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RESEARCH PERTAINING TO NEEDS ASSESSMENT AND PEOPLE WITH DISABILITIES

ACCESS TO HEALTHCARE

A focus group study of accessibility and related psychosocial issues in diabetes education for people with visual impairment.

Williams AS.

Diabetes Education Associates, 3495 Edison Road, Cleveland Heights, OH 44121, USA. aswilliams@stratos.net Diabetes Educ 2002 Nov-Dec;28(6):999-1008

Purpose: This study was conducted to identify accessibility and related psychosocial issues in diabetes care and education for visually impaired adults who have diabetes.

Methods: Two focus groups of adults with visual impairment and diabetes were conducted; data were recorded and analyzed.

Results: The 3 main issues identified were lack of access to up-to-date diabetes information in an accessible format, lack of understanding by healthcare providers of the needs and competencies of people with both visual impairment and diabetes, and lack of access to nonvisual diabetes self-management equipment.

Conclusions: This study provides qualitative support for the view that visually impaired people in the United States may, as a group, be systematically excluded from receiving high quality diabetes care and education. Equal access to diabetes care and education for visually impaired people requires increased accessibility of diabetes care and education programs, and increased professional and public awareness that the diabetes programs are accessible. Some specific recommendations are to make all patient education materials available in low-vision/nonvisual formats and to teach all diabetes education professionals how to work effectively with visually impaired people.

Access unrestricted.

McCray J, Carter S.
School of Health and Social Care, University of Portsmouth. Nurs Times 1999 Jun 9-15;95(23):47-9

Perceived dental needs of children enrolled in Iowa's Medicaid Supplemental Security Income (SSI) health plan.

Slayton RL, Damiano PC, Willard JC. Department of Pediatric Dentistry, University of Iowa, College of Dentistry, S212 DSB, Iowa City, IA 52242, USA. rebecca-slayton@uiowa.edu ASDC J Dent Child 2001 May-Jun;68(3):206-10, 152

The purpose of this study was to determine parental perception of the oral health needs of children with disabilities and whether or not they had difficulty obtaining dental care. A survey of parents of children enrolled in the Medicaid Supplemental Security Income (SSI) health plan in Iowa showed that 68 percent of children had dental needs during the previous year. Of these children, parents reported that 9.4 percent had a 'big problem' getting that care, 8.1 percent had a 'small problem' getting care and 82.5 percent stated that getting dental care was 'not a problem.' There were significantly more dental needs reported in children in the older age groups (> or = 5 years) and those with more years of experience in the program ($p < 0.01$). Further study is necessary to determine the types of barriers faced by those in the SSI program seeking dental care.

Perspectives of dentists, families, and case managers on dental care for individuals with developmental disabilities in Kansas.

Reichard A, Turnbull HR, Turnbull AP.
University of Kansas, Lawrence, KS 66045-29930, USA. Ment Retard 2001 Aug;39(4):268-85

The status of dental care for individuals with developmental disabilities in Kansas was examined. Dentists, family members, and case managers reported general, but partial, satisfaction with the availability, accessibility, appropriateness, and affordability of such care. Reasons for the results and recommendations for

The needs of patients with arthritis: the patient's perspective.

Neville C, Fortin PR, Fitzcharles MA, Baron M, Abrahamowitz M, Du Berger R, Esdaile JM.
Clinical Epidemiology Unit, Arthritis Society of Canada Research Scholar, Quebec. Arthritis Care Res 1999 Apr;12(2):85-95

Objective: To identify concerns and learning interests of patients with arthritis.
p. Methods: A questionnaire was developed, pilot tested, and then used to evaluate 197 patients with arthritis, including osteoarthritis (OA) ($n = 41$), rheumatoid arthritis (RA) ($n = 57$), back disease ($n = 55$), systemic lupus erythematosus ($n = 27$), and systemic sclerosis (SSc) ($n = 17$). Twenty concerns and 12 learning interests were rated. Questionnaires were also administered to assess physical disability (Health

