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RESEARCH ON PEOPLE WITH DISABILITIES AND HEALTH COMMUNICATION, EDUCATION, AND PROMOTION

EDUCATION OF CAREGIVERS/CONSUMERS/FAMILIES

Sexuality issues and gynecologic care of adolescents with developmental disabilities.

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Greydanus@kcms.msu.edu Pediatr Clin North Am. 2008 Dec;55(6):1315-35, viii.

All human beings are sexual from birth to death and all children and adolescents with or without disability or chronic illness must incorporate appropriate sexuality concepts into their processes of development from childhood to adolescence. This article considers sexuality issues and reproductive care of adolescents with developmental disabilities. Potential consequences of disability on sexuality are reviewed, including sexual abuse and sexual dysfunction. Comprehensive sexuality education is vital for normal growth and development of all youth including those with developmental disabilities.

Sexuality education and adolescents with developmental disabilities: assessment, policy, and advocacy.

Tice CJ, Hall DM. School of Social Work, University of Maryland Baltimore County, 1000 Hilltop Circle, Baltimore, MD 21250, USA. tice@umbc.edu J Soc Work Disabil Rehabil. 2008;7(1):47-62.

People with disabilities are sexual beings who, like all of us, benefit from sexuality education that examines relationship skills and knowledge, attitudes, behaviors, and values that promote healthy sexuality within those relationships. This article provides an overview of landmark policies relevant to persons with disabilities, defines the strengths perspective in the context of curriculum development, and describes a survey built on this perspective that evaluates sexuality education curricula on the strengths rather than the deficits of people.

Qualitative analysis of parents' information needs and psychosocial experiences when supporting children with health care needs.

Jackson R, Baird W, Davis-Reynolds L, Smith C, Blackburn S, Allsebrook J.

Section of Public Health, School of Health and Related Research, University of Sheffield, Sheffield, UK. r.jackson@sheffield.ac.uk Health Info Libr J. 2008 Mar;25(1):31-7.

OBJECTIVE: To identify the information needs of parents of children with health care needs.

METHODS: A series of three focus groups and one in-depth interview were held with parents (n = 10, 90% female) in Barnsley, South Yorkshire, UK.

RESULTS: Findings were grouped into four themes: delivery of information; levels of support; relationship between the family and professional; and management of events. Parents expressed a preference for information to be delivered on a verbal, 'one-to-one' basis by a professional, supplemented by accessible, written reference materials. The provision of a contact telephone number for a named professional, so further information could be obtained when required, was identified as a key source of support. Participants emphasized the importance of being consulted about the care of their child, the interaction between professional and child, and also of being treated as an individual by the professional.

CONCLUSIONS: Delivery of information to parents may be most effective on a verbal, 'one-to-one' basis with a professional, in conjunction with written accessible general and child-specific reference materials. The importance to parents of the provision of contact details for a named professional and specialist nurse support is also emphasized. The psychosocial experiences of parents, along with the impact of the relationship between family and professional, and requirement for good channels of communication, must be taken into account by professionals during the care of children with health care needs. These findings have important implications for professionals and service providers for the future delivery of information to parents of children with health care needs.

A qualitative study of menopause among women with disabilities.

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Few studies have examined the way women with disabilities understand and make decisions regarding menopause. This report is a qualitative descriptive study detailing how women with varying mobility impairments view the menopausal transition. Nineteen women aged 42 to 64 years were interviewed regarding their menopausal experiences. Results described their experiences as minority groups of women with disabilities using a women's ways of knowing framework. Overall, most women described menopause as a back burner issue, but maintained the need for accurate information from which to make informed decisions that might impact future health and functional outcomes.

Parents' information needs about the treatment of their chronically ill child: a qualitative study.

Hummelinck A, Pollock K. Pharmacist Pharmacy Department, Royal Shrewsbury Hospital, Mytton Oak Road, Shrewsbury SY3 8XQ, UK. alda.hummelinck@nhs.net *Patient Educ Couns.* 2006 Aug;62(2):228-34. Epub 2005 Sep 1.

Effective information provision is a prerequisite for partnership between child patients, their parents and health professionals.

OBJECTIVES: To explore the complexity of parents' information needs and how current information provision is evaluated.

METHODS: Qualitative methodology using semi-structured interviews with 27 parents of 20 families with a chronically ill child, recruited at the paediatric department of a British district general hospital.

RESULTS: The need for information varied greatly between individuals and over time, and commonly involved diagnosis, management plan and prognosis. However, most parents in this study experienced professional communication and information provision to be inadequate. Information provision appeared to be related to the diagnosis, the level of secondary care involvement and the extent to which parents were required to take responsibility for daily management of the child's condition. Parents' complex and shifting evaluations and responses point to the double-edged nature of information. Some parents actively sought out information, but resisting information, for fear of its potentially negative impact, was also noted to be a coping strategy.

CONCLUSION: Parents of chronically ill children presented with a great variety of information needs, which was not always appreciated by healthcare professionals.

PRACTICE IMPLICATIONS: This study highlights the need for good communication based on professional awareness of how parents understand and experience their child's illness, as well as the importance of sensitively individualising information provision to parents' needs so as to address their requirements but not to unnecessarily increase their anxiety or insecurity.

Keeping It Together: an information KIT for parents of children and youth with special needs.

