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Children, adolescents and young adults with a chronic illness: quality of life, social participation and health care service - a patient and family perspective

Bibliography 1995 – 2003

Volume 2: 2000 - 2003

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ISBN: 90-6905-647X – Volume 2
This bibliography was initiated and financed by NIVEL

Utrecht, 2004

Contents

Abstracts (2000-2003)	3
1 Quality of life	3
1.1 Quality of life from the patient's perspective	3
1.2 Quality of life from the family's perspective	51
1.3 Questionnaires and measures on quality of life	95
2 Social participation	118
2.1 Social participation from the patient's perspective	118
2.2 Social participation from the family's perspective	142
2.3 Questionnaires and measures on social participation	145
3 Self management	147
3.1 Coping	147
3.1.1 Coping from the patient's perspective	147
3.1.2 Coping from the family's perspective	157
3.2 Self care and compliance	168
3.2.1 Self care from the patient's perspective	168
3.2.2 Self care from the family's perspective	184
4 Health care service	195
4.1 Health care service from the patient's perspective	195
4.2 Health care service from the family's perspective	205
4.3 Health care – questionnaires	219
Author index	221
Subject index	235
Appendix 1: Search profile	241
Appendix 2 : Overview of relevant documents in reviews	243

Abstracts

1 Quality of life

1.1 *Quality of life from the patient's perspective*

Abbott J, Baumann U, Conway S, Etherington C, Gee L, Von Der Schulenburg JM, Webb K. Cross cultural differences in health related quality of life in adolescents with cystic fibrosis. *Disability and Rehabilitation*, 2001; 23(18): p.837-844

OBJECTIVE: To compare Quality of Life (QoL) between English and German adolescents with Cystic Fibrosis (CF) and their healthy peers. **METHODS:** The study comprised a cross-sectional design. The English subjects formed two groups; 58 adolescents with CF and 49 healthy controls. The German subjects consisted of 26 adolescents with CF and 75 healthy controls. Quality of life was measured using the English and German versions of the SF-36. Demographic (age and gender) and clinical data (FEV1% predicted and BMI) were also recorded. **RESULTS:** The English and German CF groups had similar age-adjusted lung function and body mass index. Both the English CF and control groups reported a poorer quality of life than their respective German counterparts across several domains of the SF-36. These were limitations in activities due to physical health problems and emotional difficulties, social functioning, energy and vitality and pain. **CONCLUSIONS:** The differences in quality of life between English and German adolescents with CF appear to be either culturally determined or due to idiosyncrasies in the translations of the SF-36 rather than a consequence of their disease or its management.

Language: English

Keywords: Cystic fibrosis / Adolescents / Quality of life / Cultural differences

Alwash RH, Hussein MJ, Matloub FF. Symptoms of anxiety and depression among adolescents with seizures in Irbid, Northern Jordan. *Seizure*, 2000; 9(6): p.412-416
NIVEL: C 8464

The objective of this study was to assess the psychosocial outcome, in particular psychiatric symptoms like anxiety and depression, of epilepsy

among adolescents. The study included 101 epileptic adolescents and 101 non-epileptic controls. Sociodemographic characteristics and all relevant clinical data were collected through interviewing the cases and controls. Identification of the symptoms of anxiety and depression was made according to DSM-IV criteria. The patients were age and sex matched with the controls. The controls had achieved a significantly better education (> 12 years education) than the patients with epilepsy. The adolescents with epilepsy were also shown to be disadvantaged in their living circumstances. Some of them were dependent on their parents in some daily physical activities, such as bathing, which might be a sign of overprotection by their parents. Those with epilepsy had a significantly higher tendency to develop symptoms of anxiety and depression than the control group. Moreover these psychiatric symptoms, especially anxiety symptoms, were more likely to happen when seizures had not been properly medically controlled. Overprotective parental behaviour towards their ill children could also delay their psychosocial maturation. Therefore, counselling of patients and parents about epilepsy is an important factor in the control of seizures and their sequelae.

Language: English

Keywords: Epilepsy / Adolescents / Anxiety / Depression

Andelman F. Analysis of quality of life among adolescents with epilepsy.

International Journal of Adolescent Medicine and Health, 2000; 12(Suppl 1): p.17-24

NIVEL: C 8545

The aim of this review is to give an overview of quality of life (QoL) studies in adolescents with epilepsy. For adolescents with epilepsy, QoL is closely related to depression, anxiety, and locus of control. Neuropsychological and QoL variables are complementary and overlapping. Cognitive and academic difficulties and achievement levels contribute to adolescents' QoL. The prevalence or severity of depression and anxiety depends on epilepsy control. Adolescent attitudes toward seizures, family relationship satisfaction, and external locus of control are significant predictors of depression. Surgical treatments have improved patients' subjective QoL quantification, and are effective adjuncts to medication for those with refractory seizures.

Language: English

Keywords: Epilepsy / Adolescents / Quality of life / Anxiety / Depression / Reviews

Annett RD, Bender BG, Lapidus J, Duhamel TR, Lincoln A. Predicting children's quality of life in an asthma clinical trial: what do children's reports tell us? *The Journal of Pediatrics*, 2001; 139(6): p.854-861
NIVEL: C 8422

OBJECTIVE: To assess the disease-specific quality of life (QOL), reported by children with asthma and focusing on predictors, and to get insight into the relationship between asthma symptoms and disease-specific QOL.
METHODS: Three hundred thirty-nine children participated at 4 of 8 Childhood Asthma Management Program clinical centers. Included in the analyses were 2 weeks of asthma symptom data, child-reported health status, and QOL scores from the Pediatric Asthma Quality of Life Questionnaire. Data were obtained 12 months after randomisation into the Childhood Asthma Management Program.
RESULTS: Children were rated at baseline as having "moderate" asthma (63%) and "mild" asthma (37%). QOL scores were correlated with the child-reported anxiety measures. Factor analysis of the QOL measure resulted in 2 factors. Stepwise multiple regression indicated that the strongest independent predictors of QOL were the child's anxiety level, age, sex, and a measure of the child's tendency to minimise or exaggerate symptoms.
CONCLUSIONS: Children had few asthma symptoms in the 2 weeks before their 12-month follow-up clinic visit and a generally positive QOL, suggesting that mild-to-moderate asthma does not significantly impair QOL. A child's QOL was predicted primarily by their level of anxiety.

Language: English

Keywords: Asthma / Quality of life / Health status / Anxiety

Austin JK, Dunn DW, Caffrey HM, Perkins SM, Harezlak J, Rose DF. Recurrent seizures and behavior problems in children with first recognized seizures: a prospective study. *Epilepsia*, 2002; 43(12): p.1564-1573
NIVEL: C 8334

OBJECTIVE: To get insight into the relationship between seizures and behaviour problems in epileptic children with new-onset seizures.
METHODS: Subjects were 224 children with new-onset seizures (aged 4-14 years) and 159 siblings (4-18 years). Caregiver's ratings of the behaviour were collected 4 times: at baseline, and at 6, 12, and 24 months. During the 2-year period, 163 (73%) children had at least one additional seizure, and 61 (27%) had none. Data were analysed by using repeated measures analysis of

variance both with and without covariates [site, age, gender, race, caregiver education (years), and seizure medications]. RESULTS: On average, children had higher CBCL Total and Internalising Behaviour Problems scores across all times when experiencing recurrent seizures than when not experiencing recurrent seizures (Total Problems, $p = 0.041$, controlling for demographics and seizure medications). Siblings had significantly lower Total and Internalising Problems scores than both children experiencing (Total Problems adjusting for covariates, $p = 0.0001$) and not experiencing recurrent seizures ($p = 0.0004$). Externalising Problems scores were not significantly different among children with recurring seizures, children without recurring seizures, and siblings. CONCLUSIONS: Recurrent seizures significantly predicted behaviour problems very early in the course of a seizure condition, even when key child, demographic, and seizure variables were controlled. Explanations for these findings include the possibilities that both seizures and behaviour problems are caused by an underlying neurological disorder, that seizures per se disrupt behaviour, or that children have negative psychological responses to seizure activity.

Language: English

Keywords: Epilepsy / Siblings / Behaviour problems / Anxiety / Depression

Austin JK, Dunn DW. Children with epilepsy: quality of life and psychosocial needs. *Annual Review of Nursing Research*, 2002; 18, p.26-47
NIVEL: C 6386

The aim of this review is to give an overview of the research related to quality of life in children with epilepsy and their psychosocial needs. Nursing and nonnursing research reports and descriptions of instruments developed between January 1994 and February 1999 are included. Most research reports described quality-of-life problems, especially psychological functioning in school-age children. Less attention was devoted to psychosocial needs. Major gaps included intervention studies and research on infants and young children. Conclusions include recommendations for future research.

Language: English

Keywords: Epilepsy / Quality of life / Patient satisfaction / Needs assessment / Reviews

Barr RD, Gonzalez A, Longchong M, Furlong W, Vizcaino MP, Horsman J, Fu L, Castillo L. Health status and health-related quality of

life in survivors of cancer in childhood in Latin America: a MISPHO feasibility study. *International Journal of Oncology*, 2001; 19(2): p.413-421
NIVEL: C 8609

This study addresses the health status and quality of life of children in Latin America who survive cancer. Spanish language versions of questionnaires for proxy assessors, based on the Health Utilities Index (HUI), were used to elicit responses from parents and physicians. The HUI is a family of multi-attribute, generic, preference-linked measures of health status and health-related quality of life that are reliable, responsive and valid, and have been used previously in pediatric oncology. Valid responses were received from 178 parents and 144 physicians in 6 centres in 4 countries (Cuba, Honduras, Colombia and Uruguay). For children with acute lymphoblastic leukaemia the major morbidity burdens were in the attributes of emotion, cognition and pain. The overall burden of morbidity was greater in children with non-Hodgkin's lymphoma. In survivors of Hodgkin's disease and Wilms' tumor the attributes most affected were emotion and pain. In general, there was considerable agreement between the assessments provided independently by parents and physicians. This study demonstrates the feasibility of conducting such measurements in developing countries, and reveals similarities in health status and health-related quality of life to comparable populations in more privileged societies.

Language: English

Keywords: Cancer / Health status / Quality of life / Latin America

Baumann DA, Landolt MA, Wetterwald R, Dubuis JM, Sizonenko PC, Werder EA. Psychological evaluation of young women after medical treatment for central precocious puberty. *Hormone Research*, 2000; 56(1-2): p.45-50
NIVEL: C 8456

OBJECTIVE: To evaluate the subjective experience and long-term behavioural and psychological effects of precocious puberty (PP).
METHODS: Nineteen female patients, aged 14-22 years, who had been treated with GnRH agonists participated in a semistructured interview and completed two standardised checklists. Their parents completed the Child Behavior Checklist (CBCL).
RESULTS: The CBCL yielded significantly elevated Internalising and Total Behaviour Problem scores. An elevated risk was found for patients with short adult stature and a relatively late onset of PP. The latter tended to neuroticism, to accentuation of their physical

appearance, and felt significantly more insecure than age-related non-PP girls. CONCLUSIONS: These findings suggest that PP can lead to specific behavioural problems, and that patients with a risk factor may need psychosocial support.

Language: English

Keywords: Precocious puberty / Adolescents / Behaviour problems / Psychosocial problems

Bilenberg N, Lie HR. Behavioral and emotional problems in children with myelomeningocele (MMC). *European Journal of Pediatric Surgery*, 2001; 11(Suppl 1): p.44-46
NIVEL: C 8452

This study was aimed at getting insight into the behavioural and emotional problems amongst children with myelomeningocele (MMC), an inborn lesion of the neural tube with spinal cord defect, resulting in motor and sensory paralysis, neuropsychological and/or psychiatric problems. A sample of 78 children with MMC was compared with a reference sample. Questionnaires like the Child Behavior Checklist (CBCL), Teachers Report Form (TRF) and Youth Self Report (YSR) were sent to the families. Mean CBCL total problem scores in the MMC group was 30.2 (sd=17.6), compared to 17.7 (sd=14.9) in the reference sample, which was highly significant. Differences regarding ADHD symptoms scores at the CBCL were equally convincing. In self-rating, no differences were found. Teachers and parents reported about 27 % of the MMC sample being under-average readers and spellers, compared to about 10 % in the reference sample. Mathematic or arithmetic abilities seemed to be even more compromised. It was concluded that behaviour problems, especially ADHD, are common in MMC children.

Language: English

Keywords: Myelomeningocele / Hydrocephalus / Behaviour problems / Attention Deficit Hyperactivity Disorder

Britto MT, Kotagal UR, Hornung RW, Atherton HD, Tsevat J, Wilmott RW. Impact of recent pulmonary exacerbations on quality of life in patients with cystic fibrosis. *Chest*, 2002; 121(1): p.64-72
NIVEL: C 8502

OBJECTIVE: To compare the health-related quality of life (HRQOL) of children and adults with cystic fibrosis (CF) to the general population, and to determine the relationship between HRQOL and clinical and demographic factors. **METHODS:** A cross-sectional analysis of an observational cohort was carried out in some outpatient clinics of a Midwestern CF center. One hundred sixty-two subjects with CF aged 5 to 45 years participated. The main outcome measures were physical and psychosocial summary scores and individual scale scores for the Child Health Questionnaire and Short Form-36. **RESULTS:** Compared with the general population, people with CF reported similar scores for most psychosocial measures, but lower scores for most physical measures, with the lowest scores on the general health perceptions scale. In multivariable analyses, pulmonary exacerbations in the past 6 months were strongly associated with the physical ($p = 0.001$) and psychosocial ($p = 0.0003$) scores. The physical score fell, on average, 6 points per exacerbation and the psychosocial score fell 3 points. Lung function, nutrition, 6-min walk distance, age, gender, and insurance status were not significantly associated with HRQOL in this study population. Those who declined to participate had significantly lower FEV(1) percent predicted and nutritional indexes. These findings may not be generalisable to the entire CF population. **CONCLUSIONS:** Recent pulmonary exacerbations have a profound negative impact on HRQOL that is not explained by differences in lung function, nutritional status, or demographic factors.

