

# AAHD

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## RESEARCH ON CAREGIVERS OF PEOPLE WITH DISABILITIES

### ABUSE

#### **Personal assistance providers' mistreatment of disabled adults.**

Oktay JS, Tompkins CJ. School of Social Work, University of Maryland at Baltimore, 21201, USA. [joktay@ssw.umaryland.edu](mailto:joktay@ssw.umaryland.edu) Health Soc Work. 2004 Aug;29(3):177-88.

This article describes a survey of 84 adults with disabilities who received personal assistance with activities of daily living from family members, informal providers, or agency personnel. Results showed that 30 percent reported mistreatment from their primary provider, and 61 percent reported mistreatment by another provider. Verbal abuse, physical abuse, and theft or extortion were the most common forms of mistreatment by primary providers. Verbal abuse, neglect, poor care, and theft were the most common forms of mistreatment by other providers. Adults with lower incomes were the most likely to experience mistreatment. Male providers were more likely to mistreat, as were providers who were inexperienced and who provided more than 50 hours of care per week.

### AUTISM

#### **Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism.**

Hastings RP. School of Psychology, University of Wales Bangor, Bangor, Gwynedd, UK. [r.hastings@bangor.ac.uk](mailto:r.hastings@bangor.ac.uk) J Intellect Disabil Res. 2003 May-Jun;47(Pt 4-5):231-7.

**BACKGROUND:** Previous research has suggested that the mothers and fathers of children with disabilities experience stress differently. Although there has been a great deal of research exploring how children affect parents, there have been many fewer studies of the interrelationships between mothers' and fathers' psychological well-being.

**METHODS:** Eighteen married couples who were the parents of children with autism reported on their stress and their general mental health (i.e. anxiety and depression). Teachers rated the behaviour problems of the children with autism.

RESULTS: Mothers and fathers did not differ in their levels of stress and depression, but mothers reported more anxiety than fathers. Partial correlation analyses revealed that child behaviour problems and fathers' mental health were associated with mothers' stress. However, neither child behaviour problems or mothers' mental health was associated with fathers' stress.

CONCLUSIONS: Although requiring replication, the results suggest that stress in mothers of children with disabilities may be affected by the psychological health of other family members, whereas fathers' stress is affected more by other factors. Methodological and conceptual issues, and the practical implications of these results are discussed.

## CAREGIVING

### **Caregiving process and caregiver burden: conceptual models to guide research and practice.**

Raina P, O'Donnell M, Schwellnus H, Rosenbaum P, King G, Brehaut J, Russell D, Swinton M, King S, Wong M, Walter SD, Wood E. McMaster University, Department of Clinical Epidemiology and Biostatistics, Hamilton, Ontario, Canada.  
[praina@mcmaster.ca](mailto:praina@mcmaster.ca) BMC Pediatr. 2004 Jan 14;4:1.

BACKGROUND: Parental care for a child with a developmental disability is an enormous responsibility, one that can far exceed that of typical parental care. While most parents adapt well to the situation of caring for a child with a disability, some do not. To understand parents' adaptations to their children's disabilities, the complex nature of stress processes must be accounted for and the constructs and factors that play a role in the caregiving must be considered.

DISCUSSION: Evidence suggests that there is considerable variation in how caregivers adapt to their caregiving demands. Many studies have sought to qualify the association between caregiving and health outcomes of the caregivers. Contextual factors such as SES, child factors such as child behaviour problems and severity of disability, intrapsychic factors such as mastery and self-esteem, coping strategies and social supports have all been associated with psychological and/or physical outcome or parents or primary caregivers. In reviewing these issues, the literature appears to be limited by the use of traditional analytic approaches which examine the relationship between a factor and an outcome. It is clear, however, that changes to single factors, as represented in these studies, occur very rarely even in the experimental context. The literature has also been limited by lack of reliance on specific theoretical frameworks.

SUMMARY: This conceptual paper documents the state of current knowledge and explores the current theoretical frameworks that have been used to describe the caregiving process from two diverse fields, pediatrics and geriatrics. Integration of these models into one comprehensive model suitable for this population of children with disabilities and their caregivers is proposed. This model may guide future research in this area.

## **Framing the public health of caregiving.**

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Caregiving has only recently been acknowledged by the nation as an important topic for millions of Americans. A psychological or sociological approach to care-giving services has been most often applied, with little attention to the population-based public health outcomes of caregivers. We conceptualize caregiving as an emerging public health issue involving complex and fluctuating roles. We contend that caregiving must be considered in the context of life span needs that vary according to the ages, developmental levels, mental health needs, and physical health demands of both caregivers and care recipients.

## **Taking care of the caregivers.**

Mittelman M. Silberstein Institute, Department of Psychiatry, New York University School of Medicine, New York, New York 10016, USA. [mary.mittelman@med.nyu.edu](mailto:mary.mittelman@med.nyu.edu) Curr Opin Psychiatry. 2005 Nov;18(6):633-9.

**PURPOSE OF REVIEW:** Comprehensive treatment for people with chronic illnesses or disabilities should include interventions for their family caregivers. In order for such interventions to achieve widespread implementation, they must first be proven efficacious in randomized controlled trials. The present review briefly summarizes the recent literature on the results of randomized controlled trials and pilot studies of psychosocial interventions for caregivers.

**RECENT FINDINGS:** Many of the recent studies of psychosocial interventions for caregivers have resulted in significant outcomes, regardless of the chronic illness of the relative or friend for whom care is being provided. While didactic interventions can provide knowledge, supportive interventions generally have more impact on caregiver and patient emotional and psychological well-being. Pilot studies suggest that new modes of intervention, such as telephone-based and web-based counseling and support, show promise and appear to be feasible. Psychosocial interventions for caregivers that are individualized and flexible, and provide long-term support appear to be the most efficacious.