Assessment Questionnaire), psychological disability (Arthritis Impact Measurement Scales 2), and pain (visual analog scale). Participants addressed accessibility of health services, satisfaction with their physician, psychosocial needs, use of self-help groups, and behavioral strategies used to assist coping. Patients with RA, OA, and back disease, at both a community and a hospital center, were tested to assess whether concerns and learning interests differed based on site of treatment. Analytic methods included analysis of variance, factor analysis, and multiple linear regression.

p. *Results:* There were no differences in concerns or learning interests based on treatment site. Between diagnostic groups, patients with SSc were more interested in learning about self-help groups. The most frequently reported concern was worsening of the illness. The majority of respondents were interested in learning more about topics that were illness specific. The physician was chosen as the preferred source of information, and the preferred format was in writing. On factor analysis, the 20 concerns were reduced to 5 factors: psychological, coping, medication, social, and financial. Three factors were identified for learning interests: the illness, traditional health management topics, and nontraditional health management topics. Stepwise multiple linear regression revealed predictors for the 5 concern and 3 learning interest factors. The concerns were best predicted by self-reported disease severity, physical disability, and psychological distress, while learning interests were best predicted by self-reported disease severity, pain, and self-help group membership.

p. *Conclusion:* Concerns and learning interests of persons with arthritis did not differ based on the center of treatment or the diagnosis, but can be predicted by the level of pain and simple measures of disability. Better understanding of the relationship between health status and patient-perceived needs will result in improved patient-centered care.

AGING

Home adaptation: helping older people age in place.

Fielo SB, Warren SA.

State University of New York's Health Science Center at Brooklyn, USA. *Geriatr Nurs* 2001 Sep-Oct;22(5):239-46; quiz 246-7

As people age, decrements in sensory, motor, and cognitive function often jeopardize their ability to manage activities of daily living safely and comfortably in their own homes. The purposes of this article are to discuss common problems faced by many elders who want to remain at home, present information about possible solutions that increase their safety and comfort, and provide resources for additional information on assistive products.

Perceptions of problems and needs for service among middle-aged and elderly outpatients with schizophrenia and related psychotic disorders.

Auslander LA, Jeste DV.
Department of Psychiatry, University of California, San Diego, USA.
lauslander@ucsd.edu Community Ment Health J 2002 Oct;38(5):391-402

We examined the perceived problems and needs for services among 72 middle-aged and elderly outpatients with schizophrenia and related psychotic disorders. The survey questionnaire included 50 Likert scaled items involving everyday functioning skills, health, clinical symptoms, and social skills. Subjects assigned the highest priority to physical health and memory. Other areas of high priority were: social functioning, education about their own mental illness, and improvements in sleep and mood. Reducing frequency of psychiatric hospitalization, and drug or alcohol rehabilitation received low priority. Focused interventions targeting health-related and social issues are needed in older patients with schizophrenia.

The orodental status of a group of elderly in-patients: a preliminary assessment.

McNally L, Gosney MA, Doherty U, Field EA.
Department of Clinical Dental Sciences, University of Liverpool, UK. Gerodontology
1999 Dec;16(2):81-4

Objective: To provide a preliminary assessment of the orodental status and dental treatment requirements of a group of elderly in-patients.

p. *Design:* Cross-sectional.

p. *Setting:* Acute Care of the Elderly and Stroke Rehabilitation units at teaching hospitals in Merseyside.