Language: English

Keywords: Cystic fibrosis / Quality of life / Health status / Psychosocial problems

Brown LK, Lourie KJ, Pao M. Children and adolescents living with HIV and AIDS: a review. *Journal of Child Psychology and Psychiatry*, 2000; 41(1): p.81-96
NIVEL: C 8546

The aim of this review is to give an overview of current studies and reports on the consequences of the acquired immunodeficiency syndrome (AIDS) epidemic in the psychiatric care and development of children and adolescents infected by HIV. From a search of all the English-language-based literature on pediatric AIDS, 140 studies are reviewed which address HIV infection and its psychological and social implications. Several topics of mental health significance are examined: (1) the epidemiology of HIV, (2) neurocognitive development among those infected, (3) psychological impact of infection, and (4) the family and social context of HIV. The transition of HIV from an acute, lethal disease to a subacute, chronic disease has

enormous implications for the neurocognitive and psychosocial development of children and families. As children and adolescents infected with HIV continue to live longer, normal developmental milestones and educational needs will take on new significance. Many children will continue to be adversely impacted by non-HIV factors such as poverty, inadequate medical services, and a lack of social support. This review outlines recent developments that hold promise to effectively reduce the treatment burden on the infected, their families, and health care providers and to decrease the incidence of transmission to the uninfected.

Language: English

Keywords: Hiv / Aids / Cognitive development / Mental disorders / Quality of life / Coping / Family environment / Socioeconomic factors / Reviews

Bryden KS, Peveler RC, Stein A, Neil A, Mayou RA, Dunger DB.
Clinical and psychological course of diabetes from adolescence to young adulthood: a longitudinal cohort study. *Diabetes Care*, 2000; 24(9): p.1536-1540
NIVEL: C 8424

OBJECTIVE: To determine the clinical and psychological course of diabetes through adolescence and the relationship with glycemic control.

METHODS: A longitudinal cohort study of adolescents recruited from the register of the outpatient pediatric diabetes clinic. A total of 76 individuals (43 male patients, 33 female patients) aged 11-18 years completed baseline assessments, and 65 individuals (86%) were reinterviewed as young adults (20-28 years of age). Longitudinal assessments were made of glycemic control (HbA(1c)), weight gain (BMI), and development of complications. Adolescents completed self-report questionnaires to assess emotional and behavioural problems as well as self esteem. As young adults, psychological state was assessed by the Revised Clinical Interview Schedule and the self-report Brief Symptom Inventory. **RESULTS:** Mean HbA(1c) levels peaked in late adolescence and were worse in female participants (average 11.1% at 18-19 years of age). The proportion of individuals who were overweight (BMI >25.0 kg/m(2)) increased during the 8-year period from 21 to 54% in female patients and from 2 to 28% in male patients. Serious diabetes-related events included death in one patient and cognitive impairment in two patients. Individuals in whom diabetic complications developed (25% of male patients and 38% of female patients) had significantly higher mean HbA(1c) levels than those without complications (difference 1.9%, 95% CI 1.1-2.7, P < 0.0001). Behavioural problems at baseline were related to higher

mean HbA(1c) during the subsequent 8 years (beta = 0.15, SEM (beta) 0.04, P < 0.001, 95% CI 0.07-0.24). CONCLUSIONS: The outcome for this cohort was generally poor. Behavioural problems in adolescence seem to be important in influencing later glycemic control.

Language: English

Keywords: Diabetes mellitus / Adolescents / Young adults / Psychosocial problems / Behaviour problems / Health status

Calaminus G, Weinspach S, Teske C, Gobel U. Quality of life in children and adolescents with cancer: first results of an evaluation of 49 patients with the PEDQOL questionnaire. *Klinische Pädiatrie*, 2000; 212(4): p.211-215
NIVEL: C 8365

OBJECTIVE: To examine the following questions: How do children with cancer reflect on their QoL in comparison to healthy children of the same age? Are there any significant differences in QoL between children with hematological disorders and children with solid tumors and if that is so, which domains are affected? METHODS: A pilotversion of a self-rating QoL questionnaire for children between 8 and 18 years (PEDQOL), especially developed for pediatric oncology, was used. Forty-nine children off treatment of whom 51% had leukaemia/lymphoma and 49% had solid tumors compared to 62 healthy school children were examined. RESULTS: The PEDQOL questionnaire was a good accepted measure among the examined children. The reliability scores of the pilotform for the evaluated domains were also satisfactory (Cronbach's-Alpha > 0.60). In general QoL was scored good by healthy as well as by ill children. In the group of children with leukaemia/lymphoma impairment of QoL was more apparent than in children with solid tumors (domains autonomy, emotional functioning, cognition and familial interactions). Survivors of solid tumors reported less impairment of QoL which was mainly seen in physical functioning and body image. CONCLUSIONS: In general QoL scored with the PEDQOL pilot questionnaire was good for most of the childhood cancer survivors. Children with solid tumors show less impairment than children with leukaemia/lymphoma. Therefore it could be suggested, that young age at diagnosis and the following longer period of being dependent on familial support, the isolation from peer groups and the longer way to become independent may be reflected by these results. To obtain reliable results how children with cancer express their QoL and what consequences illness, treatment and long term effects of therapy have on the children's QoL a

multicenter prospective study is needed. This will be realised in the near future in a project on "Long term effects and quality of life in children with leukaemia or medulloblastoma", which is supported by the "Kompetenznetz Pädiatrische Onkologie and Hämatologie".

Language: English

Keywords: Cancer / Leukaemia / Quality of life / Questionnaires

Cavusoglu H. Self-esteem in adolescence: a comparison of adolescents with diabetes mellitus and leukaemia. *Pediatric Nursing*, 2001; 27(4):

p.355-361

NIVEL: C 8574

The aim of this study was to examine the self esteem of adolescents with diabetes mellitus and leukaemia. Participants of this descriptive study were 22 adolescents with diabetes mellitus and 33 with leukaemia. No significant difference was found between the self esteem of males and females in either group. After the initial diagnosis, over time a decrease in self esteem in the leukaemia group and an increase in self esteem in the diabetes mellitus group were observed. The adolescents with leukaemia who experienced a relapse had moderate self esteem. Most of the adolescents with leukaemia could not attend school because of their illness. The mean scores of self esteem were high in the diabetes mellitus group and moderate in the leukaemia group. In both groups, the mean scores of self esteem were compared to depressive affect, daydreaming, psychosomatic symptoms, intensity of discussion, and parental interest (subscales in the Rosenberg self esteem scale). No significant difference was found between the two disease groups. There was a strong and significant correlation between self esteem and depressive affect in both groups.

Language: English

Keywords: Diabetes mellitus / Leukaemia / Adolescents / Self esteem

Chapieski L, Friedman A, Lachar D. Psychological functioning in children and adolescents with Sturge-Weber syndrome. *Journal of Child Neurology*, 2000; 15(10): p.660-665

NIVEL: C 8378

The aim of this study was to assess psychological functioning in school-aged children with Sturge-Weber syndrome. Psychological functioning was assessed in 4 areas: intellectual/academic, social skills, mood and

compliance. The data were collected from parents and teachers for 79 children and adolescents with Sturge-Weber syndrome and a group of their siblings. Besides, the results of intellectual assessment for a subset of the Sturge-Weber syndrome group were obtained. The young people with Sturge-Weber syndrome exhibited more problems than the group of siblings across a number of behavioural domains: intellectual/academic, social skills, mood, and compliance. Those children most at risk for psychological problems were those with lower levels of intellectual functioning, those with seizure disorders, and those with more frequent seizures. Larger port-wine stains were also associated with an increase in mood and social problems but only for older children. Increased age was not associated with lower levels of intellectual or academic functioning, but mood and social problems were more common in older children.

Language: English

Keywords: Sturge-Weber syndrome / School-age children / Adolescents / Cognition disorders / Mental disorders / Academic achievement / Psychosocial problems

Durst CL, Horn MV, MacLaughlin EF, Bowman CM, Starnes VA, Woo MS. Psychosocial responses of adolescent cystic fibrosis patients to lung transplantation. *Pediatric Transplantation*, 2001; 5(1): p.27-31
NIVEL: C 8418

The aim of this study was to get insight into the psychosocial and emotional responses of adolescent cystic fibrosis (CF) patients after undergoing lung transplantation (Tx). Nineteen CF lung transplant recipients were studied (eight males, 11 females: mean age at time of transplant, 15.7 +/- 2.7 yr). The mean time interval from Tx to interview was 25.4 months (range 1-58 months). Sixteen patients had living donor lobar lung Tx while three patients received cadaveric lungs. A series of 25 questions was used to assess the psychosocial impact of Tx, and a semi-structured interview focused on the following five domains: lifestyle, family functioning, social functioning, body image, and psychological functioning. The major themes identified by patients included: a strong desire to set and attain meaningful long-range goals, the need to control as many aspects of their lives as possible while dealing with parental over-protectiveness, and the adjustment to a new lifestyle. Common emotional responses included manageable fear/anxiety of lung rejection and uncertainty of the future, impatience with disruptions of daily routines caused by post-transplant medical management and its effect on the attainment of set goals, and frustration with parental over-protectiveness. In general, patients reported a positive outlook on life, with

greater emphasis on sought-after goals as well as interpersonal relationships. This study demonstrates that adolescent CF transplant recipients develop long-term goals and plans for independence. By identifying and anticipating the emotional needs of this population, health care providers can assist patients in improving the quality of their lives from a physiological, as well as a psychological, viewpoint.

Language: English

Keywords: Cystic fibrosis / Adolescents / Lung transplantation / Quality of life

Fritz GK, McQuaid EL. Chronic medical conditions: impact on development. In: Sameroff AJ, Lewis M (eds). *Handbook of developmental psychopathology* (2nd ed.). Dordrecht, Netherlands: Kluwer Academic Publishers, 2000: p.277-289
NIVEL: C 8538

In this book chapter the definitions, methodological issues, and conceptual approaches to chronic pediatric problems are reviewed. The authors review available evidence on the association of psychopathology, psychological symptoms, and adjustment problems with chronic medical conditions. Theoretical, clinical, and empirical data form the basis for a discussion of the impact of chronic conditions on specific developmental stages. Finally, conceptual models are discussed that usefully integrate potentially confounding issues. Recent conceptualisations have evolved to integrate individual physiological factors, such as reactivity to stress in autonomic and immune systems, thereby adding an important dimension that may account for individual variations in response to illness. Challenges for the future include refining the mechanisms for interaction and bringing complex developmental perspectives more fully to bear on the study of children with physical conditions.

Language: English

Keywords: Chronic diseases, general / Mental disorders / Psychosocial problems / Behaviour problems / Reviews

Ganesan V, Hogan A, Shack N, Gordon A, Isaacs E, Kirkham FJ. Outcome after ischaemic stroke in childhood. *Developmental Medicine & Child Neurology*, 2000; 42(7): p.455-461
NIVEL: C 8481

The aim of this study was to investigate the outcome for children who have had ischemic stroke. A questionnaire was distributed among the parents of children who had survived the stroke and who were seen at a hospital in London between 1990 and 1996. The results of functional assessments carried out by a physiotherapist and an occupational therapist, and of quantitative evaluations carried out by a neuropsychologist were used for validation where possible. The relationship between clinical and radiological factors and outcome were examined. The children were aged between 3 months and 15 years at the time of stroke (median age 5 years) and the period of follow-up ranged from 3 months to 13 years (median duration 3 years). Of the 90 children for whom data were obtained, 13 (14%) had no residual impairments. Outcome was good in 37 children (40%) and poor in 53 (60%) (defined according to whether impairments interfered with daily life). Agreement, as measured by Cohen's kappa, was good or very good between the parents' responses and the qualitative measures provided by the medical professionals and the therapists, but only fair to moderate for the quantitative measures provided by the neuropsychologists. This may reflect different parental perceptions of the physical and cognitive aspects of outcome. Younger age at time of the stroke was the only significant predictor of adverse outcome.

Language: English

Keywords: Cerebrovascular accident / Cognition disorders / Activities of daily living

Gillaspy SR, Hoff AL, Mullins LL, Pelt JC van, Chaney JM.
Psychological distress in high-risk youth with asthma. *Journal of Pediatric Psychology*, 2002; 27(4): p.363-371
NIVEL: C 8415

OBJECTIVE: To examine the relationship between asthma and psychological distress among adolescents already at-risk for adjustment problems due to lower economic position and educational or vocational failure. **METHODS:** Twenty-five high-risk adolescents with asthma and 25 high-risk controls without asthma 16 to 21 years old completed the Brief Symptom Inventory, the Beck Depression Inventory, and the Beck Anxiety Inventory. **RESULTS:** Adolescents with asthma had significantly higher scores on multiple measures of psychological distress. Specifically, adolescents with asthma evidenced higher levels of anxiety, depression, and global psychological distress than those without asthma. **CONCLUSIONS:** High-risk adolescents with asthma may be more likely to experience

psychological distress than those without asthma. The results of this study suggest that asthma constitutes an additional significant independent stressor or risk factor among adolescents who already are at high risk for multiple adjustment problems.