**SUMMARY:** The literature on caregiver intervention studies, conducted in research centers, suggests that treating the caregiver may be an important component of a comprehensive treatment for chronic diseases and disabilities. Interventions with demonstrated efficacy should now be tested more widely in community settings in multiple geographic settings, ethnic groups, disease entities and caregiver types, to more fully evaluate their generalizability and effectiveness.

# CEREBRAL PALSY

## The health and well-being of caregivers of children with cerebral palsy.

Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, Swinton M, Zhu B, Wood E. Department of Clinical Epidemiology and Biostatistics, McMaster Evidence-Based Practice Centre, Hamilton, ON, Canada. [praina@mcmaster.ca](mailto:praina@mcmaster.ca) Pediatrics. 2005 Jun;115(6):e626-36.

**OBJECTIVE:** Most children enjoy healthy childhoods with little need for specialized health care services. However, some children experience difficulties in early childhood and require access to and utilization of considerable health care resources over time. Although impaired motor function is the hallmark of the cerebral palsy (CP) syndromes, many children with this development disorder also experience sensory, communicative, and intellectual impairments and may have complex limitations in self-care functions. Although caregiving is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence. One of the main challenges for parents is to manage their child's chronic health problems effectively and juggle this role with the requirements of everyday living. Consequently, the task of caring for a child with complex disabilities at home might be somewhat daunting for caregivers. The provision of such care may prove detrimental to both the physical health and the psychological well-being of parents of children with chronic disabilities. It is not fully understood why some caregivers cope well and others do not. The approach of estimating the "independent" or "direct" effects of the care recipient's disability on the caregiver's health is of limited value because (1) single-factor changes are rare outside the context of constrained experimental situations; (2) assumptions of additive relationships and perfect measurements rarely hold; and (3) such approaches do not provide a complete perspective, because they fail to examine indirect pathways that occur between predictor variables and health outcomes. A more detailed analytical approach is needed to understand both direct and indirect effects simultaneously. The primary objective of the current study was to examine, within a single theory-based multidimensional model, the determinants of physical and psychological health of adult caregivers of children with CP.

**METHODS:** We developed a stress process model and applied structural equation modeling with data from a large cohort of caregivers of children with CP. This design allowed the examination of the direct and indirect relationships between a child's health, behavior and functional status, caregiver characteristics, social supports, and family functioning and the outcomes of caregivers' physical and psychological health. Families (n = 468) of children with CP were recruited from 19 regional children's rehabilitation centers that provide outpatient disability management and supports in Ontario, Canada. The current study drew on a population available to the investigators from a previous study, the Ontario Motor Growth study, which explored patterns of gross motor development in children with CP. Data on demographic variables and caregivers' physical and psychological health were assessed using standardized, self-completed parent questionnaires as well as a face-to-face home interview. Structural equation modeling was used to test specific hypotheses outlined in our conceptual model. This analytic approach involved a 2-step process. In the first step, observed variables that were hypothesized to measure the underlying constructs were tested using confirmatory

factor analysis; this step led to the so-called measurement model. The second step tested hypotheses about relationships among the variables in the structural model. All of the hypothesized paths in the conceptual model were tested and included in the structural model. However, only paths that were significant were shown in the final results. The direct, indirect, and total effects of theoretical constructs on physical and psychological health were calculated using the structural model.

**RESULTS:** The most important predictors of caregivers' well-being were child behavior, caregiving demands, and family function. A higher level of behavior problems was associated with lower levels of both psychological (beta = -.22) and physical health (beta = -.18) of the caregivers, whereas fewer child behavior problems were associated with higher self-perception (beta = -.37) and a greater ability to manage stress (beta = -.18). Less caregiving demands were associated with better physical (beta = .23) and psychological (beta = .12) well-being of caregivers, respectively. Similarly, higher reported family functioning was associated with better psychological health (beta = .33) and physical health (beta = .33). Self-perception and stress management were significant direct predictors of caregivers' psychological health but did not directly influence their physical well-being. Caregivers' higher self-esteem and sense of mastery over the caregiving situation predicted better psychological health (beta = .23). The use of more stress management strategies was also associated with better psychological health of caregivers (beta = .11). Gross income (beta = .08) and social support (beta = .06) had indirect overall effects only on psychological health outcome, whereas self-perception (beta = .22), stress management (beta = .09), gross income (beta = .07), and social support (beta = .06) had indirect total effects only on physical health outcomes.

**CONCLUSIONS:** The psychological and physical health of caregivers, who in this study were primarily mothers, was strongly influenced by child behavior and caregiving demands. Child behavior problems were an important predictor of caregiver psychological well-being, both directly and indirectly, through their effect on self-perception and family function. Caregiving demands contributed directly to both the psychological and the physical health of the caregivers. The practical day-to-day needs of the child created challenges for parents. The influence of social support provided by extended family, friends, and neighbors on health outcomes was secondary to that of the immediate family working closely together. Family function affected health directly and also mediated the effects of self-perception, social support, and stress management. In families of children with CP, strategies for optimizing caregiver physical and psychological health include supports for behavioral management and daily functional activities as well as stress management and self-efficacy techniques. These data support clinical pathways that require biopsychosocial frameworks that are family centered, not simply technical and short-term rehabilitation interventions that are focused primarily on the child. In terms of prevention, providing parents with cognitive and behavioral strategies to manage their child's behaviors may have the potential to change caregiver health outcomes. This model also needs to be examined with caregivers of children with other disabilities.

## CHILDREN

### **Achieving family and provider partnerships for children with special health care needs.**

Denboba D, McPherson MG, Kenney MK, Strickland B, Newacheck PW. Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, Parklawn Building, 5600 Fishers La, Room 18A-18 Rockville, MD 20857, USA. [ddenboba@hrsa.gov](mailto:ddenboba@hrsa.gov) Pediatrics. 2006 Oct;118(4):1607-15.