SUBJECT: 150 patients aged 58 to 94 years, in which a history could be validated at interview.

p. *Interventions:* Questionnaire administered by dentist and clinical examination.

p. *Main Outcome Measures:* Registration with a dentist, prosthetic status and difficulties with dentures, denture hygiene and identification marking, dental treatment needs and evidence of mucosal pathology.

p. *Results:* Only 27% of patients claimed registration with a dentist. Three quarters of the patients were edentulous and 66 patients wore full dentures; 18 had no prostheses. Difficulties were experienced by one quarter of patients with upper dentures, compared with a half of lower denture wearers. Of the dentures available for inspection, 61% had removable soft debris, 66% were left out at night and 75% were cleaned by the patient, whilst on the ward. No dentures had evidence of identification marking. Of the 39 partially dentate patients, 75% required interventional dental treatment. Denture stomatitis was diagnosed in 29% of patients and 19 had evidence of benign mucosal pathology.

p. *Conclusion:* The orodental status of this group of elderly in-patients was poor, with a high proportion being edentulous. Few were registered with a dentist and denture hygiene was inadequate. Lack of identification marking is a matter of concern. Closer liaison between hospital staff responsible for elderly in-patients is required, to improve the orodental health and quality of life of this medically compromised group of patients.

The prevalence of diagnoses, impairments, disabilities and handicaps in a population of elderly people living in a defined geographical area: the Gospel Oak project.

Harwood RH, Prince MJ, Mann AH, Ebrahim S.
University Department of Primary Care and Population Sciences, Royal Free Hospital, London, UK. *Age Ageing* 1998 Nov;27(6):707-14

Objective: to measure the prevalence of impairments, disabilities and handicaps in a geographically-defined elderly population.

Design: cross-sectional analysis of an interview survey.

Setting: a single North London electoral ward (district). p. *Participants:* 654 residents (74%) over the age of 65 years were interviewed from a register of 889. A random sample of 225 had additional data collected which are reported in this analysis.

p. *Main Outcome Measures:* point prevalence and distribution of the total number of reported diagnoses, impairments and disabilities, and distributions of the Office of Population Censuses and Surveys (OPCS) disability scale and the London Handicap Scale scores.

p. *Results:* participants had a median of three reported diagnoses and two impairments. Forty-three percent were in the least disabled OPCS disability category (i.e. below the disability threshold) and 41% were able to undertake all of 12 basic activities of daily living without difficulty. Overall handicap scores were heavily skewed towards no health-related disadvantage, with a median score of 83 out of 100, and 37% having a score of 90 or more. All indicators showed deteriorating health with increasing age, but age-adjusted gender differences were small.

p. *Conclusion:* an elderly population's health problems were classified using a comprehensive framework, revealing high prevalences of diagnoses, impairments, disabilities and handicaps. The schema is appropriate for health care needs assessment and is a suitable basis for describing the population's health.

QUALITY OF LIFE

Estimating health needs: the impact of a checklist of conditions and quality of life measurement on health information derived from community surveys.

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Public Health Med 2001 Sep;23(3):179-86

Background: Prevalence estimates of chronic disease vary according to the technique used. Questionnaire surveys may be susceptible to inaccuracies, which may be overcome by addition of a checklist of conditions. This paper presents SF-36 scores and NHS consultation rates for people reporting individual chronic diseases or disabilities in two questionnaire surveys, one of which employed a checklist and one of which did not. We aimed to document differences in estimates of disease

prevalence, and to determine whether or not subjective impact on quality of life is the same in people recruited by a checklist as in those who volunteer that they have a chronic disease or disability without the prompt of a checklist. We use these data to estimate the contribution that different chronic diseases and disabilities make to the burden of disease in the community.

p. *Methods:* Data were collected in two postal questionnaire surveys conducted in 1991 and 1997 with response rates of 72 per cent and 64 per cent. Both questionnaires included a question on long-standing illness, disability or infirmity, together with the SF-36 health status measure. Respondents to the 1991 survey were asked to specify their illness in a free text response, whereas the 1997 survey offered a checklist of conditions. Prevalence rates of each condition were calculated, together with an 'escalation factor' representing the increase in reporting of specific diseases between the surveys. SF-36 domain and component summary scores were calculated overall and for the groups reporting individual chronic diseases or disabilities. Disease-specific NHS consultation rates were calculated for both surveys.