Language: English

Keywords: Asthma / Adolescents / Anxiety / Depression / Psychological stress / Ethnic minorities / Socioeconomic factors / Risk factors

Gool CH van, Vries J de, Heck GL van, Hendriks HJE. Zelfbeeld en kwaliteit van leven bij kinderen met astma. (Self-image and quality of life in children with asthma.) *Tijdschrift voor Orthopedagogiek*, 2002; 41: p.3-16
NIVEL: C 85 34

The aim of this study was to examine the relationship between self image and quality of life in children with asthma. Thirty children with asthma and 33 healthy controls filled in 2 questionnaires: a feeling of competence scale (Competentiebelevingsschaal, CBSK) and a measure of quality of life (Hoe gaat het?, HGH). This last questionnaire was also filled in by one of the parents, in order to get insight into its psychometric qualities. It was hypothesised that the children in the asthma group would have lower quality of life scores than the healthy controls. However, this turned to be in only 3 subscales. Moreover, the results give a differentiated picture with respect to the predicting value of self image for quality of life. Further research is necessary to clarify this relationship.

Language: Dutch

Keywords: Asthma / Self image / Quality of life

Grey M, Whittemore R, Tamborlane W. Depression in type 1 diabetes in children: natural history and correlates. *Journal of Psychosomatic Research*, 2002; 53(4): p.907-911

The purpose of this review is to give an overview of the research on the natural history and correlates of comorbid diabetes and depression in children and adolescents. Children with diabetes have a two-fold greater prevalence of depression, and adolescents up to three-fold greater, than youth without diabetes. Correlates of depression and diabetes include gender, poorer metabolic control, and family behaviours. Very little is known about treatment in these youth, and more studies are indicated.

Language: English

Keywords: Diabetes mellitus / Depression / Comorbidity / Reviews

Grootenhuis MA, Oonk J, Scherpbier HJ, Kreyenbroek ME, Last BF. Kwaliteit van leven van Nederlandstalige kinderen met een HIV-infectie of aids. (Quality of life in Dutch children with HIV-infection or aids.)

Tijdschrift voor Kindergeneeskunde, 2001; 69(6): p.201-206

NIVEL: C 8535

OBJECTIVE: To compare the quality of life of HIV-infected children with a normative sample, to assess the agreement between parent and self-report and to inquire parents about the information they have given to their child about the diagnosis. **METHODS:** The families of 11 children with HIV or AIDS treated in the Emma Children's Hospital AMC in Amsterdam, The Netherlands, were involved in this study. For the parents the TNO/AZL Quality of Life questionnaire (TACQOL) was used which determines a health related quality of life score. For the children the Dutch Children's AZL/TNO Quality of life questionnaire (DUCATQOL) was used. **RESULTS:** Both parents and children reported lower levels of quality of life on several domains of the quality of life questionnaires. No agreement was found between parent report and self-report of the children. Six parents reported having informed their children about the diagnosis. Parents stated the need to turn to the physician to help them inform their child. **CONCLUSIONS:** HIV infected children and their parents are a vulnerable groups and need intensive support.

Language: Dutch

Keywords: Hiv /Aids / Quality of life / Social adjustment / Parent-child relations

Hawley CA. Reported problems and their resolution following mild, moderate and severe traumatic brain injury amongst children and adolescents in the UK. *Brain Injury*, 2003; 17(2): p.105-129

NIVEL: C 8500

OBJECTIVE: 1) To get insight into the behavioural, emotional, psychosocial, educational and physical problems experienced by families of children who have suffered traumatic brain injury (TBI). 2) To explore how these problems differ from those reported by control families. 3) To identify those problems most likely to resolve over time, and to examine information and follow-up requirements. **METHODS:** The families of 97 children with

mild (49), moderate (19) and severe (29) TBI, aged 5-15 at injury, were interviewed and assessed at a mean of 2.29 years post-injury and compared with 31 healthy controls. A structured questionnaire was used to collect information on problems pre- and post-TBI. Initially, respondents reported problems spontaneously, and were subsequently prompted using a checklist of problem categories. Problems of behaviour and emotion were measured using the Vineland Adaptive Behaviour Scales (VABS) and the Hospital Anxiety and Depression Scale (HADS). RESULTS: Following the TBI, 83 children (85.6%) received no therapeutic input, 74 families (76.3%) had unmet information needs, particularly regarding long-term consequences. At first interview, 1097 problems were reported by the TBI group. Behavioural and school problems were frequently reported by all TBI groups, significantly more than controls ($p < \text{or} = 0.001$). On the VABS, approximately two thirds of children with TBI exhibited 'significant' maladaptive behaviours, significantly more than controls ($p = 0.002$). Children in the mild and moderate/severe groups were significantly more anxious than controls on the HADS ($p = 0.04$). At 12 month follow-up, there were no significant differences in problem resolution between the TBI groups: 498 (53.9%) problems remained unchanged and 75 (8.1%) had worsened. Physical problems were most likely to resolve. CONCLUSIONS: Parents should be given information and support following their child's TBI, children should be routinely followed-up by health professionals and their needs assessed. It was found that children with TBI may be at risk of anxiety, yet few parents reported this as a particular concern. Future research should examine the relationship between anxiety and TBI.

Language: English

Keywords: Acquired brain injury / Behaviour problems / School / Anxiety / Cognition disorders

Hövels-Gürich HH, Konrad K, Wiesner M, Minkenberg R, Herpertz-Dahlmann B, Messmer BJ, Von Bernuth G. Long term behavioural outcome after neonatal arterial switch operation for transposition of the great arteries. *Archives of Disease in Childhood*, 2002; 87(6): p.506-510
NIVEL: C 8479

OBJECTIVE: To evaluate long term behavioural outcome, emotional development and quality of life in children aged 8-14 years after neonatal arterial switch operation for transposition of the great arteries. Additionally, the influence of risk factors during operative treatment and the involvement of neurological impairment were investigated. METHODS: Sixty children

operated as neonates with combined deep hypothermic circulatory arrest and low flow cardiopulmonary bypass were evaluated at age 7.9-14.3 years by the Child Behaviour Checklist (CBCL) and the Inventory for the Assessment of the Quality of Life in Children and Adolescents (IQCL). RESULTS: Parent reported behavioural outcome on all CBCL problem and competence scores was worse, whereas quality of life on self reported IQCL scores was not reduced compared to the normal population. On multivariate analysis, severe preoperative hypoxia was related to parent reported social problems; peri- and postoperative cardiocirculatory insufficiency was associated with internalising, externalising, attention, and total behavioural problems. Reduced expressive language was associated with total behavioural problems, and poor academic achievement was related to parent reported deficits in school performance. Impaired neurological status and reduced endurance capacity both predicted self reported stress by illness. CONCLUSIONS: The neonatal arterial switch operation with combined circulatory arrest and low flow bypass is associated with parent reported long term behavioural impairment, but not with self reported general reduction in quality of life. This discrepancy may be a result of different perception of illness. Increased risk of long term psychosocial maladjustment after neonatal corrective cardiac surgery seems to be related to the presence of neurological impairment and reduced endurance capacity.

Language: English

Keywords: Congenital heart defects / Postoperative complications / Quality of life / Behaviour problems / Social adjustment

Huurre TM, Aro HM. Long-term psychosocial effects of persistent chronic illness: a follow-up study of Finnish adolescents aged 16 to 32 years. *European Child & Adolescent Psychiatry*, 2002; 11(2): p.85-91
NIVEL: C 8577

The aim of this longitudinal study was to examine the life situation, psychosocial well-being and health habits of adolescents with persistent chronic illness from adolescence through adulthood. Adolescents reporting persistent chronic illness at ages 16, 22, and 32 years (n = 296, limiting in daily life n = 52, non-limiting n = 244) were compared with those without any chronic illness (n = 401). The data were drawn from a follow-up survey of a Finnish urban age cohort from age 16 until age 32 years. The group of persistent chronic illnesses included allergies (n = 249, 84%), non-allergic skin conditions (n = 10), migraine (n = 29), diabetes mellitus (n = 5), and others (n = 9). Results indicated that adults with persistent chronic illness

limiting their daily life reported more depression and lower self esteem than those with non-limiting chronic illness or healthy controls. Daily smoking was more common among females with any chronic illness than among healthy controls. No significant differences were found between adults with any persistent chronic illness (mainly non-severe allergic conditions) and healthy controls in psychosocial well-being. More attention in health care should be paid to psychological well-being in persons with limiting chronic illness. The study also raises the question how to improve health habit counselling within health care among females with chronic illness.

Language: English

Keywords: Chronic diseases, general / Adolescents / Young adults / Quality of life / Health behaviour

Kashikar-Zuck S, Vaught MH, Goldschneider KR, Graham TB, Miller JC. Depression, coping, and functional disability in juvenile primary fibromyalgia syndrome. *The Journal of Pain*, 2002; 3(5): p.412-419
NIVEL: C 8336

The aims of this study were to investigate pain experiences, coping, depression, and functional disability in children with juvenile primary fibromyalgia syndrome (JPFS), and to compare them with a group of children with nonmalignant chronic back pain (CBP). Subjects were 18 females (aged 9-19 yrs) diagnosed with JPFS and 18 controls with CBP. Pain duration and school absences were also assessed. Results indicate that both JPFS and CBP groups reported significant disruption in functional abilities and school attendance as a result of chronic pain. Both groups reported mildly elevated symptoms of depression overall, but there was a subgroup of JPFS subjects who reported severe levels of depression. The JPFS group had suffered from pain for significantly longer than the CBP group before being referred for specialty care. However, pain duration was not significantly related to depression, functional disability, or pain coping efficacy. The levels of functional disability were similar in both groups, but the JPFS group reported somewhat more school absences. The longer time to receive specialty care and identification of a subgroup of depressed subjects at risk for long-term psychosocial consequences are of particular concern in JPFS.

Language: English

Keywords: Fibromyalgia / Pain / Coping / Depression / Activities of daily living / School absenteeism

Key JD, Brown RT, Marsh LD, Spratt EG, Recknor JC. Depressive symptoms in adolescents with a chronic illness. *Children's Health Care*, 2001; 30(4): p.283-292
NIVEL: C 8555

The aim of this study was to examine symptoms of depression in adolescents with various chronic illnesses. A sample of 125 adolescents with chronic illnesses was compared with a sample of 21 healthy controls on self-reports of symptoms of depression. All subjects were aged 13-18 yrs. Overall, a higher percentage of adolescents with a chronic illness reported symptoms of moderate to severe depression; the frequency was highest in those adolescents with sickle cell disease. Adolescents who rated their chronic disease as moderate or severe reported more depressive symptoms than did those adolescents who rated their illness as mild. Within the limitations of this study, the authors recommend that future investigations examine patterns and symptoms of depression in adolescents coping with the stressors of a chronic illness.

Language: English

Keywords: Chronic diseases, general / Adolescents / Depression

King GA, Cathers T, Polgar JM, MacKinnon E, Havens L. Success in life for older adolescents with cerebral palsy. *Qualitative Health Research*, 2000; 10(6): p.734-749
NIVEL: C 8371

The aim of this qualitative study was to examine the desires, life goals, and meaning of success in life of older adolescents with cerebral palsy who are at the transition stage between secondary school and further education or work. Using a constant comparative method, the researchers investigated how older adolescents with cerebral palsy defined success in life and the factors they viewed as helping or hindering their success. Participants were 10 adolescents with cerebral palsy between 18 and 20 years of age who took part in a semistructured interview exploring their perceptions of success. For these adolescents, success meant being happy in life. Three key psychosocial factors were related to success in life: being believed in, believing in yourself, and being accepted by others (belonging). The findings are useful in guiding the design of services to meet the life needs of individuals with disabilities.

Language: English

Keywords: Cerebral palsy / Adolescents / Young adults / Quality of life / Self esteem / Social support

Kirkwood M, Janusz J, Yeates KO, Taylor HG, Wade SL, Stancin T, Drotar D. Prevalence and correlates of depressive symptoms following traumatic brain injuries in children. *Child Neuropsychology*, 2000; 6(3): p.195-208
NIVEL: C 8503

This study was aimed at getting insight into the prevalence and risk factors of depressive symptoms following childhood traumatic brain injuries (TBI). Data were drawn from a prospective longitudinal study. Participants included 38 children with severe TBI, 51 with moderate TBI, and 55 with orthopaedic injuries (OI). Assessments occurred shortly after injury (baseline) and at 6- and 12-month follow-ups. Children completed the Child Depression Inventory (CDI). Parents rated depressive symptoms using the Child Behavior Checklist (CBC), with baseline ratings reflecting premorbid status. Assessments also included measures of children's neurocognitive functioning and the family environment. The three groups did not differ overall in self-reported symptoms on the CDI, but did display different trends over time. The three groups did not differ on parent ratings of premorbid depressive symptoms on the CBC, but parents reported more depressive symptoms in the TBI groups than in the OI group at 6- and 12-month follow-ups. Child and parent reports were correlated for children in the TBI groups, but not for those in the OI group. Depressive symptoms were related to socioeconomic status in all groups. Socioeconomic status also was a significant moderator of group differences, such that the effects of TBI were exacerbated in children from more disadvantaged homes. Although self-reports of depressive symptoms were related inconsistently to children's verbal memory, parent reports of depressive symptoms were unrelated to IQ or verbal memory. The findings suggest that TBI increases the risk of depressive symptoms, especially among more socially disadvantaged children, and that depressive symptoms are not strongly related to post-injury neurocognitive deficits.