**BACKGROUND:** During the past 2 decades, family-centered care has evolved as the standard of care for children with special health care needs. A major principle of family-centered care is a strong partnership between the family and provider, working together to address issues and barriers to accessing comprehensive care and related services. The federal Maternal and Child Health Bureau defines a positive family-provider partnership as a core program outcome. Our objective was to assess the extent to which families of children with special health care needs feel as though they are treated as partners in decision-making by their doctors.

**METHODS:** We analyzed the 2001 National Survey of Children With Special Health Care Needs, a nationally representative telephone survey of caretakers for 38,866 children with special health care needs. Bivariate and multivariate statistical methods were used to assess the frequency of meeting the partnership core outcome, as well as the demographic and socioeconomic predictors of meeting core outcome. We also examined the effect of partnership on indicators of access and well-being for children with special health care needs.

**RESULTS:** Among children with special health care needs, 85.8% of families reported usually or always feeling like a partner in their child's care. However, living in poverty, minority racial and ethnic status, absence of health insurance, and depressed functional ability placed children with special health care needs and their families at elevated risk of being without a sense of partnership. We found that sense of partnership was associated with improved outcomes across a number of important health care measures, including missed school days, access to specialty care, satisfaction with care, and unmet needs for child and family services.

**CONCLUSIONS:** Results of the survey demonstrated that whereas most families of children with special health care needs feel they are partners in the care of their child, further work is needed, particularly for poor, uninsured, and minority children, as well as those with functional limitations. The survey results also demonstrate the importance of partnership; children whose care met the partnership core outcome experienced improved access to care and well-being.

### **Caregiving stress, immune function, and health: implications for research with parents of medically fragile children.**

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Caregiving stress has been associated with considerable demands imposed on parents responsible for the physical and emotional care of medically fragile children. With health care advances in medicine and technology, there are a growing number of children with chronic conditions and disabilities (i.e., the medically fragile) surviving longer and being cared for almost exclusively in the home by parents. The physical strains, financial constraints, emotional effects, and social isolation experienced by parents caring for children with such complex medical needs may ultimately impact their physical and emotional health. Stress associated with the caregiving of older adults has been shown to negatively impact on health and immune functioning with the potential for associated morbidity. Studies exploring the relationship of stress with biological markers of immune functioning in parents have not been widely conducted. Therefore, there is a great opportunity in parent-child health for researchers to investigate implications of stress on immune functioning and health outcomes in parents caring for medically fragile children at home. The purpose of this review article will be to provide an overview of the literature related to caregiving stress and immune functioning and to discuss implications for research in this area with parents of medically fragile children.

#### **Dilemmas in sharing care: maternal provision of professionally driven therapy for children with disabilities.**

Leiter V. Brandeis University, PO Box 9110, MS035, Waltham, MA 02454-9110, USA. [leiter@brandeis.edu](mailto:leiter@brandeis.edu) Soc Sci Med. 2004 Feb;58(4):837-49.

This paper explores some of the dilemmas that result when mothers and professionals collaborate in providing care to young children with disabilities within a US public program called Early Intervention. Successful collaboration between professionals and activist parents resulted in the program having a "family centered" approach, but the implementation of that approach is problematic. Professionals transmit therapeutic knowledge and skills to mothers of young children with special needs, urging them to perform therapeutic care work with their children. Through these efforts, professionals create a "therapeutic imperative" for mothers, expecting them to do therapeutic work that usually exceeds the amount of work that professionals do with their children. This paper explores the dilemmas mothers and professionals face when implementing family centered care and the ways in which mothers and professionals negotiate contested understandings of the optimal mixture of public (professional) and private (maternal) provision of therapeutic care to young children with disabilities.

#### **Empowerment in parents of school-aged children with and without developmental disabilities.**

Nachshen JS, Minnes P. Queen's University, Department of Psychology, Kingston, Ontario, Canada. [jnachshen@videotron.ca](mailto:jnachshen@videotron.ca) J Intellect Disabil Res. 2005 Dec;49(Pt 12):889-904.

**BACKGROUND:** Despite the widespread use of the term 'empowerment' in clinical literature to describe both a desirable process and the outcome of service delivery, the term remains more of a theoretical than practical construct. This study examined the factors that contribute to empowerment in parents of school-aged children with and without developmental disabilities (DD) using the Double ABCX model of family adaptation contrasted with the linear ACBX model.

**METHODS:** Parents of children with (n = 100, 97% mothers) and without (n = 100, 98% mothers) DD completed questionnaires relating to child behaviour problems, parent stress and well-being, and formal and informal support. Structural equation modelling was used.

**RESULTS:** Parents of children with DD reported more child behaviour problems, more stress, less well-being and more social support than parents of children without DD. Structural equation modelling supported the ACBX model for both groups. A linear relationship was found in which parent well-being and resources mediated the relationship between the stressor (child behaviour problems) and the outcome (empowerment).

**CONCLUSIONS:** The results of the current study support Hastings and Taunt's assertion in 2002, in that empowerment was adequately explained using a traditional model of family functioning. The significant prediction offered by the parent's resources points to the need to deliver services in a manner that is more family-centred. In the education system, this means providing parents with clear messages regarding the schools goals, clarifying the parent's rights and responsibilities, including the parent in planning and decision making, respecting their knowledge as caregivers and supporting their hopes for their child.