p. *Results:* The overall reported rate of chronic disease and disability increased from 28 per cent in 1991 to 42 per cent in 1997. Reported levels of mental health problems and of conditions with a perceived psychosomatic element increased substantially, whereas rates of well-defined conditions were similar. The pattern of SF-36 scores for those reporting chronic disease or disability was similar in the two surveys in spite of very different prevalence rates, and respondents reporting chronic disease had similar levels of health service use. This suggests that they were reporting conditions with similar levels of impact on quality of life. Heart disease, arthritis and mental health problems had the greatest impact on quality of life, and asthma and hypertension the least.

p. *Conclusion:* Evidence from SF-36 scores and NHS consultation rates suggests that addition of a checklist of conditions to this community health survey encouraged reporting of illnesses by the genuinely ill and not merely by those who are less severely affected by their disease. This method appears to give a more accurate reflection of health needs than information derived from routine data sources. The combination of prevalence data combined with subjective assessment of quality of life allows an alternative perspective of health needs. This approach highlights the relative importance of musculo-skeletal problems, particularly back pain, and mental health problems to the burden of disease, and the relative lack of importance of conditions such as asthma. It presents a contrast to studies based on other methods of health needs assessment.

Functional changes in persons aging with spinal cord injury.

Thompson L.

Rehabilitation Research and Training Center on Aging with Spinal Cord Injury,
Rancho Los Amigos National Rehabilitation Center, Downey, CA 90242, USA. *Assist Technol* 1999;11(2):123-9

Declines in general physical function and the effect of these changes on activities of daily living and needs for assistance were assessed in 150 individuals with spinal cord injury (SCI). The sample consisted of outpatients returning for follow-up at the spinal cord injury clinic at Rancho Los Amigos National Rehabilitation Center in

Downey, CA. The average duration of injury of the sample was 13 years (range 1-37), and average age was 38 years (range 18-64). Twenty-four percent of those sampled experienced a decline or change in their physical function within the last 5 years. Individuals experiencing declines were significantly older than those without changes, averaging 45 years versus 36 years. The group with change also had a longer duration of injury, averaging 18 years versus 11 years compared to the group reporting no declines. Fatigue was the most frequently reported problem, followed by pain and weakness. Over half of the group with changes required additional assistance with activities of daily living (ADLs). Family members were the primary helpers for both ADLs and instrumental activities of daily living (IADLs) for those persons experiencing changes. The use of assistive technology, primarily equipment for bathing, toileting, and low technology devices, increased with time. The increased vulnerability to loss of function in persons with advancing age and duration of injury in this population with SCI suggests the need for early preventative measures, routine assessments to detect changes, and access to health care and supportive services to alleviate or minimize the effect of these changes.

Predicting satisfaction with assistive technology for a sample of adults with new spinal cord injuries.

Scherer MJ, Cushman LA.

University of Rochester Medical Center, 601 Elmwood Avenue, Rochester, NY 14642, USA. IMPT97@aol.com Psychol Rep 2000 Dec;87(3 Pt 1):981-7

To assess the validity of the Assistive Technology Device Predisposition Assessment-Consumer Form for persons with a new spinal cord injury, 10 men and 10 women completed the scale and the Satisfaction with Life Scale and the Brief Symptom Inventory while in acute rehabilitation. One month postdischarge, subjects completed the Perceived Needs Inventory and rated their satisfaction with assistive technology. Significant positive correlations between items of the Assistive Technology Device Predisposition Assessment and Satisfaction with Life Scale (and their significant negative correlations with scores on the Brief Symptom Inventory-Depression) suggest the selected Assistive Technology Device Predisposition Assessment items measure quality of life (concurrent validity). Only Assistive Technology Device Predisposition Assessment scores predicted satisfied use 1-mo. postdischarge as measured by the Perceived Needs Inventory.

What do people with MS want and expect from health-care services?