Language: English

Keywords: Acquired brain injury / Depression / Socioeconomic factors / Cognition disorders / Risk factors

Kokkonen ER, Kokkonen J, Moilanen I. Predictors of delayed social maturation and mental health disorders in young adults chronically ill since childhood. *Nordic Journal of Psychiatry*, 2001; 55(4): p.237-242
NIVEL: C 8385

The purpose of this study was to analyse the risk factors for unfavourable social development and mental illness in young adults who were treated for long-term physical disorders during their childhood. A group of 407 (184 female, 223 male) subjects with chronic conditions was studied and compared with a group of 123 (63 female, 60 male) healthy controls at the age of 19-25 years. The social maturation index was formed on the basis of a demographic interview, which also reviewed the state of social development and the family situation during childhood. Mental health disorders were assessed with a Present State Examination (PSE) interview analysed with the CATEGO program. With regard to social maturation at least half of the patients and controls were doing well, whereas for 29% (CI(95), 25%-33%) of the patients and 17% (CI(95), 10%-24%) of the controls the index showed delayed maturation. Subjects with poor social maturation were found most often among the disabled patients but also among the patients without severe diseases. The prevalence of PSE-CATEGO-identified psychiatric syndromes was equal in the patients and the controls (22% versus 20%). However, the patients with severe or disabling diseases had more severe psychiatric syndromes. The prevalence of depressive syndromes was also equal, but the depression of the patients was more often a profound affective disorder. Male sex, poor scholastic and vocational success, and social problems in the family during childhood were significantly associated with poor social maturation. On the other hand, the most significant predictors of mental health problems in young adults were female sex, family distress during childhood, and a severe disease. Juvenile-onset physical disease was considered to delay social maturation in some subjects and to deepen or modulate the clinical picture of mental health disorders. It is concluded that juvenile-onset physical diseases combined with family-related factors affect in different ways the social growth and psychiatric well-being. The results suggest that the subjects with chronic diseases during childhood should be thoroughly assessed by a child psychiatrist to evaluate the orientation of psychological development and the impact of the child's disease on the family and to ensure balanced psychological and social growth.

Language: English

Keywords: Chronic diseases, general / Young adults / Mental disorders / Social development / Risk factors

Landolt MA, Nuoffer JM, Steinmann B, Superti-Furga A. Quality of life and psychologic adjustment in children and adolescents with early treated phenylketonuria can be normal. *The Journal of Pediatrics*, 2002; 140(5): p.516-521
NIVEL: C 8434

OBJECTIVE: To assess quality of life and psychological adjustment in children and adolescents with early treated phenylketonuria (PKU). **METHODS:** A cross-sectional study was conducted in which 37 patients with PKU between 3 and 18 years of age (mean, 10.9 years) were assessed, with parents used as informants. The TNO-AZL Questionnaire for Children's Health-Related Quality of Life and Child Behavior Checklist scores were compared with healthy reference groups. Predictive values of sociodemographic and clinical variables for quality of life and psychological adjustment were assessed. **RESULTS:** Most dimensions of quality of life in children with PKU were not different from reference values. The only deviation in the PKU group was a reduction of positive emotions. Psychological adjustment in patients with PKU was better than in a healthy reference group. Whereas sociodemographic variables and phenylalanine levels in the 12 months preceding the study were not associated to quality of life and psychological adjustment, a long-term negative effect of higher phenylalanine levels during the first year of life on some dimensions of quality of life and psychological adjustment could be identified. **CONCLUSIONS:** Although the results may not necessarily apply to patients with PKU in other geographic or socioeconomic contexts, they demonstrate that normal health-related quality of life and good psychological adjustment is an achievable goal in children with PKU.

Language: English

Keywords: Phenylketonuria / Quality of life / Social adjustment

LeBovidge JS, Lavigne JV, Donenberg GR, Miller ML. Psychological adjustment of children and adolescents with chronic arthritis: a meta-analytic review. *Journal of Pediatric Psychology*, 2003; 28(1): p.29-39
NIVEL: C 8437

OBJECTIVE: To get insight into possible risks for development of adjustment problems among children and adolescents with chronic arthritis. **METHODS:** The authors used meta-analytic techniques to review 21 studies reporting overall adjustment problems, internalising symptoms, externalising symptoms, or self-concept among youths with arthritis. **RESULTS:** Youths

with arthritis displayed increased risk for overall adjustment problems and internalising symptoms, but not for externalising symptoms or poor self-concept. Risk was greater in studies making comparisons to study controls rather than to norms and in studies including mixed disease samples (arthritis plus other rheumatic diseases) rather than samples of youths with arthritis only. CONCLUSIONS: Results suggest the importance of assessing for internalising problems among youths with chronic arthritis. Future research may benefit from inclusion of child self-report of adjustment problems, diagnostic specificity in reporting results, and use of adjustment measures without somatic items.

Language: English

Keywords: Rheumatoid arthritis / Self image / Behaviour problems / Anxiety / Depression / Risk factors / Meta-analysis / Reviews

Leynaert B, Neukirch C, Liard R, Bousquet J, Neukirch F. Quality of life in allergic rhinitis and asthma: a population-based study of young adults. *American Journal of Respiratory and Critical Care Medicine*, 2000; 162(4 Pt 1): p.1391-1396
NIVEL: C 8369

The aim of this study was to investigate the relative burden of asthma and allergic rhinitis with respect to quality of life. The researchers analysed answers to the SF-36 questionnaire from 850 subjects recruited in two French centres participating in the European Community Respiratory Health Survey, a population-based study of young adults. Both asthma and allergic rhinitis were associated with an impairment in quality of life. However, 78% of asthmatics also had allergic rhinitis. Subjects with allergic rhinitis but not asthma (n = 240) were more likely than subjects with neither asthma nor rhinitis (n = 349) to report problems with social activities, difficulties with daily activities as a result of emotional problems, and poorer mental well-being. Patients with both asthma and allergic rhinitis (n = 76) experienced more physical limitations than patients with allergic rhinitis alone, but no difference was found between these two groups for concepts related to social/mental health. As asthma was not found to further impair the quality of life in subjects with allergic rhinitis for concepts related to mental disability and well-being, and as subjects with asthma often also suffer from allergic rhinitis, further studies on quality of life in asthma should ensure that the impairment in quality of life attributed to asthma could not result from concomitant allergic rhinitis.

Language: English

Keywords: Asthma / Allergic rhinitis / Young adults / Quality of life / Activities of daily living

Liptak GS, O'Donnell M, Conaway M, Chumlea WC, Wolrey G, Henderson RC, Fung E, Stallings VA, Samson-Fang L, Calvert R, Rosenbaum P, Stevenson RD. Health status of children with moderate to severe cerebral palsy. *Developmental Medicine & Child Neurology*, 2001; 43(6): p.364-370
NIVEL: C 8528

The aim of this study was to evaluate a number of indicators of health status and quality of life in children with cerebral palsy (CP). A multicentre population-based cross-sectional survey of 235 children, aged 2 to 18 years, with moderate to severe impairment, was carried out using Gross Motor Function Classification System (GMFCS) levels III (n = 56), IV (n = 55), and V (n = 122). This study group scored significantly below the mean on the Child Health Questionnaire (CHQ) for Pain, General Health, Physical Functioning, and Impact on Parents. These children used more medications than children without CP from a national sample. Fifty-nine children used feeding tubes. Children in GMFCS level V who used a feeding tube had the lowest estimate of mental age, required the most health care resources, used the most medications, had the most respiratory problems, and had the lowest Global Health scores. Children with the most severe motor disability who have feeding tubes are an especially frail group who require numerous health-related resources and treatments. Also, there is a relationship among measures of health status such as the CHQ, functional abilities, use of resources, and mental age, but each appears to measure different aspects of health and well-being and should be used in combination to reflect children's overall health status.

Language: English

Keywords: Cerebral palsy / Health status / Quality of life / Health care utilisation

Luis CA, Mittenberg W. Mood and anxiety disorders following pediatric traumatic brain injury: a prospective study. *Journal of Clinical and Experimental Neuropsychology*, 2002; 24(3): p.270-279
NIVEL: C 8505

This study was aimed at examining the relationship between paediatric traumatic brain injury and the development of mood and/or anxiety

disorders. Studies of this kind have seldom been reported in the literature. Previous reports have largely focused on cognitive impairment, behavioural dysfunction, or adaptive functioning, and have typically relied on parental informants. In this study, children hospitalised for mild (N = 42) and moderate/severe (N = 19) brain injury were assessed 6-months postinjury using the Anxiety disorders Module A and the Mood disorders Module C of the Diagnostic Interview Schedule for Children - IV Revision (DISC-IV). The data collected for the brain injury groups were compared to an orthopaedic control group (N = 35). The relationship between a new onset mood and/or anxiety disorder (NOD) and injury severity indices was examined. Sequential logistical regression was also utilised to examine the impact of a brain injury, demographic variables, preinjury psychiatric disturbance, development disorders, litigation status and postinjury environmental stress on emotional outcome. Results indicated a relationship between brain injury and NOD. Multivariate analysis demonstrated that postinjury level of stress and severity of brain injury were the most robust predictors of NOD, accounting for 23% of the variance in the model. These results support the premise that the development of a mood and/or anxiety disorder following paediatric head injury is mediated by multiple determinants. The findings suggest that early psychosocial assessment and interventions aimed at increasing a child's coping may attenuate the emotional consequences of paediatric brain injury.

Language: English

Keywords: Acquired brain injury / Anxiety disorders / Mood disorders / Psychological stress / Risk factors

Maggiolini A, Grassi R, Adamoli L, Corbetta A, Charmet GP, Provantini K, Frascini D, Jankovic M, Lia R, Spinetta J, Masera G. Self-image of adolescent survivors of long-term childhood leukemia.

Journal of Pediatric Hematology/Oncology, 2000; 22(5): p.417-421

NIVEL: C 8449

The purpose of this study was to evaluate the impact that the experience of childhood leukaemia may have on self-image and attitude towards the future of a group of adolescents who had the disease cured. A questionnaire was administered at the Pediatric Hematology Center, San Gerardo Hospital, Monza, Italy, to all former patients age 12 to 20 years and off therapy from leukaemia for at least 2 years (total of 116 adolescents) during 1997; 70 patients responded to the mailing and a comparison group of 70 secondary school students was investigated. The two groups were matched as closely as

possible on key characteristics (age, gender, socio-economic level of families, education and occupation of the parents, and geographic area of residence). The Offer Self-Image Questionnaire was the instrument used in this study. Overall, the teenagers in whom leukaemia was cured showed a more positive and mature self-image (psychological, social, attitude toward family, and coping) compared with the student group (statistical evidence, $P < 0.05$). An effective psychosocial support for patients and their families during their treatment, in addition to medical therapy, is strongly recommended. The majority of survivors of childhood cancer grow successfully without serious psychological sequelae.

Language: English

Keywords: Leukaemia / Adolescents / Survivors / Self image / Coping

Malhi P, Kumar L, Singh M. Screening for psychosocial problems in children and adolescents with asthma. *Indian Pediatrics*, 2001; 38(5): p.524-530
NIVEL: C 8463

The aims of this study were to describe the psychosocial adaptation problems of children with asthma, compared with a matched group of healthy children, and to examine the relationship between demographic and illness related variables and psychosocial adaptation. Seventy children with asthma and 68 healthy children, aged 8-16 years, participated. Three measures of psychosocial adaptation were used: the Piers Harris Children's Self Concept Scale (CSCS), the Pre Adolescent Adjustment Scale (PAAS) and the Childhood Psychopathology Measurement Schedule (CPMS). There were no significant differences in the overall self concept scores, although children with asthma were less happy and satisfied, and on any one of the subscale scores on the PAAS. However, children with asthma were found to have significantly higher psychopathology scores. It was concluded that children with asthma are more at risk for emotional and behavioural problems than healthy controls. The CPMS seems to be a useful screening instrument in identifying psychosocial problems.

Language: English

Keywords: Asthma / Behaviour problems / Psychosocial problems

Marschark M, Richtsmeier LM, Richardson JT, Crovitz HF, Henry J. Intellectual and emotional functioning in college students following mild

traumatic brain injury in childhood and adolescence. *Journal of Head Trauma Rehabilitation*, 2000; 15(6): p.1227-1245
NIVEL: C 8447

OBJECTIVE: To investigate whether college students with a history of mild traumatic brain injury (TBI) in childhood or adolescence show residual deficits in intellectual functioning, approaches to studying, or emotional stability. **METHODS:** Volunteers were recruited from students taking an introductory psychology course. Seventy-nine students with a history of mild TBI, 75 students with a history of general anaesthesia, and 93 students with no history of either TBI or general anaesthesia were compared. Participants carried out tests of verbal memory, nonverbal memory, verbal fluency, and nonverbal fluency; in addition, they completed a short form of the Approaches to Studying Inventory and the Symptom Checklist-90-Revised (SCL-90-R). **RESULTS:** In comparison with the two control groups, the students with a history of mild TBI produced similar scores on the cognitive tests and similar orientations to studying. However, they showed a significantly higher level of emotional distress on the SCL-90-R. **CONCLUSION:** College students with a history of mild TBI in childhood or adolescence are intellectually unimpaired and approach their studying in a similar manner to their uninjured classmates. Nevertheless, they report more severe distress in terms of their general personal and emotional functioning.

Language: English

Keywords: Acquired brain injury / Young adults / Cognitive development / Psychological stress

Martínez Chamorro MJ, Lastra Martínez I, Luzuriaga Tomás C.
Características psicosociales de los niños y adolescentes con diabetes mellitus tipo 1. (Psychosocial characteristics of children and adolescents with type 1 diabetes mellitus.) *Anales Espanoles de Pediatría*, 2001; 55(5): p.406-412
NIVEL : C 8389

OBJECTIVES: To get insight into the psychological and social adjustment patterns of children and adolescents with type 1 diabetes compared with those of a control sample. **METHODS:** A sample of 81 children and adolescents, aged 8-18 years, from a paediatric outpatient endocrinology unit was compared with a randomised control group (n 162), paired by sex, age and school year. Information on clinical, social and family variables, self image and self esteem, health and expectations of change in health status, as

well as screening for eating disorders, was collected. Symptoms of depression and anxiety, behaviour, and psychosocial adjustment were also evaluated. RESULTS: Children and adolescents with diabetes showed lower self esteem and poorer self-image than controls. No statistical differences were found in health status and expectations of change or in anxiety symptoms between cases and controls. Differences in depressive symptoms or in personal, social and scholastic adjustment showed no relationship with diabetic status. No significant behavioural disorders were found among the cases. CONCLUSIONS: Children and adolescents with type 1 diabetes show appropriate psychosocial adjustment and do not present higher levels of anxiety and depression than healthy controls. They do, however, show lower self esteem.