Stewart D, Law M, Burke-Gaffney J, Missiuna C, Rosenbaum P, King G, Moning T, King S. CanChild Centre for Childhood Disability Research, Institute for Applied Health Sciences, McMaster University, Hamilton, ON, Canada. stewartd@mcmaster.ca Child Care Health Dev. 2006 Jul;32(4):493-500.

BACKGROUND: Provision and use of information about their children is a major concern to families who have a child with a disability. Strategies or systems to influence parents' abilities to receive, give and use information in a way that is satisfying to them have not been well validated.

METHODS: This paper reports on the development and evaluation of a Parent Information KIT ('Keeping It Together') information management system and child advocacy tool. The KIT was designed to assist parents in giving, getting and organizing information in an effective way. The KIT was evaluated by a sample of 440 parents, with outcomes of use, utility, impact and perceptions of family-centred care measured at baseline, and after 6 months, and 15 months.

RESULTS: Parents' perceptions of their ability, confidence and satisfaction when using information improved significantly after using the KIT. Parents' perceptions of care, as measured with the Measure of Processes of Care, also improved significantly in the areas of 'Enabling/Partnership' and 'Providing General Information'. Parents' ratings of the use and utility of the KIT were associated with increased impact and, in turn, predicted improved perceptions of care.

CONCLUSION: Parents who received and actively used the Parent Information KIT experienced significant increases in their perception of their ability and self-confidence in getting, giving and using information to assist their child with a disability. Strategies for improving the use of the KIT among parents are discussed.

Effect of preventive dentistry training program for caregivers in community facilities on caregiver and client behavior and client oral hygiene.

Glassman P, Miller CE. University of the Pacific School of Dentistry, San Francisco, CA, USA. N Y State Dent J. 2006 Mar-Apr;72(2):38-46.

The influx of persons with developmental disabilities into community-based programs has required the development, expansion and improved integration of community-based services. The role of caregivers in these community settings has become pivotal. However, with regard to daily activities, oral hygiene is often a low priority. Few attempts have been made to study caregiver participation in oral disease prevention and practices. This study evaluated the effects of an indirect training program, where caregivers were trained but the ultimate effects were demonstrated in adult clients. In addition, these effects were demonstrated in community care settings. A multiple baseline design, across three group homes, included 11 adult clients with developmental disabilities. This study evaluated the effects of training, instruction to use training and coaching on the presence of caregivers during oral hygiene sessions, the duration of toothbrushing and plaque scores of the clients. The results of this investigation demonstrated that there was an increase in caregiver presence and duration of brushing with a concurrent decrease in plaque scores. Caregivers responding to social validation questionnaires believed that 8 out of 11 clients had increased skills. This study demonstrates that caregiver training, combined with specific instructions to use training information and coaching of caregivers, can have a positive impact on the oral health of individuals with developmental disabilities living in community settings.

A health toolkit for people with learning disabilities.

Hunt C, Rankine P, Blackmore R. Northamptonshire Healthcare NHS Trust. Nurs Times. 2006 Mar 21-27;102(12):34-6.

People with learning disabilities are likely to have greater health needs than the majority of the population but are less likely to access health services and receive treatment. This article reports on a local initiative to develop a toolkit that people with learning disabilities can use to help them address their health needs through a simple health check and a health action plan.

F2F Connection: a community health information needs assessment of Texas families who have children with chronic illnesses and/or disabilities and their care providers.

Huber J, Dietrich J, Cugini E, Burke S. School of Library and Information Studies Texas Woman's University 1130 John Freeman Boulevard Houston, Texas 77030. jhuber@twu.edu J Med Libr Assoc. 2005 April; 93(2): 278–281.

The F2F Connection project is a collaborative effort involving the School of Library and Information Studies at Texas Woman's University, Houston Academy of Medicine-Texas Medical Center (HAM-TMC) Library, and Family to Family Network (F2FN). The overarching goal of the project is to facilitate access to relevant electronic health information resources for families who have children with special needs. The objective of the initial phase of the project is to conduct an assessment of the community health information needs of families who have children with chronic illnesses and/or disabilities as well as of their care providers. F2FN works with families, professionals, and friends of children with disabilities and/or chronic illnesses to create communities where all children belong and excel. F2FN provides information and referral services, educational programs, and direct support to this community. In addition to local programming, F2FN

operates a training program, Connections, developed for people who are committed to helping the families of children with chronic illnesses and/or disabilities. Connections teaches families about working with school systems to further their children's success. This program represents a collaborative effort between families and educators who share a common vision that all children have value and must have successful educational opportunities to accomplish their dreams.

Health literacy, morbidity, and quality of life among individuals with spinal cord injury.

Johnston MV, Diab ME, Kim SS, Kirshblum S. Kessler Medical Rehabilitation Research and Education Corp, 1199 Pleasant Valley Way, West Orange, NJ 07052, USA. mjohnston@kmrrec.org J Spinal Cord Med. 2005;28(3):230-40.

OBJECTIVES: Health literacy has been related to indicators of health outcomes in a number of populations, but not in spinal cord injury (SCI). The current study aimed to describe levels of health literacy in SCI and to investigate its possible associations with morbidity, health-related quality of life, functional independence, community participation, and life satisfaction.