### **The health of caregivers for children with disabilities: caregiver perspectives.**

Murphy NA, Christian B, Caplin DA, Young PC. University of Utah, Department of Pediatrics, Salt Lake City, UT, USA. Child Care Health Dev. 2007 Mar;33(2):180-7

**BACKGROUND:** There are an estimated 5.9 million children with severe disabilities in the USA, and most of them are cared for at home by their parents and families. Indirect evidence suggests that poor caregiver health may contribute to recurrent hospitalizations and out-of-home placements for children with chronic conditions and disabilities. Greater knowledge of caregiver health-related needs would allow for the improvement of existing services and the development of new strategies to sustain caregivers in their vital roles. This study explores caregiver perspectives of the health implications of long-term informal caregiving for children with disabilities.

**METHODS:** Forty parents/caregivers of children with disabilities residing in urban, suburban and rural regions of Utah completed questionnaires and participated in focus groups that explored their feelings regarding their current physical and emotional health and the factors that they viewed as either impairing or promoting their health. The sessions were audiotaped and transcribed. Summary statistics were generated for the questionnaire responses. Focus group content was analysed according to emerging themes and patterns in clusters of information.

**RESULTS:** The caregiving experience was captured by five themes: (i) stress of caregiving; (ii) negative impact on caregiver health; (iii) sharing the burden; (iv) worry about the future; and (v) caregiver coping strategies. Forty-one per cent of the caregivers reported that their health had worsened over the past year, and attributed these changes to a lack of time, a lack of control and decreased psychosocial energy.

**CONCLUSIONS:** Caregivers of children with disabilities describe negative physical, emotional and functional health consequences of long-term, informal caregiving. They have important insights regarding those aspects of caregiving that have positive and negative influences on their health. Interventions that address these issues may have the potential to positively impact caregiver health.

### **Helping families raise children with special health care needs at home.**

Johnson CP, Kastner TA, American Academy of Pediatrics Committee/Section on Children With Disabilities. *Pediatrics*. 2005 Feb;115(2):507-11.

One goal of Healthy People 2010 is to reduce the number of people with disabilities in congregate care facilities, consistent with permanency-planning principles, to 0 by 2010 for persons aged 21 years and under (objective 6-7). Congregate care, in this regard, is defined as any setting in which 4 or more persons with disabilities reside, regardless of whether the residence is located in the community, such as a school, group home, nursing facility, or institution. Although this particular public health objective may reflect an unfamiliar concept for some pediatricians, the American Academy of Pediatrics supports the goals and objectives of Healthy People 2010 as well as the medical home and the provision of community-based, culturally effective, coordinated, and comprehensive care for children with special health care needs and their families. To advise families caring for children with special health care needs effectively, the pediatrician should be familiar with the principles of permanency planning and well informed of local family-support services. The pediatrician should also work with the family to identify the range of long-term supports and services available for their child. These supports may include respite for biological families as well as various additional parenting models such as shared parenting, foster care, alternate parents, and adoption. Although family-based supports are preferable, families may consider other out-of-home placements including group homes, placement in a nursing facility, or other forms of institutional care when sufficient family-based services are not available. Once all the options are understood, issues regarding quality of care can be individualized and judged by the parent or guardian, in close collaboration with the pediatrician and other professionals with expertise in permanency planning and long-term supports and services. The purpose of this clinical report is to educate physicians on the philosophy of providing a permanent family environment (permanency planning) for all children, including those with special health care needs, and the importance of adequate and accessible community services to support and maintain the well-being of all family members.

### **Low back pain in adult female caregivers of children with physical disabilities.**

Tong HC, Haig AJ, Nelson VS, Yamakawa KS, Kandala G, Shin KY. Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, MI 48108, USA. [hct@umich.edu](mailto:hct@umich.edu) Arch Pediatr Adolesc Med. 2003 Nov;157(11):1128-33.

**BACKGROUND:** Low back pain (LBP) in occupational settings has been studied extensively. There are fewer studies on LBP in domestic settings, especially in an informal caregiving setting.

**OBJECTIVES:** To compare the prevalence of LBP in adult female primary caregivers of children with physical disabilities who need assistance with transfers (eg, moving from a bed to a wheelchair) with the prevalence of LBP in adult female primary caregivers of children with nondisabling medical illnesses and to evaluate the factors associated with LBP.

**DESIGN:** A 15-minute, self-administered, cross-sectional survey.

**SETTING:** University-based clinics. Subjects Ninety consecutive adult female caregivers of children presenting to a pediatric physical medicine and rehabilitation clinic and 23 consecutive adult female caregivers of children presenting to a pediatric endocrine clinic were studied. General exclusionary criteria included the following: male sex, a history of back surgery or fracture, the caregiver was younger than 18 years old at the time of the completion of the questionnaire, or the caregiver was caring for any child younger than 2 years old. Caregivers visiting the pediatric endocrine clinic were excluded if they were caring for 1 or more children needing assistance with transfers.

**MAIN OUTCOME MEASURES:** The dependent variable was the presence of LBP. The independent variables were mood, work status, amount of lifting at work, physical functioning of the child, demographic variables of the caregiver, and demographic variables of the child.

**RESULTS:** The prevalence of having LBP (71.1%) in the physical medicine and rehabilitation group is higher than the prevalence (43.5%) in the endocrine clinic group (odds ratio, 3.2; 95% confidence interval, 1.25-8.21). The prevalence of having LBP (80.3%) when the child required physical assistance with transfers was significantly higher than the prevalence (40.5%) when the child did not require physical assistance with transfers (odds ratio, 2.56; 95% confidence interval, 2.56-14.0). Forward multiple logistic regression showed that the factors related to LBP in the caregiver were the transferability of the child, mood of the caregiver, and a history of LBP in the caregiver.

**CONCLUSIONS:** The prevalence of LBP is higher in caregivers of children needing assistance with transfers. This increased prevalence is associated with the transferability of the child and mood of the caregiver. Results of this study suggest that physical and psychological factors both contribute to the presence of nonoccupational LBP.