Language: Spanish

Keywords: Diabetes mellitus / Social adjustment / Self esteem / Depression / Anxiety

McGrath P, Huff N. 'What is it?': findings on preschoolers' responses to play with medical equipment. *Child: Care, Health and Development*, 2001; 27(5): p.451-462
NIVEL: C 8440

The authors wanted to get insight into the impact of intensive hospital treatment on preschool children with leukaemia. In order to understand the impact of hospital treatment it was considered necessary to have comparative information on healthy peers who have not been exposed to such treatment experiences. The authors conducted a qualitative study that explored the beliefs held by healthy preschoolers about what happens in hospital, what it means to be sick, their reactions to and knowledge of medical equipment and their level of knowledge regarding cancer and leukaemia. It is the hope and expectation that the findings will be used comparatively to contribute to a deeper understanding of the world of the child coping with leukaemia and related disorders.

Language: English

Keywords: Leukaemia / Pre-school children / Coping / Cognitive development / Sick role / Play and playthings

McQuaid EL, Kopel SJ, Nassau JH. Behavioral adjustment in children with asthma: a meta-analysis. *Developmental and Behavioral Pediatrics*, 2001; 22(6): p.430-439

NIVEL: C 8392

The aim of this meta-analytic review was to assess the relationship between childhood asthma and behavioural adjustment. Of 78 studies initially reviewed, 26 studies (encompassing 28 data sets), reflecting data on nearly 5,000 children with asthma (mean age = 8.4 years; 40% female), met criteria for inclusion. Effect size estimates were calculated across studies using standard methods. Separate effect sizes were calculated for internalising and externalising behavioural problems, degrees of asthma severity, and differences in control group used (i.e., sample controls or normative data). Results indicate that children with asthma have more behavioural difficulties than do healthy children, with the effect for internalising behaviours being greater than that for externalising behaviours ($d(mn) = .73$ vs $.40$). Increased asthma severity was associated with greater behavioural difficulties. Results did not differ by comparison group (healthy controls vs normative data). The findings suggest that patients with asthma, particularly children with severe asthma, should be considered at higher risk for behavioural difficulties that may necessitate psychosocial intervention.

Language: English

Keywords: Asthma / Behaviour problems / Anxiety / Depression / Reviews / Meta-analysis

Meyer EA, Kieran MW. Psychological adjustment of 'surgery-only' pediatric neuro-oncology patients: a retrospective analysis. *Psycho-Oncology*, 2002; 11(1): p.74-79

NIVEL: C 8513

Paediatric brain tumour survivors are at risk for short and long-term psychological adjustment problems. Most studies regarding these survivors have focused on children who have received combinations of surgery, radiation, and chemotherapy as medical treatment. The sub-group of patients who receive surgery as the only form of medical treatment has not been closely followed for adjustment problems. The aim of this study was to examine the prevalence of psychological adjustment problems in surgery-only children. Data were retrospectively collected from semi-structured clinical interviews with 34 'surgery-only' paediatric neuro-oncology patients who were 2 weeks to 5 years off medical treatment for their tumour. These data suggest that these survivors may be experiencing significant short and long-term mood, behavioural, and academic adjustment problems in comparison to national averages for children regarding these issues.

Additional research examining the psychological adjustment process for surgery-only paediatric neuro-oncology patients is needed to validate these preliminary findings and facilitate the development of targeted interventions to address the identified adjustment problems.

Language: English

Keywords: Cancer / Brain tumour / Quality of life / Social adjustment

Nichols S, Mahoney EM, Sirois PA, Bordeaux JD, Stehbens JA, Loveland KA, Amodei N. HIV-associated changes in adaptive, emotional, and behavioral functioning in children and adolescents with hemophilia: results from the Hemophilia Growth and Development Study. *Journal of Pediatric Psychology*, 2000; 25(8): p.545-556
NIVEL: C 8388

OBJECTIVE: To assess the effects of disease progression over four years on behavioural, social and adaptive functioning in children and adolescents with haemophilia and with or without HIV infection and to evaluate the relationship of these changes to immune status. **METHODS:** Participants were 277 HIV-seropositive and 126 HIV-seronegative boys with haemophilia. Participants with HIV infection were divided into three groups based on trajectory of immune functioning (CD4+ cell counts) over the course of the study. Caregivers completed the Vineland Adaptive Behavior Scales and Pediatric Behavior Scale (PBS). **RESULTS:** Results showed declining Vineland Communication scores for participants with consistently poor immune functioning. These participants also started with more PBS Attention Deficit and Deviation symptoms, which then decreased more sharply than for other groups. Low CD4+ counts were consistently associated with more Health and Depression-Anxiety symptoms on the PBS. However, with few exceptions, group means remained within normal limits. **CONCLUSIONS:** According to their caregivers, boys with haemophilia and HIV infection showed considerable resilience with regard to adaptive behaviour and emotional and behavioural problems. However, over time changes occurred in these areas that appear to be related to immune functioning.

Language: English

Keywords: Haemophilia / Hiv / Behaviour problems / Depression / Anxiety / Health status / Social adjustment

Palmer ML, Boisen LS. Cystic fibrosis and the transition to adulthood.

Social Work in Health Care, 2002; 36(1): p.45-58

NIVEL: C 8345

The purpose of this exploratory study was to get insight into the psychosocial impact of cystic fibrosis (CF) on becoming an adult. This is relevant because the life expectancy for those with CF has been steadily on the rise and now reaches well into adulthood. A qualitative in-depth design was conducted in a sample of 39 young adults, aged 20-28. Their perceptions regarding the impact of the disease on their lives were examined, especially during the transition from adolescence to adulthood. The findings indicate concerns about health insurance and finances, as well as the achievement of independence and optimism for the future.

Language: English

Keywords: Cystic fibrosis / Young adults / Quality of life

Sabaz M, Cairns DR, Lawson JA, Bleasel AF, Bye AM. The health-related quality of life of children with refractory epilepsy: a comparison of those with and without intellectual disability. *Epilepsia*, 2001; 42(5): p.621-628

NIVEL: C 8393

OBJECTIVE: To determine whether refractory epilepsy affects the health-related quality of life (HRQOL) of children with or without intellectual disability (ID), and if the presence of ID independently compromises HRQOL in children with refractory epilepsy. **METHODS:** One hundred two families of children with refractory epilepsy participated. Children had the presence or absence of ID determined by formal neuropsychological or educational assessment. The relative effect of epilepsy on the two intellectual ability groups was determined using relevant clinical variables. Parents completed a valid epilepsy-specific HRQOL questionnaire for children, the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE), and, depending on intellectual ability level, the Child Behaviour Checklist or Developmental Behaviour Checklist. **RESULTS:** Both intellectually normal children with epilepsy and children with epilepsy and ID were more likely to have psychosocial problems compared with their respective intellectual ability reference populations. The results also revealed that children with ID had reduced HRQOL compared with intellectually normal children; a result independent of epilepsy. Analysis of the relationship between epilepsy variables and HRQOL revealed that the QOLCE was the most sensitive in detecting variation in age at onset, seizure frequency, and medications taken.

CONCLUSIONS: The HRQOL of children with refractory epilepsy is greatly affected, regardless of intellectual ability level. The presence of ID in children with epilepsy independently depresses HRQOL outcomes. Compared with two generic HRQOL measures, the QOLCE was the most sensitive measure to variation in epilepsy variables.

Language: English

Keywords: Epilepsy / Quality of life / Health status / Mental retardation

Sällfors C, Fasth A, Hallberg LR. Oscillating between hope and despair: a qualitative study. *Child: Care, Health & Development*, 2002; 28(6): p.495-505
NIVEL: C 8382

OBJECTIVE: To get insight into the quality of life and psychosocial experiences in daily living of children with juvenile chronic arthritis (JCA) who suffer chronic pain. **METHODS:** Taped open qualitative interviews with 22 children (aged 6-17 years) were transcribed verbatim and analysed using the comparative method for grounded theory. **RESULTS:** A core category, labelled oscillating between hope and despair, was identified and related to four additional categories labelled disturbed order, dependency, ambivalence and uncertainty about the future. There were relationships between the children's subjective experience of pain and their experiences of disturbed order in daily life, dependency on treatment, health care and significant others, ambivalence related to environmental reactions and uncertainty about the future. Chronic pain and disease control the children's lives and lead to restricted participation in social life. **CONCLUSIONS:** Chronic pain is a substantial problem for children with JCA, which must be considered in health care. The pain affected and disturbed the children's ordinary way of life. It blocked a number of goals. Psychological and physiological processes interact in the phenomenological experience of pain, and the response of the environment elicits, maintains or decreases the experience of pain. Hopefully, the findings contribute to a deeper understanding of the life situation of children suffering from JCA and can be of importance in developing rehabilitation programmes for these children.

Language: English

Keywords: Rheumatoid arthritis / Chronic pain / Quality of life / Psychosocial problems

Sarimski K. Social adjustment of children with a severe craniofacial anomaly (Apert syndrome). *Child: Care, Health and Development*, 2001; 27(6): p.583-590
NIVEL: C 8547

OBJECTIVE: To examine the profile of social and emotional adjustment in school-aged children with Apert syndrome, a bone disease characterised by craniofacial anomalies. **METHODS:** Parent reports (Child Behaviour Checklist) were obtained from 25 children with Apert syndrome. **RESULTS:** Fourteen children were characterised by clinically significant social problems, 10 by attentional problems, nine by social withdrawal. Total CBCL-scores were in the clinical range for eight children. **CONCLUSIONS:** Information on psychosocial state should be included in regular check-ups of children with a severe craniofacial anomaly in order to identify children who are in need of psychological interventions.

Language: English

Keywords: Apert syndrome / School-age children / Behaviour problems / Cognition disorders / Psychosocial problems

Schlösser M, Colland V. Kwaliteit-van-leven onderzoek bij kinderen met astma. (Quality of life research in children with asthma.) *Pulmonair*, 2001; 8(2): p.7-11
NIVEL: C 6650

The aim of this review was to get insight into the health-related quality of life in children with asthma and its determinants and existing instruments to measure quality of life. There is not a direct relationship between the subjective experience and the objective severity of the illness; determinants like anxiety, shame and discontinuity of the illness have a mediating influence. There exist several questionnaires on quality of life, of which disease specific instruments are preferred.

Language: Dutch

Keywords: Asthma / Quality of life / Questionnaires / Reviews

Schwankovsky L, Mousa H, Rowhani A, Di Lorenzo C, Hyman PE. Quality of life outcomes in congenital chronic intestinal pseudo-obstruction. *Digestive Diseases and Sciences*, 2002; 47(9): p.1965-1968
NIVEL: C 8521

This study was aimed at assessing the quality of life of children with chronic intestinal pseudo-obstruction. A retrospective chart review was used to identify children with congenital chronic intestinal pseudo-obstruction, then a structured telephone interview was held with parents that included the Child Health Questionnaire to gather information about the current status and quality of life for each patient and family. Children with chronic intestinal pseudo-obstruction had less freedom from pain, depression, and anxiety than healthy children or children with juvenile rheumatoid arthritis ($P < 0.05$ for all three parameters). Parents of children with chronic intestinal pseudo-obstruction had poorer emotional status than parents of healthy children or children with juvenile rheumatoid arthritis. The time required for parents to care for children with chronic intestinal pseudo-obstruction was greater than the time required to care for healthy children or children with juvenile rheumatoid arthritis ($P < 0.01$). In conclusion, the quality of life for children with chronic intestinal pseudo-obstruction lags behind that of healthy children and children with another chronic illness. Appropriate treatment of chronic pain may improve the quality of life for children with chronic intestinal pseudo-obstruction and their families. Moreover, attention to reducing each family's burden of time and emotional distress may help them cope better with their chronically ill child.

Language: English

Keywords: Intestinal pseudo-obstruction / Quality of life / Parents

Schwimmer JB, Burwinkle TM, Varni JW. Health-related quality of life of severely obese children and adolescents. *JAMA*, 2003; 289(14): p.1813-1819

OBJECTIVE: To examine the health-related QOL of obese children and adolescents compared with children and adolescents who are healthy or those diagnosed as having cancer. **METHODS:** A cross-sectional study was conducted with 106 children and adolescents (57 males) between the ages of 5 and 18 years (mean [SD], 12.1 [3] years), who had been referred to an academic children's hospital for evaluation of obesity. Children and adolescents had a mean (SD) body mass index (BMI) of 34.7 (9.3) and BMI z score of 2.6 (0.5). Outcome measures were the child self-report and parent proxy report versions of a paediatric QOL inventory generic core scale (range, 0-100). The inventory was administered by an interviewer for children aged 5 through 7 years. Scores were compared with previously published scores for healthy children and adolescents and children and adolescents diagnosed as having cancer. **RESULTS:** Compared with healthy

children and adolescents, obese children and adolescents reported significantly ($P < .001$) lower health-related QOL in all domains (mean [SD] total score, 67 [16.3] for obese children and adolescents; 83 [14.8] for healthy children and adolescents). Obese children and adolescents were more likely to have impaired health-related QOL than healthy children and adolescents (odds ratio [OR], 5.5; 95% confidence interval [CI], 3.4-8.7) and were similar to children and adolescents diagnosed as having cancer (OR, 1.3; 95% CI, 0.8-2.3). Children and adolescents with obstructive sleep apnea reported a significantly lower health-related QOL total score (mean [SD], 53.8 [13.3]) than obese children and adolescents without obstructive sleep apnea (mean [SD], 67.9 [16.2]). For parent proxy report, the child or adolescent's BMI z score was significantly inversely correlated with total score ($r = -0.246$; $P = .01$), physical functioning ($r = -0.263$; $P < .01$), social functioning ($r = -0.347$; $P < .001$), and psychosocial functioning ($r = -0.209$; $P = .03$). **CONCLUSIONS:** Severely obese children and adolescents have lower health-related QOL than children and adolescents who are healthy and similar QOL as those diagnosed as having cancer. Physicians, parents, and teachers need to be informed of the risk for impaired health-related QOL among obese children and adolescents to target interventions that could enhance health outcomes.