DESIGN: Cross-sectional survey of 107 community-living people with SCI recruited in a New Jersey outpatient SCI center. Primary measures were the Test of Functional Health Literacy in Adults (TOFHLA), standard questions about morbidity from the Behavioral Risk Factors Surveillance Study, the Craig Handicap Assessment and Reporting Technique (CHART), Short Form-12 (SF-12), and Diener's Satisfaction with Life Scale. **RESULTS:** Health literacy was marginal or inadequate (TOFHLA = 0-74) in only 14% of the sample. TOFHLA scores correlated significantly with physical health morbidity, even after control for severity of motor paralysis and education. American Spinal Injury Association (ASIA) Motor Scores were correlated with physical morbidity and CHART Physical Independence scores; and education was related to community Mobility, Occupation, and Economic Independence, and Satisfaction with Life scores, independent of other factors. Rasch analysis identified ceiling measurement limitations in the TOFHLA.

CONCLUSIONS: Health literacy levels in this sample were higher than those found in other groups. Health literacy was independently related to physical health morbidity, but its associations with other outcomes were limited, entwined with education, and affected by severity of injury. Future research might examine higher-level aspects of health literacy to overcome ceiling measurement problems. Mediators of the association between health literacy and morbidity, such as health self-care behaviors, should also be examined.

EDUCATION OF HEALTH PROFESSIONALS

Sexuality in children and adolescents with disabilities.

Murphy N. Department of Pediatrics, University of Utah, 50 North Medical Drive, Salt Lake City, UT 84132, USA. nancy.murphy@hsc.utah.edu Dev Med Child Neurol. 2005 Sep;47(9):640-4. Comment in: Dev Med Child Neurol. 2008 Aug;50(8):563.

This review presents a discussion of the sexual development of children and adolescents with disabilities, described in the framework of body structure and function,

individual activities, and societal perspectives presented in the World Health Organization's International Classification of Functioning, Disability and Health. Issues of sexual development, gynecological care and contraception, sexual functioning, societal barriers, sexual victimization, and sexuality education are presented. Overall, adolescents with disabilities seem to be participating in sexual relationships without adequate knowledge and skills to keep them healthy, safe, and satisfied. Although their sexual development may be hindered both by functional limitations and by intentional or unintentional societal barriers, the formal and informal opportunities for teenagers with disabilities to develop into sexually expressive and fulfilled persons do exist. Health care providers are urged to increase their awareness of this unmet need and to implement strategies that promote the physical, emotional, social, and psychosexual independence of children, teenagers, and young adults with disabilities.

Dental education and special-needs patients: challenges and opportunities.

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Pediatric dentists have, by tradition and default, provided care for persons with special health care needs (PSHCN), regardless of age. Deinstitutionalization of PSHCN in the 1960s, however, overwhelmed the dental care system, and oral health care became one of the greatest unmet needs of this population. This presentation follows the history of training for dentists in this aspect of care, from the first demonstration programs in the 1970s to the current educational programs in U.S. dental schools. Today's dental students must be competent in assessing the treatment needs of PSHCN, but accreditation standards do not require competency in the treatment of this group of patients. Recommendations to rectify this include revising dental school curricula to be more patient-centered, improving technology in schools, earlier clinical experiences for dental students, and the use of community-based clinics.

Interprofessional educational partnerships in school health for children with special oral health needs.

Mabry CC, Mosca NG. Louisiana State University Health Sciences Center School of Dentistry, Advanced Education and Hospitals, 8000 G.S.R.I. Avenue, Building 3110, Baton Rouge, LA 70802, USA. cconni@lsuhsc.edu J Dent Educ. 2006 Aug;70(8):844-50.

Dental caries is an infectious yet preventable disease that is rampant in some subpopulations in the United States, in particular among individuals with neurodevelopmental/intellectual disabilities (ND/ID). This article reports on the implementation and evaluation of the Louisiana State University Health Sciences Center (LSUHSC) School of Dentistry interprofessional school health educational model to improve oral health assessment and referral for children with ND/ID in an inner-city school system. During this project, dental hygiene students and elementary school nurses were paired to assess the oral health status of 255 inner-city children with developmental disabilities, improve referral/access to dental care for those identified as having need, and propose dental hygiene curriculum changes that would incorporate participation in a "real-life public health setting" for those with ND/ID. Following the program, 66 percent of dental hygiene students said their likelihood of participating in

future oral health programs had increased and 75 percent of school nurses rated the educational process as very good or excellent. Modifications in dental hygiene curricula that provide students with training and experience in oral health risk assessment and referral for people with ND/ID is recommended to address the new Commission on Dental Accreditation educational standards 2-18 and 2-26 (implemented January 1, 2005) and dental standard 2-26 (implemented January 1, 2006), which state that dental hygiene and dental graduates must be competent in assessing the treatment needs of patients with special needs.

Sexuality of children and adolescents with developmental disabilities.

Murphy NA, Elias ER. Pediatrics. 2006 Jul;118(1):398-403.

Children and adolescents with developmental disabilities, like all children, are sexual persons. However, attention to their complex medical and functional issues often consumes time that might otherwise be invested in addressing the anatomic, physiologic, emotional, and social aspects of their developing sexuality. This report discusses issues of puberty, contraception, psychosexual development, sexual abuse, and sexuality education specific to children and adolescents with disabilities and their families. Pediatricians, in the context of the medical home, are encouraged to discuss issues of sexuality on a regular basis, ensure the privacy of each child and adolescent, promote self-care and social independence among persons with disabilities, advocate for appropriate sexuality education, and provide ongoing education for children and adolescents with developmental disabilities and their families.

