is also needed now is an increase awareness and competency training of physicians on a variety of disability issues. The results have implications for both medical school curriculums and continuing education programs. As previously suggested by others educational policy should encourage generalist expertise and create a workforce of highly skilled physicians capable of caring for patients in a technologically advanced clinical environment.¹

In today's health care environment the primary care physician often finds himself in the role of pathfinder and is responsible for not only assessing the health needs of patients but also making referrals that are medically necessary and appropriate. These patients necessarily include those with physical disabilities.

In order to promote their health, prevent secondary conditions, and eliminate disparities between people with and without disabilities ³² quality primary health care needs to be provided. The survey reported here suggests that there is a continued need for disability awareness training in medical schools, residency programs, and continuing medical education courses.

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