Language: English

Keywords: Obesity / Cancer / Quality of life / Social adjustment / Psychosocial problems

Seiffge-Krenke I. Are discrepancies between developmental status and aspired goals a sufficient motivation for developmental progression? In: Heckhausen J (ed). *Motivational psychology of human development: Developing motivation and motivating development. Advances in psychology, 131*. New York, NY, US: Elsevier Science, 2000: p.251-270
NIVEL: C 8537

In this book chapter, processes of developmental regulation in adolescents with a chronic illness are analysed. Based on longitudinal data comparing chronically ill adolescents and healthy peers as well as their families, a unique insight is offered into the capacity of afflicted adolescents to balance adaptation to illness and developmental progression. Particular consideration is given to the processes of self-regulation by which the adolescents themselves initiate all necessary developmental steps and sequences to reach aspired goals. The adolescents' efforts to prevent or eliminate developmental pressure depend heavily on the developmental context and result in the

emergence of different pathways for solving the dilemma between developmental progression and adaptation to illness.

Language: English

Keywords: Chronic diseases, general / Adolescents / Coping / Child development

Stancin T, Drotar D, Taylor HG, Yeates KO, Wade SL, Minich NM. Health-related quality of life of children and adolescents after traumatic brain injury. *Pediatrics*, 2002; 109(2): E34
NIVEL: C 8487

OBJECTIVE: To get insight into the longer-term impact of traumatic brain injury (TBI) on children's daily functioning, especially the broader outcome domain referred to as health-related quality of life (HRQL), by examining the nature and predictors of HRQL outcomes in children with moderate to severe TBI an average of 4 years postinjury. **METHODS:** The study used a concurrent cohort-prospective design involving postinjury assessments of 3 groups of traumatically injured children and their families including 42 with severe TBI, 42 with moderate TBI, and 50 with orthopaedic injuries only. Parent and child perceptions of HRQL and child adaptive behaviour measures were obtained along with parent descriptions of the child's health problems and use of medical and mental health services. Predictors included indices of injury severity, social factors, and ratings of preinjury child behaviour problems and school performance. **RESULTS:** Based on parent report, adolescents who sustained severe TBI had lower HRQL related to overall psychosocial functioning and in the domains of behaviour, mental health, general health, and family impact than adolescents who sustained orthopaedic injuries only. Communication skills, daily living skills, and general adaptive functioning also were rated lower in the severe TBI group. In contrast to parent reports, adolescents with severe TBI did not rate their HRQL in most domains differently than did adolescents with orthopaedic injuries. There were no group differences in frequency of persistent physical limitations. Sixty-seven percent of families of children with severe TBI used mental health counselling at some point after the injury. Risks for poorer HRQL outcomes were related to family social disadvantage and poorer preinjury child behavioural and academic functioning. **CONCLUSIONS:** Findings underscore the importance of using comprehensive measures of HRQL, along with traditional indicators of functional outcomes, when evaluating the longer-term impact of injuries in children. Identification of predictors suggests the need for close monitoring and intervention of high-risk children.

Language: English

Keywords: Acquired brain injury / Quality of life / Activities of daily living / Social adjustment / Health status

Steinhausen HC, Dorr HG, Kannenberg R, Malin Z. The behavior profile of children and adolescents with short stature. *Developmental and Behavioral Pediatrics*, 2000; 21(6): p.423-428
NIVEL: C 8496

This study was aimed at getting insight into the behavioural adaptation of children who have a short stature as a result of endocrinological disease, like growth hormone deficiency, Turner syndrome, or chronic renal insufficiency. The relation between behaviour profiles and short stature was assessed in 311 children and adolescents. The mean Child Behavior Checklist (CBCL) and Youth Self-Report (YSR) profile of the entire group of children with growth deficiency significantly exceeded population norms on all scales and scores. However, there were no significant differences between five major diagnostic groups across CBCL scales. Neither age, gender, socioeconomic status, nor severity of short stature had any effect on the various CBCL and YSR scores. Correlations between parent (CBCL) and child (YSR) scores were significant, though only at a low to medium level. It was concluded that probably short stature per se, rather than a specific diagnosis, has an impact on behavioural adaptation.

Language: English

Keywords: Dwarfism / Behaviour problems / Psychosocial problems / Social adjustment

Sullivan JE. Emotional outcome of adolescents and young adults with early and continuously treated phenylketonuria. *Journal of Pediatric Psychology*, 2001; 26(8): p.477-484
NIVEL: C 8374

OBJECTIVE: To examine the quality and pattern of emotional adjustment of adolescents and young adults with early and consistently treated phenylketonuria (PKU). METHODS: Twenty PKU-affected participants, ages 14-25, were compared with age-matched chronically ill (n = 17) and peer (n = 16) controls on a structured clinical interview, the Minnesota Multiphasic Personality Inventory, and the Tennessee Self-Concept Scale-2. Affected participants and nonparticipants were assessed using a multidomain assessment of functioning interview. RESULTS: There were no significant

differences between groups for observable psychiatric disorders or emotional and functional symptoms. No significant differences were found in self-concept. Although there were no differences between groups for IQ or treatment variables, PKU-affected participants were more likely than nonparticipants to have sought help for psychological concerns.

CONCLUSIONS: Results suggest that early-treated PKU-affected adolescents and young adults do not show a higher risk for psychological disturbance than appropriate controls.

Language: English

Keywords: Phenylketonuria / Adolescents / Young adults / Mental disorders / Psychosocial problems / Self esteem

Szabo CA, Rothner AD, Kotagal P, Erenberg G, Dinner DS, Wyllie E. Symptomatic or cryptogenic partial epilepsy of childhood onset: fourteen-year follow-up. *Pediatric Neurology*, 2001; 24(4): p.264-269
NIVEL: C 8494

This study aimed at examining long-term psychosocial outcome of childhood-onset partial epilepsy with complex partial seizures. Twenty-nine patients were followed prospectively over 14 years. Many were refractory at the time of enrolment. At 14-year follow-up, information was acquired on seizure type and frequency, psychiatric history, substance abuse, criminal activity, in addition to educational, vocational, and marital status through chart reviews and/or structured telephone interviews. Sixteen patients were only treated medically. They were divided by their following responses to medications: eight patients with less than one seizure per month were in the medically responsive group and eight patients with at least one seizure per month constituted the medically refractory group. Thirteen patients underwent focal resection for medically refractory epilepsy. Medically refractory patients displayed worse educational, vocational, social, and behavioural outcomes than medically responsive patients. Behavioural abnormalities persisted or evolved in five medically refractory patients when they became seizure free. Other studies have indicated that patients with medically refractory complex partial seizures have poor psychosocial outcomes. Although behavioural problems can occur even when seizures are well controlled, their early detection and treatment may be essential to the improvement of psychosocial outcomes.

Language: English

Keywords: Epilepsy / Social adjustment / Academic achievement / Employment / Marital status / Mental disorders / Behaviour problems

Torigoe K, Numata O, Ogawa Y, Kaneko U, Usuda T, Imamura M, Takeuchi K, Suzuki H, Endo H. Contingent negative variation in children with orthostatic dysregulation. *Pediatrics International*, 2001; 43(5): p.469-477
NIVEL: C 8495

OBJECTIVE: Orthostatic dysregulation (OD), which is frequently observed in Japan, is a clinical entity with altered cardiovascular control when standing, due to a dysfunction of the autonomic nerve system. Children with OD appear to have hypodynamia, as well as the symptoms described in the OD criteria. Hypodynamia, which is greatly influenced by motivation, volition and concentration, is unexceptionally recognised in their everyday life. It has been suggested that the symptoms and hypodynamia aggravate considerably the quality of life (QOL) of children with OD. The purpose of this study was to distinguish the characteristics of contingent negative variation (CNV) and post imperative negative variation, which may reflect the level of attention and motivation in children with OD. **METHODS:** Twelve patients with OD aged 10-15 years and 23 age-matched healthy children were included. The CNV was recorded from Fz, Cz and Pz linked to earlobes during 30 trials consisting of a warning stimulus and an imperative stimulus with an interstimulus interval (ISI) of 2 s and an intertrial interval (ITI) of 10 s. The imperative stimulus of each trial required a button to be pressed. **RESULTS:** The untreated children with OD did not have a significantly smaller CNV amplitude than healthy children. Children with OD treated with midodrine and autonomic training had a significantly larger CNV amplitude than the untreated children, in the area of early, late and total CNV at the three sites. **CONCLUSIONS:** The present study confirms that children with OD have diminished motivation and deterioration of concentration, which cause hypodynamia in everyday life. Treatment for OD improves the symptoms, diminished motivation and deterioration of concentration, consequently restoring dynamia. Treatment for OD should be recommended to ameliorate QOL of children with OD.

Language: English

Keywords: Orthostatic dysregulation / Hypodynamia / Quality of life / Motivation / Attention

Trent ME, Rich M, Austin SB, Gordon CM. Quality of life in adolescent girls with polycystic ovary syndrome. *Archives of Pediatrics & Adolescent Medicine*, 2002; 156(6): p.556-560
NIVEL: C 8509

OBJECTIVE: To get insight into illness experiences and health-related quality of life (HRQL) in adolescents with polycystic ovary syndrome (PCOS). **METHODS:** A cross-sectional study of female adolescents with a comparison group of healthy adolescents was conducted at an urban, hospital-based adolescent medicine clinical practice. Participants were 97 adolescent patients with PCOS and 186 healthy patients who were seen for care between October 15, 1999, and March 2, 2001. Main outcome measures were health-related quality-of-life scores as determined by the Child Health Questionnaire-Child Self-Report Form. **RESULTS:** Adolescents with PCOS scored lower on subscales measuring general health perceptions, physical functioning, general behaviour, and limitations in family activities because of illness. Patients scored higher on the change in health in the last year subscale, and most had been diagnosed and initiated treatment for PCOS in the last year. Patients who had higher self-perceived severity of illness also scored lower on the general health perceptions subscale, but clinical severity was not associated with differences in HRQL. **CONCLUSIONS:** Adolescents with PCOS experience lower HRQL compared with healthy adolescents. Polycystic ovary syndrome and perceived severity of illness negatively affect HRQL in adolescents. This study suggests a need to develop interventions to reduce the distress that patients with PCOS may face as adolescents and young adults.

Language: English

Keywords: Polycystic ovary syndrome / Adolescents / Quality of life / Sick role

Vessey JA, O'Sullivan P. A study of children's concepts of their internal bodies: a comparison of children with and without congenital heart disease. *Journal of Pediatric Nursing*, 2000; 15(5): p.292-298
NIVEL: C 8439

The aim of this study was to get insight into the way children with congenital heart disease (CHD) conceptualise their internal bodies and how their views differ from those of nonaffected children. The authors examined the following: (1) the knowledge children with and without congenital heart disease have about their internal bodies, (2) the relationship of this knowledge with age, disease severity, and previous health care experiences, and (3) how the differences between beliefs about the interior body and the value assigned to specific body parts differed between children with congenital heart disease and their unaffected peers. One hundred participants, 50 with cardiac disease and 50 comparisons, between 5 and 15

years of age, completed the Inside the Body Test; the severity of the conditions of the children with cardiac problems was evaluated with the Permanent Impairment Evaluation Guide. Results indicated that there were no differences between the 2 groups on knowledge of body parts, body-part function, nor the values that were assigned. Implications for practice are discussed.

Language: English

Keywords: Congenital heart defects / Body image

Viguiet D, Dellatolas G, Gasquet I, Martin C, Choquet M. A psychological assessment of adolescent and young adult inpatients after traumatic brain injury. *Brain Injury*, 2001; 15(3): p.263-271
NIVEL: C 8460

The aims of this study were to get insight into the frequency of cognitive, behavioural, depressive and self-awareness disorders in adolescents and young adults with severe traumatic brain injury, to approach the problems of awareness of the difficulties by comparing self-evaluation and clinicians' evaluation and to investigate some correlates of depressive mood. Two groups of patients with (n = 83) and without (n = 103) TBI, aged 14-25 years, hospitalised after severe traumatic pathology, were compared using the clinician's report and self-report. A higher frequency of depressive tendencies in TBI patients than in controls was shown in the clinician's therapeutic attitude (i.e. prescription of antidepressant drugs), the clinician's report and the self-report. The same difference between the two groups was observed for behavioural and schooling problems in the clinician's report, but not in the self-report. Discrepancies between self- and clinician's evaluation were in favour of a lack of self-awareness of behavioural and cognitive disorders among TBI patients. Correlations of depressive mood with anxiety and cognitive complaints were stronger in TBI than in non-TBI patients. Depression in TBI patients seems compatible with some degree of lack of self-awareness of cognitive and behavioural difficulties.

Language: English

Keywords: Acquired brain injury / Adolescents / Young adults / Depression / Behaviour problems / Psychosocial problems / Cognition disorders

Vinson JA. Children with asthma: initial development of the child resilience model. *Pediatric Nursing*, 2002; 28(2): p.149-158
NIVEL: C 8583

OBJECTIVE: To develop and test a conceptual model of resilience in children based on theoretical relationships between family environment, specific child characteristics, and selected health outcomes. **METHODS:** A correlational study method was used to study a nonprobability, volunteer sample of 235 children, diagnosed with asthma on daily medication. **RESULTS:** Findings revealed that the paths in the inner core of a resilience model were statistically significant. Fifteen percent of the variance in the illness indices outcome for children with asthma was explained by family environment, specific child characteristics, appraisal and coping, and child perceived quality of life. A child's sense of coherence and self esteem, as mediated by a child's appraisal of asthma, accounted for 37% of the variance explained in the perceived quality of life. **CONCLUSIONS:** Nurses and physicians, committed to working in partnerships with parents, can help foster specific child characteristics that impact the effects of asthma.