Somerset M, Campbell R, Sharp DJ, Peters TJ.

Division of Primary Health care, University of Bristol, UK. m.somerset@bris.ac.uk Health Expect 2001 Mar;4(1):29-37

Objective: To determine the health-care preferences of people with Multiple Sclerosis (MS).

Design: Cross-sectional survey using a postal questionnaire comprising standardized measures of health related quality of life (SF-36) and of depression

(BDI) and original questions about issues linked to health-care, prioritized by people with MS during an earlier qualitative phase.

p. *Participants*: A stratified sample of 318 people with MS in Scotland and England.

p. *Results*: Questionnaires were sent to 471 people with multiple sclerosis. The 318 respondents (68%) reported a wide variation in quality of life, but on average scored significantly lower than normative values in all dimensions of the SF-36. The most commonly used home treatment during the previous year was evening primrose oil, taken by almost half of the sample (47%). Use of cannabis was acknowledged by 8%. There was evidence that many preferences concerning health services were not satisfied. For instance lack of advice about at least one MS related issue was reported lacking for three-quarters of the sample and 17% lacked advice in at least five areas. Advice about exercise was the single most requested area. The most frequently consulted health professional was the GP (78%) followed by the hospital consultant (50%). The professional that respondents most commonly said they would like to have seen was a specialist MS nurse (30%). Forty-three percent of the sample said they had attended a special meeting for people with MS or disabilities. They were equally divided between those who did and who did not find their last attendance helpful.

p. *Conclusion*: People with MS display a wide variation in their preference for services and unmet needs. Information about management (both conventional and unconventional), relevant tailored advice and access to appropriately skilled professionals should be feasible components of high quality care. This work has highlighted the value of involving people with MS in the identification of their preferences; further research is needed to show how these might be provided most effectively.

UNMET NEEDS

A pilot study of needs assessment in acute psychiatric inpatients.

Stansfeld S, Orrell M, Mason R, Nicholls D, D'Ath P.

Department of Psychiatry and Behavioural Sciences, University College London Medical School, UK. Soc Psychiatry Psychiatr Epidemiol 1998 Mar;33(3):136-9

The needs of acute psychiatric patients have been less studied than those of long-term patients. A pilot study of needs assessment using the MRC Needs for Care Assessment Schedule is reported in 35 consecutive acute inpatients who had been in hospital for 1 month or more. Unmet clinical needs included treatment of drug side effects and dangerous and socially embarrassing behaviour. Unmet social needs were widespread and included household shopping, cooking meals, occupation and money management. Although the MRC Needs for Care Assessment was found unsuitable for assessing needs in very acutely ill patients whose mental status was rapidly changing, we did find it a useful instrument in more stable acute patients, both on an individual basis and for identifying service underprovision.

A questionnaire assessment of unmet needs for rehabilitation services and resources for people with multiple sclerosis: results of a pilot survey in five

European countries. Needs Task group of MARCH (Multiple Sclerosis and Rehabilitation, Care and Health Services Research in Europe).

Kersten P, McLellan DL, Gross-Paju K, Grigoriadis N, Bencivenga R, Beneton C, Charlier M, Ketelaer P, Thompson AJ.
Health Research Unit, School of Health Professions and Rehabilitation Sciences,
University of Southampton, UK. paula@soton.ac.uk Clin Rehabil 2000 Feb;14(1):42-9

Objective: To develop an international services and needs assessment instrument (SUN) for people with multiple sclerosis and their carers and to pilot this in different countries of the European Community.

Design: Interview study of people with multiple sclerosis, their carers and nominated key professionals examining the unmet needs of patients and carers.

Setting: Belgium, Estonia, Greece, Italy and the United Kingdom.

Main Outcome Measures: Needs assessment questionnaire.