Mandating education of dental graduates to provide care to individuals with intellectual and developmental disabilities.

Waldman HB, Perlman SP. Department of General Dentistry, SUNY at Stony Brook, Stony Brook, NY 11794-8706, USA. hwaldman@notes.cc.sunysb.edu Ment Retard. 2006 Jun;44(3):184-8.

In 2004, The Commission on Dental Accreditation adopted new standards for dental and dental hygiene education programs to ensure the preparation of practitioners to provide oral health services for persons with special health care needs. The course of action leading to the adoption of the new standards, together with the continuing obstacles of limited government support for dental services and the availability of faculty members to provide the needed dental educational experiences is reviewed. Expanding Health Resources and Services Administration definition of medically underserved areas is presented as one approach to improving the delivery of dental services.

General dentists and special needs patients: does dental education matter?

Dao LP, Zwetchkenbaum S, Inglehart MR. School of Dentistry, University of Michigan, Ann Arbor, MI 48109-1078, USA. J Dent Educ. 2005 Oct;69(10):1107-15.

Special needs patients are one of the underserved dental patient groups in the United States. This study investigates whether undergraduate dental education about special needs patients affects general dentists' a) professional behavior, b) practice characteristics, and c) attitudes concerning special needs patients. Data were collected from 208 general dentists (178 male/30 female; average age: 49.85 years) who were members of the Michigan Dental Association. The more the respondents agreed that dental education had prepared them well, the more likely they were to treat various types

of special needs patients and to set up their practices so they could treat them and the more they liked treating these patients. In conclusion, most general dentists did not think their undergraduate dental education had prepared them well to treat special needs patients. However, the better they reported to have been educated, the more likely they were to treat special needs patients. Given the access to care problems for many special needs patients, it seems crucial to revise dental curricula and provide more didactic and clinical education concerning the treatment of special needs patients.

Education of dentists in the treatment of patients with special needs.

Thierer T, Meyerowitz C. Eastman Department of Dentistry, University of Rochester, School of Medicine and Dentistry, New York 14642, USA. J Calif Dent Assoc. 2005 Sep;33(9):723-9.

The dental education system has been suggested as the vital link in providing a workforce capable of improving oral health for people with special needs. Dental education institutions not only train dental professionals for their role in providing oral health services for people with special needs, they also provide a significant amount of services to this population in their clinical environments. However, there is no consensus about whether to concentrate the educational efforts on the pre- or postdoctoral level, or both. Furthermore, it is not clear if educational initiatives in the care of patients with special needs will translate into a larger oral health workforce willing to treat these patients. However, for the purposes of this paper, it will be assumed that more education and training in special care dentistry will lead to better-educated dentists and the desired result of better access to care for special needs patients. The authors will define special needs patients as those who have a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that the general population requires. This paper will describe accreditation issues and discuss the advantages and disadvantages of special care education in pre- and postdoctoral training and beyond.

Preparing dental graduates to provide care to individuals with special needs.

Waldman HB, Fenton SJ, Perlman SP, Cinotti DA. Department of General Dentistry, State University of New York at Stony Brook, Stony Brook, NY 11794-8706, USA. hwaldman@notes.cc.sunysb.edu J Dent Educ. 2005 Feb;69(2):249-54.

In 2004, the Commission on Dental Accreditation (CODA) adopted a new standard that directs dental and dental hygiene programs to prepare dental professionals for the care of persons with special health care needs. This article reviews the demographics of individuals with special needs, documents that most dental schools provide their students with very limited educational opportunities related to the care of this population, describes the path that was followed to bring about change in the accrediting standard, and discusses the difficulties involved in developing the needed educational programs. Educational programs at two dental schools are presented as examples of how schools can provide students with learning experiences pertinent to the new CODA standard that states: "Graduates must be competent in assessing the treatment needs of patients with special needs."

HEALTH COMMUNICATION

Computer and internet use by persons after traumatic spinal cord injury.

Goodman N, Jette AM, Houlihan B, Williams S. Department of Public Health, Boston University, Boston, MA 02118, USA. naomirgoodman@yahoo.com Arch Phys Med Rehabil. 2008 Aug;89(8):1492-8.

OBJECTIVE: To determine whether computer and internet use by persons post spinal cord injury (SCI) is sufficiently prevalent and broad-based to consider using this technology as a long-term treatment modality for patients who have sustained SCI.

DESIGN: A multicenter cohort study.

SETTING: Twenty-six past and current U.S. regional Model Spinal Cord Injury Systems.

PARTICIPANTS: Patients with traumatic SCI (N=2926) with follow-up interviews between 2004 and 2006, conducted at 1 or 5 years postinjury.

INTERVENTIONS: Not applicable.

RESULTS: Results revealed that 69.2% of participants with SCI used a computer; 94.2% of computer users accessed the internet. Among computer users, 19.1% used assistive devices for computer access. Of the internet users, 68.6% went online 5 to 7 days a week. The most frequent use for internet was e-mail (90.5%) and shopping sites (65.8%), followed by health sites (61.1%). We found no statistically significant difference in computer use by sex or level of neurologic injury, and no difference in internet use by level of neurologic injury. Computer and internet access differed significantly by age, with use decreasing as age group increased. The highest computer and internet access rates were seen among participants injured before the age of 18. Computer and internet use varied by race: 76% of white compared with 46% of black subjects were computer users ($P<.001$), and 95.3% of white respondents who used computers used the internet, compared with 87.6% of black respondents ($P<.001$). Internet use increased with education level ($P<.001$): eighty-six percent of participants who did not graduate from high school or receive a degree used the internet, while over 97% of those with a college or associate's degree did.