**Spiritual experiences of parents and caregivers who have children with disabilities or special needs.**

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Despite the fact that faith has been described as a universal concern, and despite the realization that the presence of social supports is an essential element in successful coping, there has been no systematic examination of the quality of spiritual networks important to families impacted by childhood disability. There is also little understanding of how spirituality in children influences the lived experience of faith in the adults who care for them. Findings reported here come out of a larger existential phenomenology study that examined the lived experience of parents or caregivers who sought to obtain formal religious education for their children with special needs. Participants included 26 parents/caregivers representing 44 children with special needs and 15 different faith traditions. Narratives indicated that many clergy and members of faith communities either devalue or fail to recognize the spiritual lives of disabled children. This lack of recognition was associated with participant disillusionment or crises of faith and a sense of alienation from potential sources of emotional support. In contrast, those participants whose children were welcomed reported feeling sustaining support and strengthened faith. No parent or caregiver perceived nurses as having an awareness of or interest in spirituality within families of children who have special needs.

**Stress and compliance with a home exercise program among caregivers of children with disabilities.**

Rone-Adams SA, Stern DF, Walker V. Program in Physical Therapy, Nova Southeastern University, Ft. Lauderdale, Florida. Pediatr Phys Ther. 2004 Fall;16(3):140-8.

**PURPOSE:** To determine the relationship between caregiver stress and compliance with home programs in caregivers of children with disabilities.

**METHODS:** Sixty-six caregivers of children with disabilities responded to a mailed survey to determine their level of compliance with a prescribed home physical therapy program and the level of caregiver stress. Compliance was defined as the degree to which caregivers followed the prescribed frequency of the home program.

**RESULTS:** Sixty-six percent of the caregivers reported some level of noncompliance with their home program. Linear regression analysis revealed a significant relationship between the caregivers' level of noncompliance with the home program and the level of stress that they reported. Correlation coefficients showed a significant relationship between family problems and noncompliance with home programs. As caregiver and family problems increased, noncompliance with home programs increased.

**CONCLUSIONS:** Caregivers of children with disabilities experience stress that should be addressed by therapists to maximize compliance with home programs.

**"This is a Spiritual Experience": perspectives of Latter-Day Saint families living with a child with disabilities.**

Marshall ES, Olsen SF, Mandleco BL, Dyches TT, Allred KW, Sansom N. College of Nursing, Brigham Young University, Provo, Utah, USA. Qual Health Res. 2003 Jan;13(1):57-76.

The presence of a child with disabilities elicits a variety of stress demands on the family. Religion is recognized as a powerful personal, family, and cultural variable. However, little is known about the influence of religion in dealing with disability among families within particular religious groups. This descriptive study explored themes of spiritual belief and religious support among families of the Church of Jesus Christ of Latter-Day Saints (LDS, or Mormon) with a child with developmental disabilities. Parents shared perspectives of meaning that emerged from experiences with religion and family beliefs perceived to be unique. The core theme, "This is a Spiritual Experience," provides the foundation for a descriptive model that depicts aspects of finding meaning and perceived transcendence.

## DEVELOPMENTAL DISABILITIES

### **Consumer-directed supports: economic, health, and social outcomes for families.**

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The impact of a consumer-directed support program on family caregivers of adults with developmental disabilities was explored. Economic, health, and social outcomes were compared between families in the program and families on the waiting list for the program. Caregivers of adults in the program reported fewer out-of-pocket disability expenses, greater access to health care, engagement in more social activities, and greater leisure satisfaction. There also appeared to be greater impacts on lower income families; these caregivers reported better mental health and access to health care than did similar caregivers on the waiting list.

### **Controlled evaluation of support groups for grandparent caregivers of children with developmental disabilities and delays.**

McCallion P, Janicki MP, Kolomer SR. University of Albany, Albany, NY 12222, USA. [mcclion@csc.albany.edu](mailto:mcclion@csc.albany.edu) Am J Ment Retard. 2004 Sep;109(5):352-61.

There have been growing reports of older women and men caring for their grandchildren and great grandchildren. Many of these grandparents are caring for children with developmental disabilities. To systematically examine the effectiveness of a support group intervention for such grandparents, we recruited 97 grandparents through three agencies in New York City and assigned them to treatment and wait list control conditions. Significant reductions in symptoms of depression and increases in sense of empowerment and caregiving mastery were found for the treatment group. Similar effects were found for the control subjects when they later received the intervention.

**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.

**The effect of religious coping on caregiving appraisals of mothers of adults with developmental disabilities.**

Miltiades HB, Pruchno R. Department of Social Work and Gerontology, Shippensburg University, PA 17257-2299, USA. [HBMilt@wharf.ship.edu](mailto:HBMilt@wharf.ship.edu) Gerontologist. 2002 Feb;42(1):82-91.

**PURPOSE:** This article explores the association between race and religious coping on caregiving appraisals for mothers who coreside with an adult child with mental retardation.

**DESIGN AND METHODS:** 71 Black and 71 White women (aged 50 or older) were matched on demographic characteristics to control for the association between race and socioeconomic status. Structural equation analysis was used to examine the relationship between race, religious coping, and caregiving appraisals.

**RESULTS:** Black women were more likely to use religious coping. Religious coping was associated with higher levels of caregiving satisfaction, but not with burden. Blacks experienced higher levels of caregiving satisfaction. Blacks also experienced higher levels of caregiving burden due to their poor health.

**IMPLICATIONS:** The needs of Blacks should be considered when developing "best practices" in service provision. Culturally sensitive outreach approaches should not ignore the importance of faith and faith-based organizations in the lives of Blacks.

### **The Family Stress and Coping Interview for families of individuals with developmental disabilities: a lifespan perspective on family adjustment.**

Nachshen JS, Woodford L, Minnes P. Department of Psychology, Queen's University, Kingston, Ontario, Canada. J Intellect Disabil Res. 2003 May-Jun;47(Pt 4-5):285-90.