Language: English

Keywords: Asthma / Family relations / Coping / Quality of life / Self esteem / Explanatory models

Voll R. Aspects of the quality of life of chronically ill and handicapped children and adolescents in outpatient and inpatient rehabilitation.

International Journal of Rehabilitation Research, 2001; 24(1): p.43-49

NIVEL: C 8585

In this article, the advantages of inpatient and outpatient rehabilitation with regard to quality of life of chronically ill adolescents are reported. The aim of psychosocial rehabilitation is to reduce handicaps as far as possible. One handicap in chronically ill adolescents is the impairment of quality of life. The quality of life of chronically ill or handicapped adolescents can be defined with a bio-psychosocial model. The connections between adaptation level, severity of the physical disability and experienced helplessness of young wheelchair users with paraplegia or tetraplegia are demonstrated.

Language: English

Keywords: Physically disabled / Paralysis / Quality of life / Rehabilitation

Wake M, Hesketh K, Cameron F. The Child Health Questionnaire in children with diabetes: cross-sectional survey of parent and adolescent-reported functional health status. *Diabetic Medicine*, 2000; 17(10): p.700-707

NIVEL: C 8368

OBJECTIVE: To examine health status and quality of life in children with diabetes, from both the children's and parents' point of view. **METHODS:** Subjects were 5-18-year-olds attending a diabetes clinic at a tertiary children's hospital. Outcome measures were: (1) Child Health Questionnaire (CHQ) PF-50, a functional health status measure for children aged 5-18 years (parents); (2) CHQ CF-80, a similar self-report measure (adolescents aged 12-18 years); (3) 11 study-designed questions related to diabetes-specific concerns (parents); (4) global ratings of physical and psychosocial health (clinicians); (5) HbA1c level (all subjects). CHQ data were compared with Australian normative data collected six months earlier. **RESULTS:** Reports were obtained from 128 parents and 71 adolescents (90 and 92% response). The CHQ demonstrated good psychometric properties in this sample of children with diabetes. Parents reported children with diabetes to have generally poorer health than children in the normative sample, especially on psychosocial and parent/family scales. Psychosocial health was markedly lower in 5-11-year-olds with HbA1c > 8.8%, but not in 12-18-year-olds. Presence of diabetes-related symptoms and concerns correlated with lower physical and psychosocial functioning. Parents and clinicians concurred in their ratings of health for 12-18-year-olds but not 5-11-year-olds. Adolescents reported their own health similarly to adolescents in the normative sample. **CONCLUSIONS:** Parents report children aged 5-18 years with diabetes to have poorer health than children in the normative sample across all domains. Clinicians may underrate the impact of diabetes for younger children, with possible therapeutic implications. In providing an overall description of health, instruments like the CHQ may add another dimension to the care of children with diabetes and can feasibly be used within clinical settings.

Language: English

Keywords: Diabetes mellitus / Health status / Quality of life / Psychosocial problems / Parents / Questionnaires

Waters EB, Wake MA, Hesketh KD, Ashley DM, Smibert E. Health-related quality of life of children with acute lymphoblastic leukaemia: comparisons and correlations between parent and clinician reports.

International Journal of Cancer, 2003; 103(4): p.514-518

NIVEL: C 8507

The aim of this study was to get insight into the health and well-being of children with acute lymphoblastic leukaemia (ALL). Few studies have examined relationships and differences in reported results between the

parent, child and clinician. In this study, parent-proxy and clinician-reported functional status and health-related quality of life for children and adolescents with ALL were examined. Children and adolescents, 5-18 years, in the maintenance phase of treatment for ALL attending an outpatient clinic were eligible. Measures included: 1) parent-reported functional health and well-being (Child Health Questionnaire [CHQ]); 2) parent-reported condition specific quality of life (Pediatric Cancer Quality of Life inventory [PCQL]); 3) clinician ratings of physical and psychosocial health; and 4) clinical indicators. Insufficient numbers of older patients prohibited collection of adolescent self-reports. The response was 94 %, with 31 participants. Mean time since diagnosis: 1.5 (SD 0.4) years. Parents reported significantly lower functioning and well-being than population norms for all CHQ scales, whereas cancer-specific quality of life was comparable to PCQL norms. Clinician reports of the child's global physical and psychosocial health were moderately associated with each other ($r(s) = 0.56$, $p < 0.001$), and with the parent-reported physical ($r(s) = 0.47$, $p < 0.01$) and psychosocial ($r(s) = 0.56$, $p < 0.001$) CHQ summary scores. Clinician reports of the child's psychosocial health were not associated with any clinical indicators reported regularly. The results demonstrate that the social, physical and emotional health and well-being of children with ALL is significantly poorer than the health of their community-based peers. Routinely collected indicators of clinical progress conceal the psychosocial burden of ALL. Data on health, well-being and quality of life can easily be incorporated into clinical care.

Language: English

Keywords: Leukaemia / Quality of life / Health status / Social adjustment / Psychosocial problems

Weiss RT von, Rapoff MA, Varni JW, Lindsley CB, Olson NY, Madson KL, Bernstein BH. Daily hassles and social support as predictors of adjustment in children with pediatric rheumatic disease. *Journal of Pediatric Psychology*, 2002; 27(2): p.155-165
NIVEL: C 8514

OBJECTIVE: To examine the effect of social support on the adjustment of children with paediatric rheumatic diseases (PRDs). The hypotheses were tested that social support moderates the effects of daily stress on the psychosocial adjustment of children with PRDs and that among multiple sources of support, classmate and parent support are significant predictors of adjustment, after controlling for demographic and disease severity variables.

METHODS: Children with PRDs (N = 160 children; 8-17 years) were recruited from three paediatric rheumatology centers and completed measures of daily hassles, social support, depressive symptoms, and state and trait anxiety; their parents completed measures of internalising and externalising behaviours. **RESULTS:** Fewer daily hassles and higher social support predicted fewer adjustment problems. Among the sources of support, classmate and parent support were significant predictors. Tests for moderation were significant only for a Hassles x Classmate Support interaction in the prediction of depression. A plot of the interaction between hassles and classmate support showed that children with high classmate support had lower levels of depression than children with low classmate support under high or low levels of daily hassles. Furthermore, children with high classmate support had lower levels of depression under conditions of low versus high daily hassles. **CONCLUSIONS:** Results are consistent with a main effect rather than buffering model for social support. Interventions should focus on management of daily hassles and increasing social support for children with PRDs.

Language: English

Keywords: Rheumatoid arthritis / Psychological stress / Social support / Depression / Anxiety / Behaviour problems

Willis E, Miller R, Wyn J. Gendered embodiment and survival for young people with cystic fibrosis. *Social Science & Medicine*, 2001; 53(9): p.1163-1174

The aim of this qualitative study was to get insight into how young people with cystic fibrosis experience the process of transition to adulthood, with a focus on the differential life expectancy for young men against young women. A theory of gendered embodiment is proposed to explain this differential. The social construction of masculinity and femininity as social practices resulted in the former being more conducive to survival than the latter in this case. There were marked differences between the young women and young men in attitudes to: the meaning of life, death, career and body image; all of which affected adherence to medical regimen.

Language: English

Keywords: Cystic fibrosis / Adolescents / Young adults / Sex differences / Body image / Patient compliance

Wirén L, Johannsson G, Bengtsson BA. A prospective investigation of quality of life and psychological well-being after the discontinuation of GH treatment in adolescent patients who had GH deficiency during childhood. *The Journal of Clinical Endocrinology & Metabolism*, 2001; 86(8): p.3494-3498
NIVEL: C 8364

Some patients given pharmacotherapy for growth hormone deficiency in childhood will remain GH deficient in their adult lives and hence could benefit from continued GH replacement therapy. The aim of this longitudinal study was to assess whether quality of life declines after GH discontinuation in late adolescence, and whether differences can be discerned in quality of life in patients whose GH deficiency persists into adulthood and those whose GH secretory capacity falls within normal ranges. Forty patients, aged 16-21 yr at baseline, were assessed over a 2-yr period commencing with discontinuation of GH therapy. Twenty-one patients were assigned to a GH deficiency group, and 19 were assigned to a GH-sufficient group. Quality of life assessments were made using the Nottingham Health Profile, Psychological General Well-Being Index, and Mood Adjective Check List Measures. Visual analogue assessment of personality and affect and cognitive function tests were performed. The Mood Adjective Check List and visual analogue assessments identified between-group and temporal changes in a limited number of the various personality domains assessed. The Psychological General Well-Being Index assessment indicated greater baseline impairment in the GH deficiency group than in the GH-sufficient group in overall score and in the domains of depression and general health. There was also a between-group difference in anxiety score at the 2-yr assessment, with the GH deficiency group having greater anxiety. Measurement of cognitive factors failed to reveal differences between groups. These results indicate that the discontinuation of GH therapy in late adolescence does not risk an immediate decline in the perceived quality of life detectable with the Nottingham Health Profile and Psychological General Well-Being Index measures. However, differences detected with the Mood Adjective Check List and visual analogue assessments hint at clinically significant changes in the life experiences of adolescents discontinued from GH for which traditional measures may lack sensitivity.

Language: English

Keywords: Growth hormone deficiency / Adolescents / Quality of life / Drug utilisation

Wurst E, Herle M, Fuiko R, Hajszan M, Katkhouda C, Kieboom A, Schubert MT. Zur Lebensqualität chronisch kranker und psychisch auffälliger Kinder: erste Erfahrungen mit dem Inventar zur Erfassung der Lebensqualität bei Kindern und Jugendlichen (ILK). (The quality of life of chronically ill and psychiatrically disturbed children: initial experiences with an inventory for assessing quality of life in children and adolescents.) Zeitschrift für Kinder- und Jugendpsychiatrie und Psychotherapie, 2002; 30(1): p.21-28
NIVEL: C 8506

OBJECTIVES: The get insight into the quality of life of chronically ill children and children with emotional and behavioural problems, as reported both by the children themselves and by their mothers. **METHODS:** A series of questionnaires (Inventar zur Erfassung der Lebensqualität bei Kindern und Jugendlichen, ILK, Mattejat et al.) were administered to 360 patients and 288 mothers at the Vienna University Children's Hospital. **RESULTS:** The results clearly show that patients with diabetes rate themselves as the most emotionally burdened and impaired in nearly all aspects of life: a picture which is confirmed by their mothers. Children and adolescents with psychological problems judge the initial problem as well as their social environment as significantly more burdensome. The respective mothers of these psychologically ill children feel that their impairments are greater in more aspects of life than do mothers of children who are chronically ill. The children generally pinpoint most of their difficulties in the areas "ability to occupy myself" and "psychological health". Among adolescents the most negative ratings occur in the areas "school", "psychological health", and "initial problem". **CONCLUSIONS:** The child's problems seem to weigh heavily upon the mothers. Interventions aimed at adolescents and mothers should be based on problem solving: supportive and anxiety-reducing approaches seem best suited for chronically ill children. Children with psychological problems primarily need problem-centred and practical support.

Language: German

Keywords: Chronic diseases, general / Quality of life / Mothers / Psychological stress / Behaviour problems

Yi MS, Britto MT, Wilmott RW, Kotagal UR, Eckman MH, Nielson DW, Kociela VL, Tsevat J. Health values of adolescents with cystic fibrosis. The Journal of Pediatrics, 2003; 142(2): p.133-140
NIVEL: C 8512

OBJECTIVES: To get insight into the health values, i.e. the desirability of health states through one's willingness to undergo risky treatments or to sacrifice longevity in order to improve health, in adolescents with cystic fibrosis (CF). Besides, this study aimed at evaluating how these health values are affected by health status and clinical factors. **METHODS:** Adolescents 12 to 18 years of age completed the Child Health Questionnaire (CHQ), Health Utilities Index Mark 2 (HUI2), and 3 health value measures: the visual analogue scale (VAS), time tradeoff (TTO), and standard gamble (SG). Severity of illness was measured by percent of predicted forced expiratory volume in 1 second (FEV(1)) and frequency of pulmonary exacerbations. **RESULTS:** The mean age (+/- SD) of the 65 adolescents was 15.1 (+/- 2.1) years; 53.8% were male; their mean FEV(1) was 72.8% (+/- 27.0%) predicted. The mean TTO utility was 0.96 (+/- 0.07) and the mean SG utility was 0.92 (+/- 0.15). In multivariable analysis, the General Health Perceptions domain from the CHQ was the only health status scale significantly associated with the VAS, TTO, and SG. No clinical or demographic measures were significantly related to both TTO and SG scores. **CONCLUSIONS:** Direct utility assessment in adolescents with CF is feasible. Their TTO and SG utilities are generally high, indicating that they are willing to trade very little of their life expectancy or take more than a small risk of death to obtain perfect health. Their self-rated health perceptions are related to their health values, but, as in adult populations, only moderately so, indicating that health values are highly individualistic. Therefore, health values should be ascertained directly from adolescents.

Language: English

Keywords: Cystic fibrosis / Adolescents / Attitude / Health status / Risk taking / Quality of life

Yildiz S, Savaser S, Tatlioglu GS. Evaluation of internal behaviors of children with congenital heart disease. *Journal of Pediatric Nursing*, 2001; 16(6): p.449-452
NIVEL: C 8373

The aim of this study was to evaluate behaviour problems and mood disorders in children with congenital heart disease (CHD). The study group included the mothers of 96 children randomly selected (ages ranging from 4 to 11 years) who were being monitored at the Institute of Cardiology. A 21-item questionnaire was administered to obtain information about the mother and the child. Internal subsets of the Child Behavior Check List (CBCL)/4-18 were performed, including withdrawn aggressive behaviours, somatic

complaints, and anxiety/depression tests. The results showed that factors influencing withdrawn aggressive behaviour were low parent education ($p = .000$), poor economic status of the family ($p = .02$), and aggravation of the haemodynamic status of the disease ($p = .003$). The factors influencing somatic complaints were low parent education ($p = .000$) and severity of the haemodynamic status of the disease ($p = .02$). An increase in the number of children in the family seemed to have an effect on anxiety/depression levels ($p = .009$).