CONCLUSIONS: While the internet holds considerable potential as a long-term treatment modality after SCI, limited access to the internet by those who are black, those injured after age 18, and those with less education does reduce its usefulness in the short term for these subgroups.

Internet education for spinal cord injury patients: focus on urinary management.

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The goal of this project was to develop a Web site with articles that focus on urinary self-care management for those with spinal cord injuries. The investigator wrote 18 articles on topics that were selected by two review panels--one whose members have long-term spinal cord injuries and another consisting of rehabilitation nurses. The panel members critically reviewed the articles for content and topic. After revisions, nine of the 18 articles were translated from English into Spanish and then translated back into English to ensure accuracy. Consumers were asked to rate their satisfaction with the articles on a scale of 1-10, with 10 being the highest. There were a total of 1,162 hits on the Web site during a period of 13 months; 811 were for the Spanish articles, and 351 were for the English articles. The mean rating score for the articles was 8.02, with a standard

deviation of 1.38. These findings are consistent with reports that the Internet can provide both user-friendly education for those living with disabilities and culturally sensitive health information for those who have limited access to other sources of information.

Intellectual impairment and sexual health: information needs.

Clark LI, O'toole MS. Florence Nightingale School of Nursing and Midwifery, King's College, London. Br J Nurs. 2007 Feb 8-21;16(3):154-6.

Inclusion into the wider community for people with learning disabilities and intellectual impairment has been problematic for many people and in some cases the result has been an exacerbation of mental health problems or a reduction in adaptive functioning. Research has found that people who have chronic mental illness or intellectual impairment are a sexually active group although they might not always be perceived as such. Therefore, there are questions that may be raised over an identified lack of sexual health promotion and practices surrounding safe sex. This short article will examine particular barriers to sexual health care for this patient group in the areas of consent (to sexual acts, screening and treatment), communication and health promotion in this field. Implications for future practice are discussed.

People with intellectual disabilities and their need for cancer information.

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Many people with intellectual disabilities will be affected by cancer in their lifetime. There is a lack of available knowledge about people with intellectual disabilities' understanding and experience of cancer, and about their need for cancer information. The principal aim of the study was to explore the information needs of people with intellectual disabilities who are affected by cancer. This was a qualitative, hypothesis generating study. Nine people with intellectual disabilities who were affected by cancer were identified using a purposive sampling method; five of these participated in the study. Data collection included observation of the use of a pictorial cancer information book designed for people with intellectual disabilities, and semi-structured interviews. Data analysis revealed three themes: (1) "Nobody told me": the desperate need for cancer information; (2) "That reminds me": telling my own story; and (3) "I don't know much about cancer": the difficulties of the staff supporting people with intellectual disabilities to read the cancer information book. The people with intellectual disabilities in this study were not provided with information about cancer. They wanted this information, and appeared to be capable of comprehending it. Further development of accessible information materials around cancer and palliative care is needed.

Surfing for scoliosis: the quality of information available on the Internet.

Mathur S, Shanti N, Brkaric M, Sood V, Kubeck J, Paulino C, Merola AA. Department of Orthopaedic Surgery, SUNY Downstate Medical Center, Brooklyn, NY 11203-2098, USA. Spine. 2005 Dec 1;30(23):2695-700.

STUDY DESIGN: A cross section of Web sites accessible to the general public was surveyed.

OBJECTIVE: To evaluate the quality and accuracy of information on scoliosis that a patient might access on the Internet.

SUMMARY OF BACKGROUND DATA: The Internet is a rapidly expanding communications network with an estimated 765 million users worldwide by the year 2005. Medical information is one of the most common sources of inquires on the Web. More than 100 million Americans accessed the Internet for medical information in the year 2000. Undoubtedly, the use of the Internet for patient information needs will continue to expand as Internet access becomes more readily available. This expansion combined with the Internet's poorly regulated format can lead to problems in the quality of information available. Since the Internet operates on a global scale, implementing and enforcing standards have been difficult. The largely uncontrolled information can potentially negatively influence consumer health outcomes.

METHODS: To identify potential sites, five search engines were selected and the word "scoliosis" was entered into each search engine. A total of 50 Web sites were chosen for review. Each Web site was evaluated according to the type of Web site, quality content, and informational accuracy by three board-certified academic orthopedic surgeons, fellowship trained in spinal surgery, who each has been in practice for a minimum of 8 years. Each Web site was categorized as academic, commercial, physician, nonphysician health professional, and unidentified. In addition, each Web site was evaluated according to scoliosis-specific content using a point value system of 32 disease-specific key words pertinent to the care of scoliosis on an ordinal scale. A list of these words is given. Point values were given for the use of key words related to disease summary, classifications, treatment options, and complications. The accuracy of the individual Web site was evaluated by each spine surgeon using a scale of 1 to 4. A score of 1 represents that the examiner agreed with less than 25% of the information while a score of 4 represents greater than 75% agreement.

