

A NATIONAL SURVEY OF ACCESSIBILITY OF MEDICAL INSTRUMENTATION

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ABSTRACT

The RERC on Accessible Medical Instrumentation evaluates and develops methods and technologies to increase accessibility and usability of diagnostic, therapeutic, and procedural healthcare equipment, and associated assistive technologies, for people with disabilities. This paper outlines the methods employed in creating the national survey designed to assess difficulties people with disabilities have experienced as patients using medical instrumentation for healthcare, describes strategies employed to recruit a diverse national sample, and presents preliminary results from the survey.

KEYWORDS

Medical devices, equipment, accessibility, survey, online, needs assessment

BACKGROUND

The Rehabilitation Engineering Research Center (RERC) on Accessible Medical Instrumentation is a five-year project that evaluates methods and technologies to increase the accessibility and usability of diagnostic, therapeutic, and procedural healthcare equipment, and associated assistive technologies, for people with disabilities. It works closely with consumers, healthcare practitioners, medical facility administrators, and medical device manufacturers. The RERC is based at Marquette University, with major subcontracts to the Center for Disability Studies and the Health Professions at Western University of Health Sciences, and to the Ergonomics Lab at the University of California at Berkeley and San Francisco. It also has subcontracts to Human Spectrum Design, L.L.C., the University of Wisconsin at Milwaukee, and the University of Connecticut. Major collaborators on the project are Kaiser Permanente and the U.S. Food and Drug Administration.

METHOD

The RERC on Accessible Medical Instrumentation is analyzing the medical instrumentation needs of three major constituencies: consumers with disabilities, healthcare service providers, and medical instrumentation manufacturers through three distinct research projects. This paper focuses on the first project, *Project R.1.1 / Healthcare Consumer Needs Assessment*, that is conducting activities to identify the nature of obstacles related to medical instrumentation (and related policies) that prevent people with disabilities from receiving healthcare services. The first two stages of this project are outlined below.

Stage 1. Delphi Study. A Delphi approach (1) (2) was used to construct the instrument to be distributed in the national survey. A list of nationally respected key informants/experts in the field of disabilities, who have a working knowledge of medical instrumentation, was assembled and responded to a draft questionnaire that was carefully constructed to extract information regarding healthcare consumer needs relative to medical equipment. Through a structured, iterative process, the experts provided input that improved this instrument prior to its national distribution.

Stage 2. National Survey. The first section of the national survey collected personal demographic information and data about personal abilities. The second section of the questionnaire asked about

experiences respondents have had with fifteen specific categories of medical equipment representing the full range of classifications; a sample is shown below.

Type of medical equipment:

Chairs (e.g., dental, oral surgery, eye exam, laboratory, reclining procedure chairs [chemotherapy, dialysis, transfusion, etc.]

Your experience with Chairs:

None / Little / Moderate / Frequent / Extensive

Your difficulty or discomfort with Chairs:

None / Little / Moderate / Extreme / Impossible

What difficulties did you have? (Please describe.)

Too small, narrow. Too loose or stiff, shift suddenly or not at all. No back support. No head support or too high built-in pillow. Side rails sharp or unforgiving.

What changes might be made to improve the ease and/or discomfort of using Chairs?

Adjustable. Raise and lower. Back support. Variable head support. Perhaps both inflatable. Chairs that assist with rise and tilt back. Better cushion seat for long dialysis sessions. Softer cover surface. Naugahyde sticks to skin and promotes sweat. Railings that drop down and replace with cushioning.

The survey was available in a wide variety of formats: as an online form, as a Word form, as a text document, and as a PDF document in either regular or large print that could be printed out and completed by hand. The survey could also be completed over the telephone or in person.

To identify obstacles related to medical instrumentation preventing people with disabilities from receiving healthcare services, the questionnaire was disseminated to a diverse array of organizations and individuals throughout the United States. The desired sample for this study needed to contain individuals with disabilities who were diverse in age, abilities, ethnicity, geographic location, and socio-economic status. This objective presented a number of challenges.

The questionnaire initially was introduced through the following channels, with a request that the announcement be passed on to others: an e-mail message was sent to members of the RERC's national advisory council; messages were sent by e-mail to disability-related lists, directories, and Internet chat rooms; flyers were distributed at national and regional conferences: APHA, NCIL, RespectAbility, etc.; flyers were mailed to disability-related organizations (for inclusion in their newsletters, etc.): MDA, UCPA, etc.; and telephone calls were placed to specific individuals and organizations: colleagues and friends of the researchers, including WID and a large number of independent living centers.

The initial 300 responses to the questionnaire were received in the first four weeks from a fairly homogeneous group of individuals, who did not represent the diverse population the researchers had hoped to recruit. Initial respondents (n = 300) were predominantly white (94.5%), between 25 and 64 years old (88.6%), and had at least a Bachelor's degree (60.0%; 29.5% held Master's or Doctorate degrees). To address this problem, additional efforts were made to reach underrepresented populations: racial and ethnic minorities, people between ages 18 and 25 as well as age 65 and older, and less educated individuals. To reach these groups, the researchers made additional contacts to organizations that work with racially and ethnically diverse populations, to disabled student services and other youth organizations, to associations of older adults, and to specific disability support organizations such as for

post polio syndrome, diabetes, Alzheimer's disease, and sickle cell anemia. Initially, the target sample size was set at 300; but given the characteristics of early respondents, data collection will continue until a representative sample has been obtained. It is anticipated this will be achieved by the end of 2003.

RESULTS

As of this writing, only preliminary analyses of the data have been performed. Early results have helped to identify some types of instrumentation that cause difficulties for patients with disabilities when using the healthcare system. Of the 93% of respondents with experience with examination tables, 34% had moderate and 33% had extreme difficulty. Eight percent of participants indicated they were impossible to use. Of the 77% with experience using various types of medical chairs, 30% had moderate and 17% had extreme difficulty. Four percent of respondents said chairs were impossible to use. Of the 85% of people with x-ray equipment experience, 32% had moderate and 32% had extreme difficulty. Again, four percent indicated that these machines were impossible to use. Of the 76% of individuals with experience using rehabilitation or exercise equipment, 35% had moderate and 17% had extreme difficulty. Rehabilitation or exercise equipment was rated "impossible" for 5% of respondents. Weight scales presented problems for the 73% of respondents who had used them, with 26% having moderate difficulty, 14% having extreme difficulty, and 13% said they were impossible to use. More complete survey results will be available for presentation at the RESNA conference in June 2004.

DISCUSSION

While the scope of the problem of access to and utilization of healthcare services is vast, one of the major barriers can be identified as the accessibility and usability of medical instrumentation. Unfortunately, the scope of problems resulting from inaccessible equipment has not been documented. Little is known about the extent to which device manufacturers consider the needs of either patients or healthcare providers with disabilities. To date, there have been few studies focusing on access, utilization, and frequency of use and usability of the medical instrumentation used by and for persons with disabilities.

Carefully structured national needs assessments are needed in order (a) to improve both access to healthcare services and utilization of these services by individuals with disabilities, and (b) to improve access to healthcare equipment by healthcare providers with disabilities. The activities of the research project described herein will begin to provide this necessary information.

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