**BACKGROUND:** The present study investigated the psychometric properties of the Family Stress and Coping Interview (FSCI), a questionnaire designed to quantitatively and qualitatively examine the experiences of parents of children with developmental disabilities (DDs).

**METHODS:** The participants consisted of 106 primary caregivers of 106 individuals with DDs from centres in Eastern, Central and North-western Ontario, Canada. The participants completed a demographic questionnaire, the FSCI, and the Vineland Adaptive Behaviour Scales.

**RESULTS:** The results of this study indicate that the FSCI has adequate reliability (i.e. internal consistency and long-term stability) and validity (i.e. independent item ratings and discriminant validity).

**CONCLUSIONS:** The results of this study support the use of the FSCI as a measure of family stress in research and practice.

### **Health outcomes of midlife and older Latina and black American mothers of children with developmental disabilities.**

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[MAGANA@Waisman.Wisc.Edu](mailto:MAGANA@Waisman.Wisc.Edu) Ment Retard. 2006 Jun;44(3):224-34

The impact of caring for a child with a developmental disability on the physical and mental health of Latina and Black American women was examined. We used the National Health Interview Survey to compare the health of older mothers who were co-residing with a child who had a developmental disability to the health of same age mothers without caregiving responsibilities. Findings show that for both groups, older adult caregivers were more likely to report having limitations from arthritis than their noncaregiving counterparts. Caregiving was associated with more depressive symptoms for Latinas, but this relationship was not found for Black American women. Findings suggest that physical and mental health of caregivers need more attention in research and practice.

### **Juggling and struggling: a preliminary work-life study of mothers with adolescents who have developmental disabilities.**

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A focus group study was conducted to develop an understanding of the experiences of mothers who are trying to balance employment with caring for an adolescent with developmental disabilities. Mothers reported facing considerable difficulties balancing

work and caregiving responsibilities because support services rapidly declined when their child reached adolescence. Service cuts were related to the fact that adolescents are expected to be able to care for themselves, despite the fact that for many adolescents with disabilities, this is not possible. The mothers also reported that the preponderance of the responsibility for arranging care for their children was theirs and was not shouldered by their partners. Policy implications are discussed.

### **Normalization in families raising a child who is medically fragile/technology dependent and developmentally delayed.**

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The authors combined and analyzed parent data from two field studies examining family experiences in raising children who were both medically fragile and developmentally delayed or disabled to compare these families' experiences to published attributes of normalization. Normalization is usually considered a useful conceptual and coping strategy for families of children with chronic conditions, but it has not been examined in families whose children have both complex physical and developmental disabilities. Developmental delays compounded the effects of the children's physical chronic conditions, severely affecting how families organized and managed their daily lives, with the result that families did not fit currently established attributes of normalization. Instead, parents recognized normal and positive aspects of their lives while acknowledging the profound challenges that their families faced. Parents concluded that it was possible to have a good life that was not necessarily normal by usual standards.

### **Personality, coping style and well-being of parents rearing children with developmental disabilities.**

Glidden LM, Billings FJ, Jobe BM. Department of Psychology, St. Mary's College of Maryland, St. Mary's City, MD 20686, USA. [lmglidden@smcm.edu](mailto:lmglidden@smcm.edu) J Intellect Disabil Res. 2006 Dec;50(Pt 12):949-62.

**BACKGROUND:** Parents with children with developmental disabilities (DD) encounter a variety of stressors associated with rearing their children and must develop effective coping mechanisms in order to adapt successfully to these challenges. Previous research has failed to establish the role of parental individual differences in the reported use of different coping strategies. The current study explores parental personality and whether children with DD were adopted or born into the families and their influence on the coping strategies used by mothers and fathers.

**METHODS:** A total of 97 mother-father dyads rearing at least one child with DD were participants. They narrated stressful situations related to their child and completed the Ways of Coping Questionnaire twice. Data were also collected with regard to personality, depression and subjective well-being (SWB).

**RESULTS:** Both adoptive and birth mothers and fathers used more problem-focused than emotion-focused strategies. Personality factors, Neuroticism especially, were predictive of coping strategy use. Higher levels of Positive Reappraisal were associated

with higher levels of SWB, whereas higher levels of Escape-Avoidance were associated with lower levels of SWB, but only for mothers. Results were consistent with a dispositional model of strategy use in that frequency of use was associated with personality characteristics, was consistent over time, and for different children in the same families. Future research should focus on the persistence of the associations between strategy use and well-being and whether they hold true at different stages of the lifespan when coping contexts may change quite dramatically.

### **A preliminary study of perceived stress in adults with intellectual disabilities according to self-report and informant ratings.**

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[Yona\\_Lunsky@camh.net](mailto:Yona_Lunsky@camh.net) J Intellect Dev Disabil. 2006 Mar;31(1):20-7

**BACKGROUND:** Stress is a major risk factor for mental health problems in individuals with intellectual disabilities, however few studies on stress have been conducted that take into account the perspective of both the person with the disability and the caregiver. The present study evaluated an informant version of the Lifestress Inventory, and compared it to the self-report version.

**METHOD:** Seventy individuals with intellectual disability paired with their caregivers completed the Lifestress Inventory, the Inventory of Negative Social Interactions and the Birleson Depression Scale.

**RESULTS:** Informant and self-report ratings on the Lifestress Inventory were internally reliable, showed modest agreement with each other and correlated with the Negative Social Interactions and Depression measures. The most troublesome stressors reported by informants and self-reports differed, however, and families tended to agree more with self-reports than did staff informants.

**CONCLUSIONS:** The informant version of the Lifestress Inventory is a suitable parallel instrument but not a replacement for self-reports.