Results: The study comprised 137 people with multiple sclerosis, 125 carers and 111 professionals. Patients reported on average 2.9 unmet needs for themselves; their carers and professionals reported on average 2.4. Needs were categorized into seven broad categories. Due to difficulties experienced by the local researchers in distinguishing between needs and objectives a large proportion of needs had to be assigned to the 'other' category.

Conclusions: The SUN is a valuable and practicable tool for the identification of unmet needs for people with multiple sclerosis and their carers. Formal validation and reliability testing of the different language versions is recommended.

Improving primary health care for people with learning disabilities.

Bollard M.
Learning Disability Service, Coventry Healthcare NHS Trust. Br J Nurs 1999 Oct 14-27;8(18):1216-21

'Signposts for Success' (Department of Health (DoH), 1998a) states that specialist learning disability services (SpLDS) must promote liaisons with, and offer specialist advice to, primary healthcare teams (PHCTs). With the advent primary care groups (DoH, 1998b), genuine collaboration and partnership-forging is necessary and timely to prevent people with learning disabilities being excluded from healthcare services. The project described in the article had three broad aims: first, to establish a practice register of people with learning disabilities in all practices involved in the project; second, to enable practice nurses (PNs), with support, to carry out a systematic health check within the practice of people with learning disabilities; and third, to enable the project nurse to act as a crucial link between SpLDS and the PHCT. The health checks highlighted unmet health and social needs, which were then met

through appropriate referral and intervention, mainly to specialist services. Follow ups were conducted to measure any health gain as a result of the applied Interventions. Evidence of health gain was revealed, pointing to the clinical effectiveness of performing such checks within the PHCTs.

Lifetime care needs of individuals with multiple sclerosis.

Stolp-Smith KA.

Department of Physical Medicine and Rehabilitation, Mayo Clinic, Rochester, MN, USA. J Spinal Cord Med 1998 Apr;21(2):121-3

Reliability and validity of the CANDID--a needs assessment instrument for adults with learning disabilities and mental health problems.

Xenitidis K, Thornicroft G, Leese M, Slade M, Fotiadou M, Philp H, Sayer J, Harris E, McGee D, Murphy DG.

Section of Community Psychiatry (PRISM), Institute of Psychiatry, London. Br J Psychiatry 2000 May;176:473-8

Background: People with learning disabilities and mental health problems have complex needs. Care should be provided according to need. AIM: To develop a standardised needs-assessment instrument for adults with learning disabilities and mental health problems.

Methods: The Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID) was developed by modifying the Camberwell Assessment of Need (CAN). Concurrent validity was tested using the Global Assessment of Functioning (GAF) and the Disability Assessment Schedule (DAS). Test-retest and interrater reliability were investigated using 40 adults with learning disabilities and mental health problems.

p. *Results:* CANDID scores were significantly correlated with both DAS ($P < 0.05$) and GAF scores ($P < 0.01$). Correlation coefficients for interrater reliability were 0.93 (user), 0.90 (career), and 0.97 (staff ratings); for test-retest reliability they were 0.71, 0.69 and 0.86 respectively. Mean interview duration was less than 30 minutes.

p. *Conclusion:* The CANDID is a brief, valid and reliable needs assessment instrument for adults with learning disabilities and mental health problems.

WOMEN'S HEALTH

Deaf women: experiences and perceptions of healthcare system access.

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Department of Psychiatry, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania, USA. drannie@mail.med.upenn.edu J Womens Health (Larchmt) 2002 Oct;11(8):729-41

Background: The authors investigated the knowledge, attitudes, and healthcare experiences of Deaf women.

p. *Methods*: Interviews with 45 deaf women who participated in focus groups in American Sign Language were translated, transcribed, and analyzed. Deaf women's understanding of women's health issues, knowledge of health vocabulary in both English and American Sign Language, common health concerns among Deaf women, and issues of access to information, including pathways and barriers, were examined. As a qualitative study, the results of this investigation are limited and should be viewed as exploratory.