RESULTS: Of the total 50 Web sites evaluated, 44% were academic, 18% were physician based, 16% were commercial, 12% were unidentified, and 10% were nonphysician health professionals. The quality content score (maximum, 32 points) for academic sites was 12.6 +/- 3.8, physician sites 11.3 +/- 4.0, commercial sites 11 +/- 4.2, unidentified 7.6 +/- 3.9, and nonphysician health professional site 7.0 +/- 1.8. The accuracy score (maximum, 12 points) was 6.6 +/- 2.4 for academic sites, 6.3 +/- 3.0 for physician-professional sites, 6.0 +/- 2.7 for unidentified sites, 5.5 +/- 3.8 for nonphysician professional sites, and 5.0 +/- 1.5 for commercial Web sites. The academic Web sites had the highest mean scores in both quality and accuracy content scores.

CONCLUSION: The information about scoliosis on the Internet is of limited quality and poor information value. Although the majority of the Web sites were academic, the content quality and accuracy scores were still poor. The lowest scoring Web sites were the nonphysician professionals and the unidentified sites, which were often message boards. Overall, the highest scoring Web site related to both quality and accuracy of information was www.srs.org. This Web site was designed by the Scoliosis Research Society. The public and the medical communities need to be aware of these existing limitations of the Internet. Based on our review, the physician must assume primary responsibility of educating and counseling their patients.

Accessibility compliance rates of consumer-oriented Canadian health care Web sites.

O'Grady L. Ontario Institute for Studies in Education, University of Toronto, Toronto, Canada. logrady@oise.utoronto.ca Med Inform Internet Med. 2005 Dec;30(4):287-95. Vast amounts of consumer-based health care information are widely available on the World Wide Web. However, for some this material is inaccessible due to reliance on specialized computer equipment or software known as assistive technology. These tools, designed for people with sensory, physical, or learning disabilities, act as a median to interpret Web pages in accessible ways. Unfortunately, many websites, including those with health-related content are not designed to accommodate this equipment. No research has yet been published examining the extent of this problem in Canadian consumer-oriented health care sites. The purpose of this study was to investigate the percentage of accessible consumer-based health care websites of Canadian origin. A listing of such sites was randomly sampled for study inclusion. Each was assessed for accessibility based on the World Wide Web Consortium (W3C) Web Accessibility Initiative (WAI) Web Content Accessibility Guidelines (WCAG) 1.0 using the validation software Bobby. The results indicated that only about 40% of pages investigated were free of errors in accordance with WCAG 1.0 Priority 1 level. Websites should be constructed in compliance with these standards to better accommodate those using assistive devices.

Family-centred service: moving ideas into practice.

Law M, Teplicky R, King S, King G, Kertoy M, Moning T, Rosenbaum P, Burke-Gaffney J. CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, ON, Canada. lawm@mcmaster.ca Child Care Health Dev. 2005 Nov;31(6):633-42.

BACKGROUND: With parents more involved in their child's day-to-day care, concepts of family-centred service (FCS) are increasingly adopted in children's health and rehabilitation service organizations.

METHODS: In this paper, we report the results of a study to develop and evaluate educational materials for parents, service providers and health sciences students about FCS. The materials focus on the nature and philosophy of FCS, and the practical skills and systemic changes required for its implementation.

RESULTS: Thirty-six participants (12 families, 12 service providers and 12 rehabilitation science students) were randomly assigned to receive one of the six FCS educational packages, each containing three FCS educational sheets. Participants' ratings of the format and content, and the impact of the FCS Sheets were very high, with overall means above 5.0 on a 7-point scale. Using a mixed model analysis, we found significant differences in participants' ratings of familiarity with the materials (students were less familiar than service providers). After statistical adjustment for familiarity, there were no significant differences between the groups or the packages on ratings of format and content or impact.

CONCLUSIONS: There were no significant differences in the way in which the participant groups rated the impact of the FCS Sheets and the specific packages did not have an effect on the participants' ratings. The FCS educational materials, even those less familiar to participants, were rated highly on format and content, and impact. Results indicate that the material was perceived to be important to each group, and was formatted and written in a way that was easy to understand. This finding counters current recommendations in the knowledge transfer literature that suggest different versions should be written for different target groups.

Computer and World Wide Web accessibility by visually disabled patients: problems and solutions.

Chiang MF, Cole RG, Gupta S, Kaiser GE, Starren JB. Department of Ophthalmology, Columbia University College of Physicians and Surgeons, New York, New York 10032, USA. chiang@dbmi.columbia.edu Surv Ophthalmol. 2005 Jul-Aug;50(4):394-405.

Rapid advances in information technology have dramatically transformed the world during the past several decades. Access to computers and the World Wide Web is increasingly required for education and employment, as well as for many activities of daily living. Although these changes have improved society in many respects, they present an obstacle for visually disabled patients who may have significant difficulty processing the visual cues presented by modern graphical user interfaces. This article reviews the specific barriers to computer and Web access faced by visually disabled patients, describes clinical evaluation methods, summarizes traditional low vision methods as well as newer assistive computer technologies for universal accessibility, and discusses emerging technologies and future directions in this area.

Camp for all connection: a community health information outreach project.