### **Providing family support through community guides.**

Romer LT, Richardson ML, Nahom D, Aigbe E, Porter A. Division of Developmental Disabilities and the Center for Disability Policy and Research, Department of Health Services, 146 N. Canal St., Suite 313, University of Washington, Seattle WA 98103, USA. [edpr@u.washington.edu](mailto:edpr@u.washington.edu) Ment Retard. 2002 Jun;40(3):191-200.

The Family Support Opportunities program in the state of Washington has a unique component. People with extensive knowledge of local communities, referred to as community guides, were made available to all families enrolled in the program. Community guides assisted families by seeking information about community resources that families needed and helping families connect to those resources. Responses from a survey of 312 families were analyzed to determine the impact of the community guides' services. Results suggest that when families indicated satisfaction with their community guides, they reported better outcomes in terms of their needs being met, satisfaction with Family Support Opportunities, and connections to their local communities.

## **Support for family carers of children and young people with developmental disabilities and challenging behaviour.**

McGill P, Papachristoforou E, Cooper V. Tizard Centre, University of Kent, Canterbury, Kent, UK. [p.mcgill@kent.ac.uk](mailto:p.mcgill@kent.ac.uk) Child Care Health Dev. 2006 Mar;32(2):159-65.

**BACKGROUND:** This study gathered information about perceptions of family carers of children and young people with developmental disabilities and challenging behaviour of the help, support and treatment received from services and professionals.

**METHODS:** A total of 66 family carers completed postal questionnaires on the nature of, and their satisfaction with, services, professional help and advice received in respect of their family member's challenging behaviour.

**RESULTS:** Most carers were dissatisfied with support and services received. Almost half reported receiving no professional input or none that was helpful. Over two-thirds reported receiving respite care but, in a third of these, the child had been excluded because of challenging behaviour.

**CONCLUSIONS:** Families of children with challenging behaviour often do not receive services and supports that they find helpful. Treatments provided are not always evidence based. The 'rationing' of services creates a danger of inequality of access. We need a more proactive approach to identifying and meeting the need for family support.

## **DIABETES**

### **Informal caregiving for diabetes and diabetic complications among elderly Americans.**

Langa KM, Vijan S, Hayward RA, Chernew ME, Blaum CS, Kabeto MU, Weir DR, Katz SJ, Willis RJ, Fendrick AM. Division of General Medicine, Department of Medicine, University of Michigan, Ann Arbor 48109-0429, USA. [klanga@umich.edu](mailto:klanga@umich.edu) J Gerontol B Psychol Sci Soc Sci. 2002 May;57(3):S177-86

**OBJECTIVES:** Little is known regarding the amount of time spent by unpaid caregivers providing help to elderly individuals for disabilities associated with diabetes mellitus (DM). We sought to obtain nationally representative estimates of the time, and associated cost, of informal caregiving provided to elderly individuals with diabetes, and to determine the complications of DM that contribute most significantly to the subsequent need for informal care.

**METHODS:** We estimated multivariable regression models using data from the 1993 Asset and Health Dynamics Among the Oldest Old Study, a nationally representative survey of people aged 70 or older (N = 7,443), to determine the weekly hours of informal caregiving and imputed cost of caregiver time for community-dwelling elderly individuals with and without a diagnosis of DM.

RESULTS: Those without DM received an average of 6.1 hr per week of informal care, those with DM taking no medications received 10.5 hr, those with DM taking oral medications received 10.1 hr, and those with DM taking insulin received 14.4 hr of care ( $p < .01$ ). Disabilities related to heart disease, stroke, and visual impairment were important predictors of diabetes-related informal care. The total cost of informal caregiving for elderly individuals with diabetes in the United States was between \$3 and \$6 billion per year, similar to previous estimates of the annual paid long-term care costs attributable to DM.

DISCUSSION: Diabetes imposes a substantial burden on elderly individuals, their families, and society, both through increased rates of disability and the significant time that informal caregivers must spend helping address the associated functional limitations. Future evaluations of the costs of diabetes, and the cost-effectiveness of diabetes interventions, should consider the significant informal caregiving costs associated with the disease.

## PSYCHIATRIC DISABILITIES

### **Predictors of psychological distress in family caregivers of persons with psychiatric disabilities.**

Provencher HL, Perreault M, St-Onge M, Rousseau M. Faculty of Nursing, Laval University, Centre de Recherche Universite Laval-Robert Giffard, Quebec, Canada. [helene.provencher@fsi.ulaval.ca](mailto:helene.provencher@fsi.ulaval.ca) J Psychiatr Ment Health Nurs. 2003 Oct;10(5):592-607.

The purpose of the study was to determine the relationships of primary and secondary stressors, and informal and formal supports, to psychological distress in 154 family caregivers of persons with psychiatric disabilities. All caregivers were members of self-help groups located in the Province of Quebec in Canada. Psychological distress was significantly lower among older caregivers, those working full time, and those experiencing lower objective and subjective burdens. Contrary to the hypotheses, caregivers who perceived more support from friends and had more contacts with their relatives' primary mental health providers experienced a higher level of psychological distress.

### **The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness.**

Kim HW, Greenberg JS, Seltzer MM, Krauss MW. School of Social Work, University of Indiana, Indianapolis, Indiana 46202, USA. [heakim@iupui.edu](mailto:heakim@iupui.edu) J Intellect Disabil Res. 2003 May-Jun;47(Pt 4-5):313-27

BACKGROUND: Mothers who have a child with intellectual disability (ID) or mental illness face a lifetime of caregiving responsibilities and challenges. The present study investigated changes over time in how mothers cope with the challenges of caring for an adult child with disabilities and the effects of changes in coping on maternal well-being.

**METHODS:** A sample of 246 ageing mothers of adults with ID and 74 mothers of adults with mental illness was drawn from two parallel longitudinal studies of later-life caregiving.