p. *Results*: A lack of health knowledge was evident, including little understanding of the meaning or value of cancer screening, mammography, or Pap smears; purposes of prescribed medications, such as hormone replacement therapy (HRT); or necessity for other medical or surgical interventions. Negative experiences and avoidance or nonuse of health services were reported, largely due to the lack of a common language with healthcare providers. Insensitive behaviors were also described. Positive experiences and increased access to health information were reported with practitioners who used qualified interpreters. Providers who demonstrated minimal signing skills, a willingness to use paper and pen, and sensitivity to improving communication were appreciated.

p. *Conclusion*: Deaf women have unique cultural and linguistic issues that affect healthcare experiences. Improved access to health information may be achieved with specialized resource materials, improved prevention and targeted intervention strategies, and self-advocacy skills development. Healthcare providers must be trained to become more effective communicators with Deaf patients and to use qualified interpreters to assure access to healthcare for Deaf women.

Double jeopardy. The health care system slights women with disabilities.

Smeltzer SC.

Villanova University College of Nursing, PA, USA. Am J Nurs 2000 Aug;100(8):11

Excerpts of an Executive Summary of Research and Evaluation of the International Leadership Forum for Women with Disabilities (ILFWD), Bethesda, MA, USA, 1997.

Doe T.

Int J Rehabil Res 2000 Dec;23(4):333-4

Family planning for women with learning disabilities.

Taylor G, Pearson J, Cook H.

Merton and Sutton Community NHS Trust. Nurs Times 1998 Oct 7-13;94(40):60-1

Gynecologic and reproductive services for women with developmental disabilities.

Kopac CA, Fritz J, Holt RA.

Georgetown University School of Nursing, Washington, DC 20007, USA. Clin Excell Nurse Pract 1998 Mar;2(2):88-95

A two-phase study using mail-out questionnaires examined the availability and accessibility of gynecologic and reproductive services for women with developmental disabilities. First, 127 women with developmental disabilities responded to queries about the accessibility and type of available services, the providers of necessary care, and satisfaction with the services. The age range of the women was 18-80 years, with a mean age of 40 years. Of the women queried, 40% indicated that they had not received health education regarding gynecologic and reproductive needs, and 27% indicated that they disliked health education about such matters. In the second phase of the study, agencies that provide services to these women were queried about patterns of the providers, available services, and identified barriers, including financial problems, difficulty in finding a provider, family perceptions, and fear of and distaste for examinations. A surprising finding was that more than one-third of the reporting agencies indicated that questions about the identification and treatment of sexual abuse were not applicable to their agencies. The findings are discussed with an emphasis on identified barriers to care, available services, and the implications for nurse practitioner practice.

Women with spinal cord injury and the impact of aging.

Pentland W, Walker J, Minnes P, Tremblay M, Brouwer B, Gould M.
School of Rehabilitation Therapy, Queen's University, Kingston, Ontario, K7L 3N6,
Canada.
Spinal Cord 2002 Aug;40(8):374-87

Objective: The objectives of this study were to describe what women with longstanding spinal cord injury (SCI) feel they are experiencing as they age, how they are coping and what they require in order to ensure their continued social and economic participation in society.

Study Design, Methods, and Setting: A naturalistic approach was taken, incorporating three focus groups (n=10) and key informant interviews (n=19) of women with SCI ranging in age from 31 to 70 years and living in rural and urban communities in Ontario, Canada.

Results: The women feel isolated and sense many of their key concerns are ignored or dismissed by health care and service providers. The common physical changes and concerns were gynecological/sexual and bowel and bladder issues. Socio-emotional changes with age included impact of their age-related changes on important relationships and re-evaluation of personal priorities. They articulated worries including declining health, increasing dependency and financial stresses. Additional resources they need to age successfully include improved environmental accessibility, assistive devices, more flexible and responsive attendant and household support, access to recreation and fitness opportunities and peer and psychological support.