Huber JT, Walsh TJ, Varman B. Texas Woman's University, 1130 John Freeman Boulevard, Houston, Texas 77030, USA. jhuber@mail.twu.edu J Med Libr Assoc. 2005 Jul;93(3):348-52.

PURPOSE: The purpose of the Camp For All Connection project is to facilitate access to electronic health information resources at the Camp For All facility.

SETTING/PARTICIPANTS/RESOURCES: Camp For All is a barrier-free camp working in partnership with organizations to enrich the lives of children and adults with chronic illnesses and disabilities and their families by providing camping and retreat experiences. The camp facility is located on 206 acres in Burton, Texas. The project partners are Texas Woman's University, Houston Academy of Medicine-Texas Medical Center Library, and Camp For All.

BRIEF DESCRIPTION: The Camp For All Connection project placed Internet-connected workstations at the camp's health center in the main lodge and provided training in the use of electronic health information resources. A train-the-trainer approach was used to provide training to Camp For All staff.

RESULTS/OUTCOME: Project workstations are being used by health care providers and camp staff for communication purposes and to make better informed health care decisions for Camp For All campers.

EVALUATION METHOD: A post-training evaluation was administered at the end of the train-the-trainer session. In addition, a series of site visits and interviews was conducted with camp staff members involved in the project. The site visits and interviews allowed for ongoing dialog between project staff and project participants.

Use of the Internet for health information by older adults with arthritis.

Tak SH, Hong SH. College of Nursing, University of Arkansas for Medical Sciences, Little Rock, USA. Orthop Nurs. 2005 Mar-Apr;24(2):134-8.

BACKGROUND: Despite the information available on the Internet and the increasing number of older adults who use the Internet, little is known about Internet use for health information by elders with arthritis.

PURPOSE: The purposes of this study were (1) to examine the use of computers and the Internet by elders with arthritis and (2) to describe demographic and illness-related characteristics of elders who use the Internet to find health information.

SAMPLE: Seventy-one elders with arthritis completed survey questionnaires.

FINDINGS: Twenty-eight percent had a computer in their home, of whom 95% had Internet access. Thirty-nine percent sought arthritis information on the Internet. People with more education were more likely to use the Internet. However, age and functional disability resulting from arthritis were not associated with Internet use.

IMPLICATIONS: Health professionals need to be aware of Internet resources and assist elders in finding appropriate Internet-based arthritis information.

Patterns of Internet use by persons with spinal cord injuries and relationship to health-related quality of life.

Drainoni ML, Houlihan B, Williams S, Vedrani M, Esch D, Lee-Hood E, Weiner C. Boston University School of Public Health, New England Spinal Cord Injury Center, MA, USA. drainoni@bu.edu Arch Phys Med Rehabil. 2004 Nov;85(11):1872-9.

OBJECTIVES: To examine patterns of computer and Internet use among persons with spinal cord injuries (SCI) and to assess the relationship between Internet use and health-related quality of life (HRQOL).

DESIGN: Cross-sectional survey design.

SETTING: National Model Spinal Cord Injury Systems.

PARTICIPANTS: People with SCI enrolled in a national database.

INTERVENTIONS: Not applicable.

MAIN OUTCOME MEASURES: Patterns of Internet use and relationship to HRQOL indicators: self-perceived health status, health status compared with 1 year ago, severity of depression, social integration score, occupation score, contacts with friends, business contacts, and satisfaction with life.

RESULTS: Most subjects owned computers, had Internet access, and used the Internet regularly-primarily for email, disability and health information, and shopping. Bivariate analysis revealed significant differences in Internet access based on sociodemographics, particularly among subjects with less education and among African Americans and Hispanics. In initial univariate analysis, most HRQOL indicators were significantly better for Internet users; once sociodemographic factors were included, 4 indicators remained significant.

CONCLUSIONS: Complex factors contribute to Internet access among people with SCI, with more barriers among specific subgroups. A significant HRQOL benefit from Internet use is suggested. Targeted interventions and studies of usage patterns are recommended.

Web content accessibility of consumer health information web sites for people with disabilities: a cross sectional evaluation.

Zeng X, Parmanto B. Department of Health Information Management, School of Health and Rehabilitation Sciences, University of Pittsburgh, Pittsburgh, PA 15260, USA. xizst9@pitt.edu J Med Internet Res. 2004 Jun 21;6(2):e19.

BACKGROUND: The World Wide Web (WWW) has become an increasingly essential resource for health information consumers. The ability to obtain accurate medical information online quickly, conveniently and privately provides health consumers with the

opportunity to make informed decisions and participate actively in their personal care. Little is known, however, about whether the content of this online health information is equally accessible to people with disabilities who must rely on special devices or technologies to process online information due to their visual, hearing, mobility, or cognitive limitations.

OBJECTIVE: To construct a framework for an automated Web accessibility evaluation; to evaluate the state of accessibility of consumer health information Web sites; and to investigate the possible relationships between accessibility and other features of the Web sites, including function, popularity and importance.

METHODS: We carried out a cross-sectional study of the state of accessibility of health information Web sites to people with disabilities. We selected 108 consumer health information Web sites from the directory service of a Web search engine. A measurement framework was constructed to automatically measure the level of Web Accessibility Barriers (WAB) of Web sites following Web accessibility specifications. We investigated whether there was a difference between WAB scores across various functional categories of the Web sites, and also evaluated the correlation between the WAB and Alexa traffic rank and Google Page Rank of the Web sites.