**RESULTS:** There was considerable variability at the individual level in the degree to which mothers changed over time in their use of problem-focused and emotion-focused coping strategies. For both groups, an increase in their use of emotion-focused coping led to declining levels of well-being. For the parents of adults with ID, an increase in their use of problem-focused coping resulted in a reduction in distress and an improvement in the quality of the relationship with their adult child. For the parents of adults with mental illness, an increase in the use of problem-focused coping had no effect on levels of distress, but led to an improved relationship with their adult child.

**CONCLUSIONS:** The present study underscores the importance of coping in the lives of older mothers of adults with disabilities.

## RESPITE CARE

### **Effects of respite care for children with developmental disabilities: evaluation of an intervention for at risk families.**

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Respite child care programs that provide temporary child care, support, and referral services to families of children with developmental disabilities are thought to be a critical component of formal social support interventions deemed necessary to promote healthy family functioning and prevent child maltreatment. This study describes sociodemographic characteristics, parenting stress levels, foster care placement, and founded child maltreatment rates in families of children with developmental disabilities who were using respite care services in a rural Midwestern state. Comparison of matched pre- and post-test Parenting Stress Index scores indicated significant decreases in Total Stress scores ( $t=3.27$ ,  $df=86$ ,  $p=0.0016$ ), Parent Domain scores ( $t=3.55$ ,  $df=86$ ,  $p=0.0006$ ), and Child Domain scores ( $t=2.2$ ,  $df=86$ ,  $p=0.02$ ) following provision of respite care. Through logistic regression, it was determined that life stress, social support, and service level were significantly related to the occurrence of child maltreatment during enrollment ( $p < 0.05$ ). The investigator suggests that public health nurses can enhance their case management strategies when working with the parents of children with developmental disabilities by monitoring for caregiver burnout in addition to ensuring that the child is receiving care appropriate for his or her level of need.

### **Getting out of the house: the challenges mothers face when their children have long-term care needs.**

Yantzi NM, Rosenberg MW, McKeever P. Nursing, Health Care, Technology and Place, Toronto, Canada. [nyantzi@laurentian.ca](mailto:nyantzi@laurentian.ca) Health Soc Care Community. 2007 Jan;15(1):45-55.

In most industrialised countries, the care needs of those who are sick, disabled and frail are increasingly met in peoples' homes. One of the implications of this shift in the site of care is that individuals with long-term care needs and their family care providers experience social and spatial isolation. Many are housebound and most face considerable challenges in getting out of the house. This paper illuminates these challenges as they are experienced by mothers of children with long-term care needs, and the resulting isolation and disconnection that they experience. Eleven semistructured interviews were conducted in two regions of Ontario, Canada. Grounded theory informed the analysis of the mothers' accounts of their experiences of getting out of the house. The present findings are derived from a larger investigation of the meanings and experiences of the home as a place of caring for families with children who have long-term care needs. Secondary analysis of the data found that three main challenges restricted the mothers' abilities to leave their houses. Mothers experienced difficulties getting out of the house when they attempted to leave with the child, and when the child was left with an alternative care provider. Physical challenges were associated with the work and planning required in moving the child's equipment and supplies, meticulous planning of the outing within the daily schedule, and navigating barriers in the built and natural environments. Social challenges reflected the lack of people within the mothers' social network of family and friends who have the knowledge and expertise to care for the child. Service challenges resulted from the gaps between the policies and practices of paid respite, and the conditions that must be satisfied in order for mothers to be able and/or willing to leave the house. The authors also examined the reasons why some of the mothers worked from home, and the strategies that they used to get out of the house for employment. In this paper, the authors discuss each challenge, and how it contributes to the mothers' social and spatial isolation. The mothers' experiences elucidate the differences between living in a community and being part of a community. The consequences of the isolation on mothers' daily lives are not recognised in home and community care policy. The suggestions that are put forward concerning paid respite have relevance for home and community care policy and practice.

## **SPIRITUAL BELIEFS**

### **Disability, spiritual beliefs and the church: the experiences of adults with disabilities and family members.**

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[linda.treloar@sccmail.maricopa.edu](mailto:linda.treloar@sccmail.maricopa.edu) J Adv Nurs. 2002 Dec;40(5):594-603.

AIMS: This paper reports the findings of a qualitative interpretive study that explored how people with disabilities and family members use their spiritual beliefs to establish meaning for disability, and to respond to the challenges of lived experience with disability. The participants' perceptions of the evangelical Christian church's influence on their spiritual experiences related to disability suggest recommendations for improved integration by the church. Applications are drawn for helping professionals and religious leaders who provide holistic care.

**BACKGROUND/RATIONALE:** Although there is a well-established literature on coping in families with disabled children, little is known about how people use spiritual beliefs to establish meaning for and respond to life with disability. Even less is known about how people with a particular set of shared spiritual beliefs make meaning for lived experience with disability.

**DESIGN/METHODS:** The author interviewed 30 persons, comprising two major groups: 13 parents of children with mixed developmental disabilities and nine adults with physical disabilities. Predominantly white, the participants lived in a south-western metropolitan area in the United States of America (USA) in 1998.

**FINDINGS:** Trial or difficulty contributed to spiritual challenge, the breaking of self, reliance on God, and strengthened faith in God. The participants chose to live with thankfulness and joy despite difficulties common to experience with disability. The participants' spiritual beliefs stabilized their lives, providing meaning for the experience of disability, assistance with coping and other benefits. The participants' recommendations include increased assistance by the church in promoting theological understanding of disability, and religious support using a continuing model of caring.

**CONCLUSIONS:** Although the study design limits the generalizability of the findings, applications can be drawn for helping professionals and religious leaders who provide holistic care.

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