Conclusion: Many of the issues raised by the women were consistent with the authors' previous examination of aging in men with SCI and women with disabilities. The most striking difference was their profound sense of isolation and perceptions

that health care and service providers were unprepared or unwilling to address the unique issues they face as women living and now aging with SCI.

YOUTH

A qualitative study of the transition to adulthood for youth with physical disabilities.

Stewart DA, Law MC, Rosenbaum P, Willms DG.
School of Rehabilitation Science, CanChild Centre for Childhood Disability,
McMaster University, Hamilton, Ontario, Canada. *Phys Occup Ther Pediatr*
2001;21(4):3-21

The purpose of this qualitative study was to explore the experiences, perceptions, and needs of youth with physical disabilities in transition from adolescence to adulthood. Purposeful sampling strategies were used to select 34 study participants who lived in three regions of south-central Ontario, Canada. Data collection methods were individual and focus group interviews, and were guided by a set of open-ended questions. An editing style of analysis sorted the text into codes for description and interpretation. Themes emerged about context, the transition process, needs, and services. Participants identified a poor fit between young persons with disabilities and the adult world they were entering. They recommended that services be focused on environmental supports to enable them to “build their own bridges” to the adult world. Community-based transition services need to be planned in collaboration with youth with disabilities and their parents. Concepts of person-environment fit and health promotion can be incorporated into services to enable young persons with disabilities to experience a smooth transition from adolescence to adulthood.

Duchenne muscular dystrophy--parental perceptions.

Bothwell JE, Dooley JM, Gordon KE, MacAuley A, Camfield PR, MacSween J.
The Division of Pediatric Neurology, IWK Health Centre and Dalhousie University,
Halifax, Nova Scotia, Canada. *Clin Pediatr (Phila)* 2002 Mar;41(2):105-9

Quality of life and availability of services are important for boys with Duchenne muscular dystrophy (DMD) and their families. Families attending our neuromuscular clinic completed a questionnaire on parental perception regarding the importance of services, health issues, and quality of life issues both “now” and “in the future.” Eighty-nine percent of the families (31/35) completed questionnaires. Services and health issues related to prolonging ambulation were most important, especially for the parents of younger boys. Mental health issues such as social isolation, anger, and depression were very important, particularly for the families of older boys and were anticipated to be more important in the future. Pediatricians should be aware of both the immediate needs of families to meet the physical and emotional challenges of DMD and the increasing requirement to address the social needs of these patients and their families as the boys become older.

Needs assessment in a spina bifida program: a comparison of the perceptions by adolescents with spina bifida and their parents.

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cburan@clarian.com Clin Nurse Spec 2002 Sep;16(5):256-62

The primary purpose of this study was to describe and compare medical, psychosocial, and economic needs of adolescents and young adults with a neural tube defect and their parents. A secondary aim of the study was to establish the psychometric properties of a previously published needs assessment tool. Forty-nine adolescent and 59 parents receiving services from a comprehensive spina bifida program at a large children's hospital completed a needs assessment survey designed to measure perceived needs for health and social services. The Needs Assessment Questionnaire includes 8 subscales (Accessibility/Transportation/Independence, Financial Concerns, Medical Resources, Communication/Acceptance of individuals with spina bifida, Family/Socialization, Education of others regarding spina bifida, School Services, and Vocational Training). Factors related to perceived needs and differences between adolescents and parents were explored. There was a significant difference ($<.05$) between parents and adolescents in 6 of the 8 subscales. On the remaining 2 subscales, differences between parents and adolescents approached significance. In all areas of needs for services, parents were less satisfied with the delivery of services and reported that needs were not being met. A significant negative correlation between age of the adolescent and perceived needs related to Transportation/Independence ($= -0.35$) and School Services ($= -0.31$) was found. Parents with more than a high school education perceived significantly greater needs for Vocational Training than those with less education ($= -2.1, =.04$). Identification of medical, psychosocial, and economic needs of adolescents with a neural tube defect and their families has implications for quality improvement and program development.

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