RESULTS: We found that none of the Web sites we looked at are completely accessible to people with disabilities, i.e., there were no sites that had no violation of Web accessibility rules. However, governmental and educational health information Web sites do exhibit better Web accessibility than the other categories of Web sites ($P < 0.001$). We also found that the correlation between the WAB score and the popularity of a Web site is statistically significant ($r = 0.28$, $P < 0.05$), although there is no correlation between the WAB score and the importance of the Web sites ($r = 0.15$, $P = 0.111$).

CONCLUSIONS: Evaluation of health information Web sites shows that no Web site scrupulously abides by Web accessibility specifications, even for entities mandated under relevant laws and regulations. Government and education Web sites show better performance than Web sites among other categories. Accessibility of a Web site may have a positive impact on its popularity in general. However, the Web accessibility of a Web site may not have a significant relationship with its importance on the Web.

Evaluation of consumer health website accessibility by users with sensory and physical disabilities.

Chiang MF, Starren J. Department of Biomedical Informatics, Columbia University, New York, NY 10032, USA. chiang@dbmi.columbia.edu Stud Health Technol Inform. 2004;107(Pt 2):1128-32.

Growth of the World Wide Web is beginning to create new opportunities for direct patient access to health care resources. At the same time, advances in medical care have produced demographic shifts in which an increasing number of patients have sensory and physical disabilities that may limit their ability to access these new information tools. This study uses automated and manual methods to measure the compliance of 30 popular consumer health websites with the World Wide Web Consortium (W3C) content accessibility guidelines. Among these 30 sites, 22 failed to satisfy at least one W3C Priority-1 accessibility checkpoint, making it impossible for some groups of disabled users to access information from them. All websites failed to satisfy at least one Priority-2 checkpoint, making it difficult for some groups to access information from the sites. These results suggest that accessibility of many consumer health websites to disabled

users is very limited. The health informatics community must become more aware of this problem, particularly because many critical accessibility problems may be easily addressed if they are recognized.

HEALTH PROMOTION

Improving the health and health behaviors of women aging with physical disabilities: A peer-led health promotion program.

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susanrw@bcm.tmc.edu Womens Health Issues. 2006 Nov-Dec;16(6):334-45.

OBJECTIVE: To examine the efficacy of a health promotion program for women aging with physical disabilities.

METHOD: A sample of 137 middle-aged and older women with physical disabilities was randomly assigned to either an 8-week health promotion program or to a wait-list control group. Both groups completed questionnaires before, immediately after, and 3 months after the intervention.

RESULTS: Relative to women in the control group, women in the health-promotion program demonstrated improvements in health behaviors, most of which were maintained at follow-up. The intervention group showed some improvements on measures of physical health, but there was little evidence of improvement in psychological health outcomes. Testing our theoretical model, self-efficacy was supported as a mediator of the effect of the intervention on health behaviors, and health behaviors combined with self-efficacy were supported as mediators of the effect of the intervention on physical health outcomes. Contrary to our hypotheses, our measures of social support and social connectedness were not affected by the intervention.

CONCLUSIONS: A brief, peer-led, group health promotion program resulted in improved scores on measures of self-efficacy, increased health behavior, and physical health. Self-efficacy, which was supported as a mediator in the effect of the intervention on behaviors and health outcomes, should remain an important focus of future interventions with this population.

Attitudinal and psychosocial outcomes of a fitness and health education program on adults with down syndrome.

Heller T, Hsieh K, Rimmer JH. Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Department of Disability and Human Development, University of Illinois at Chicago, 60608-6904, USA. theller@uic.edu Am J Ment Retard. 2004 Mar;109(2):175-85.

Attitudinal and psychosocial outcomes of a fitness and health education program for adults with Down syndrome were examined. Participants were 53 adults with Down syndrome ages 30 years and older (29 females, 24 males, M age = 39.72 years) who were randomized into a training (n = 32) or control group (n = 21). The training group participated in a 12-week, 3 days per week, exercise and health education program. Outcome measures included attitudes towards exercise (cognitive-emotional barriers, outcomes expectations, and performance self-efficacy) and psychosocial well-being

(community integration, depression, and life satisfaction). Compared to controls, the training group showed significant changes in attitudes towards exercise, including increased exercise self-efficacy, more positive expected outcomes, fewer cognitive-emotional barriers, improved life satisfaction, and marginally lower depression.

Accessible online health promotion information for persons with disabilities.

Smeltzer SC, Zimmerman V, Frain M, DeSilets L, Duffin J. Villanova University College of Nursing, PA, USA. suzanne.smeltzer@villanova.edu Online J Issues Nurs. 2004 Jan 31;9(1):11.

Online health promotion materials have great potential to reach persons with disabilities and provide valuable information to this vulnerable population. While health promotion efforts are important for everyone, they are crucial for individuals with disabilities. Yet information needed to support these efforts is often presented in such a way that its access is limited or its content is inappropriate for this population. Whether designing or selecting online materials for individuals with disabilities, nurses can benefit from knowledge about strategies to make web sites more accessible or to assess the accessibility of existing web sites. The task of providing health promotion information to women with disabilities was undertaken as part of the "Health Promotion for Women with Disabilities Project" at Villanova University's College of Nursing. A web site was created as one method of providing information. This paper presents strategies that are used to make this site accessible.

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