Language: Congenital heart defects / Behaviour problems / Depression / Anxiety / Family environment

1.2 *Quality of life from the family's perspective*

Anderson BJ. Children with diabetes mellitus and family functioning: translating research into practice. *Journal of Pediatric Endocrinology & Metabolism*, 2001; 14 (Suppl 1): p.645-652
NIVEL: C 8431

This article reviews the specific challenges of living with diabetes mellitus (DM) which the child and parent must confront at each developmental stage from infancy through adolescence. This discussion is divided into four developmental stages: 1) DM in infancy (0-2 years of age); 2) DM in toddlers and preschoolers (2-5 years); 3) DM in the school-age child (6-11 years); and 4) DM during early- to mid-adolescence (12-16 years). The central milestones of normal psychosocial development are discussed and a summary is provided of recent research at each developmental stage with an emphasis on clinical implications for paediatric diabetes care teams.

Language: English

Keywords: Diabetes mellitus / Infants / Pre-school children / School-age children / Adolescents / Child development / Family relations / Social support / Reviews

Anyanwu I, Anyanwu E. Assessment of the psychosocial impacts of sickle cell disease on adolescents and how parents and relatives cope with pain in the family. *International Journal of Adolescent Medicine and Health*, 2001; 13(2): p.131-143
NIVEL: C 8543

The aim of this study was to assess the psychosocial impacts of sickle cell disease (SCD) in adolescents and how parents and relatives cope with pain

in the family. An effort was made to understand how families and sufferers cope with the emotional distress and social influences on family functioning. Twenty families participated in this study; data were collected by semi-structured interviews and a number of questionnaires. Besides, two cases were examined in order to identify the predictors and burdens of coping with pain among adolescent SCD sufferers and their relatives and the extent to which the National Health Service professionals are involved in the management of SCD in the adolescent. It was found that the psychosocial impacts of SCD on adolescents and their families are higher than previously reported. Females have more psychosocial complications than male adolescents. A majority showed more depressive and associated attributional, and externalising, behavioural difficulties than did non-SCD siblings. It was found that adolescent sicklers who regularly received psychosocial guidance consider their quality of life to be more satisfactory despite the high level of discomfort caused by the disease. Access to the psychosocial services to the adolescent SCD sufferers was found to vary geographically.

Language: English

Keywords: Sickle cell disease / Adolescents / Family / Coping / Psychological stress / Psychosocial problems / Quality of life

Aromaa M, Sillanpaa M, Rautava P, Helenius H. Pain experience of children with headache and their families: a controlled study. *Pediatrics*, 2000; 106(2 Pt 1): p.270-275
NIVEL: C 8411

OBJECTIVE: To get insight into the pain sensitivity of children with headache and their family members, as well as the prevalence of recurring aches, psychosocial life, and family environment of children with headache at preschool age. **METHODS:** A representative population-based sample of 1443 families expecting their first child were followed over 7 years. A screening questionnaire relating to the child's headache was sent to parents of a representative sample of 1132 6-year-old children. Of 144 children suffering from headache, 106 (76%) were examined and interviewed clinically. Ninety-six children with primary headache (58 migraine and 38 tension-type headache children) and matched controls (n = 96) were included in further examinations. **RESULTS:** Children with headache were more often extremely sensitive to pain according to their parents, were more excited about physical examinations, cried more often during blood sampling or vaccination, avoided play or games more often because they

were afraid of hurting themselves, and had recurring abdominal and growing pains more often than did control children. The fathers of children with headache were more often extremely sensitive to pain. Children with headache reacted with somatic symptoms, usually with pain and functional intestinal disorders in stress situations, felt more tired, and had more ideations of death during the previous month. They had also had more problems in day care and fewer hobbies such as scout or club meetings than did control children. More mothers of tension-type headache children than those of migraine children reported that they were considerably sensitive to pain. Tension-type headache children also had a poorer family environment; the family atmosphere was more often unhappy and the relationship between the parents was more often distant than in the families of children with migraine. **CONCLUSIONS:** In addition to somatic factors, it is important to consider the child's pain sensitivity, reaction to various stress situations, and family functioning when studying childhood headache. The child's coping mechanisms can be supported by information given by the parents. School entry can be considered a suitable period for careful investigation into possible occurrence of headache and also for giving information about headache and its management.

Language: English

Keywords: Tension headache / Migraine / Pain / Pre-school children / Psychosocial problems / Family relations / Activities of daily living

Bender BG, Annett RD, Ikle D, DuHamel TR, Rand C, Strunk RC for the CAMP Research Group. Relationship between disease and psychological adaptation in children in the Childhood Asthma Management Program and their families. *Archives of Pediatrics & Adolescent Medicine*, 2000; 154(7): p.706-713
NIVEL: C 8423

OBJECTIVE: This study addresses the relationship between illness and adaptation in children with asthma. It was hypothesised that the burden of childhood asthma compromises psychological adaptation and that the degree of compromise increases with disease severity. **METHODS:** A multicentre randomised clinical trial, the Childhood Asthma Management Program (CAMP), was initiated and funded by the National Heart, Lung, and Blood Institute. Study sites were located in Albuquerque, NM, Baltimore, Md, Boston, Mass, Denver, Colo, St Louis, Mo, San Diego, Calif, Seattle, Wash, and Toronto, Ontario. A total of 1,041 children aged 5 to 12 years were randomised to the trial after confirming their mild to moderate asthma. Main

outcome measures were psychological questionnaires administered at baseline to parents and participants assessing anxiety, depression, behavioural competence, social support, and family functioning. RESULTS: Psychological difficulty was not increased in this group of asthmatic children and their families. Psychological adaptation in the children was associated with the psychological adaptation of the family but not with disease-related variables. Scores from the Impact on Family Scale, a measure of family quality of life related to the child's illness, were associated more strongly with the overall psychological characteristics of the family and child and very little with disease characteristics or severity. CONCLUSIONS: Mild to moderate asthma has imposed modest effects on the daily life but not the psychological health of this group of children. Variation in the psychological characteristics of these children was, as is the case for most children, traceable to the overall psychological adaptation of their families.

Language: English

Keywords: Asthma / Coping / Family relations / Quality of life

Best M, Streisand R, Catania L, Kazak AE. Parental distress during pediatric leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. *Journal of Pediatric Psychology*, 2001; 26(5): p.299-307
NIVEL: C 8414

OBJECTIVE: The first aim was to evaluate prospectively the association between parental anxiety during treatment for childhood leukaemia and posttraumatic stress symptoms after treatment ends. A secondary aim was to explore concurrent variables associated with parental avoidance after treatment ends. METHODS: This was a longitudinal follow-up study of 113 parents of children treated for leukaemia who previously participated in a study of procedural distress during treatment. Data included parental self-report questionnaires completed during treatment and after treatment. RESULTS: Using hierarchical multiple regression, anxiety during treatment was found to be a significant predictor of later PTSS for mothers, but not fathers. Anxiety, self-efficacy, posttraumatic growth and length of time since treatment ended were associated with parental avoidance. CONCLUSIONS: Highly anxious parents are at risk for PTSS and may benefit from approaches that decrease anxiety during treatment and afterward. Enhancing self-efficacy related to follow-up care and identifying positive aspects of the traumatic experiences are suggested as treatment approaches for families after cancer treatment.

Language: English

Keywords: Leukaemia / Parents / Anxiety / Posttraumatic stress symptoms / Coping / Risk factors.

Bleil ME, Ramesh S, Miller BD, Wood BL. The influence of parent-child relatedness on depressive symptoms in children with asthma: tests of moderator and mediator models. *Journal of Pediatric Psychology*, 2000; 25(7): p.481-491
NIVEL: C 8472

OBJECTIVE: To assess the influence of parent-child relationship quality and its possible mediating role on the association between illness-related functional status and depressive symptoms in children with asthma.

METHODS: Questionnaire data were collected from the child, caregiver, and physician. Fifty-five children with asthma (8-17 years of age), their caregivers, and physicians participated. **RESULTS:** Regression analyses suggest that patterns of mother-child relatedness (secure vs. insecure)

mediate the relationship between functional status and depressive symptoms.

CONCLUSIONS: The parent-child relationship may be an important pathway by which illness influences symptoms of depression in children with asthma. This study suggests that impaired functional status does not directly contribute to symptoms of depression, but rather influences the parent-child relationship in ways that may promote the development of depressive symptoms in the child.

Language: English

Keywords: Asthma / Parent-child relations / Depression

Brace MJ, Scott Smith M, McCauley E, Sherry DD. Family reinforcement of illness behavior: a comparison of adolescents with chronic fatigue syndrome, juvenile arthritis, and healthy controls. *Developmental and Behavioral Pediatrics*, 2000; 21(5): p.332-339
NIVEL: C 8544

The purpose of this study was to explore the hypothesis that parental encouragement of illness behaviour correlates with psychosocial dysfunction in adolescents with chronic illness. Ten adolescents with chronic fatigue syndrome (CFS), 16 with juvenile rheumatoid arthritis (JRA) and 14 healthy adolescents, aged 11 to 17 years, were recruited for this study. Measures included the Achenbach parent and youth self report forms, the Family Adaptability and Cohesion Evaluation Scale-II (FACES II), the Children's

Depression Rating Scale, and number of days absent from school. The Illness Behavior Encouragement Scale (IBES) generated measures of parental reinforcement of illness behaviour. As predicted, the teens with CFS scored statistically higher on measures of depression, total competence, and number of days of school missed in the previous 6 months (mean = 40). Children with JRA scored significantly lower than the CFS group on the measure of parental reinforcement of illness behaviour. The healthy group produced intermediate scores. Results and implications for future clinical and research activity are discussed.

Language: English

Keywords: Chronic fatigue syndrome / Rheumatoid arthritis / Adolescents / Parent-child relations / Family relations / Depression / School absenteeism / Social adjustment

Burke SO, Kauffmann E, LaSalle J, Harrison MB, Wong C. Parents' perceptions of chronic illness trajectories. *Canadian Journal of Nursing Research*, 2000; 32(3): p.19-36
NIVEL: C 8498

The aim of this study was to quantitatively describe chronic illness trajectories from the perspective of parents of children with a chronic condition. It was hypothesised that factor analysis would confirm 3 trajectories similar to those in the qualitative literature and that parents' perceptions of their child's trajectory would differ significantly from medically based perceptions. A total of 140 parents provided data on their perceptions of the past, present, and future course of the condition of their repeatedly hospitalised child. Fourteen time-related items from the Coping Health Inventory for Parents Questionnaire on Resources and Stress and the Parenting Stress Index were analysed. Pre- and post-hospitalisation factor analyses extracted the same 8 items to construct 3 trajectories: Life Threatening; Declining; and Stable, Optimistic. The views of approximately one third of the parents differed from medically based classifications. Type of nursing care had no bearing on the perceptions of the parents.

Language: English

Keywords: Chronic diseases, general / Parents / Psychological stress / Hospitalisation / Sick role

Cederbaum JA, LeMons C, Rosen M, Ahrens M, Vonachen S, Cederbaum SD. Psychosocial issues and coping strategies in families

affected by urea cycle disorders. *The Journal of Pediatrics*, 2001; 138(Suppl 1): p.72-80
NIVEL: C 8430

The aim of this study was to assess the psychological stresses and psychosocial needs of families of children with a urea cycle disorder. A survey was sent to the American members of the National Urea Cycle Disorders Foundation to ascertain the types and extent of stress imposed on families. Forty percent of the surveys were returned. The greatest sources of stress were financial, fear of death, and the restrictions imposed by the diet. Other than removal of the economic stress and uncertainty, the results did not suggest that any specific support systems required augmentation. Instructions to mitigate frustrations occurring in emergency situations would, however, be a great help to families.

Language: English

Keywords: Metabolic diseases / Psychological stress / Psychosocial problems / Family / Needs assessment

Eiser C, Eiser JR. Social comparisons and quality of life among survivors of childhood cancer and their mothers. *Psychology and Health*, 2000; 15(3): p.435-450

The purpose of this study was to get insight into the mechanisms of social comparison concerning quality of life in children who survived cancer and their mothers. Sixty-three survivors (aged 9.8-26.1 yrs) of childhood cancer and their mothers were interviewed and completed questionnaires individually about the impact their illness had on their life. The interviews were analysed and coded for statements of favourable, unfavourable or neutral social comparisons. Responses given by survivors were compared with their mothers. Positive correlations between survivors' self-ratings and mothers' proxy ratings on four separate measures of quality of life were observed. Both mothers and survivors made more favourable than unfavourable comparisons. As predicted, among survivors, those making a greater proportion of favourable comparison had higher scores on the perceived illness experience scale, suggesting a better adjustment to the illness and its treatment. A similar result was found for mothers; those with higher positivity scores reported fewer problems for their child on all four dependent measures.

Language: English

Keywords: Cancer / Mothers / Quality of life / Sick role

Ellis N, Upton D, Thompson P. Epilepsy and the family: a review of current literature. *Seizure*, 2000; 9(1): p.22-30
NIVEL: C 8553

The aim of this review is to give an overview of the present state of family research, examining the influence of both childhood and adulthood epilepsy on the psychological and social well-being of family members. Studies indicate that epilepsy may cause high levels of psychosocial difficulties for all family members, including stigmatisation, stress, psychiatric morbidity, marital problems, poor self esteem and restriction of social activities. Studies also suggest that the family environment may be an important intervening factor between the condition and the outcome for the family unit, and a number of family factors are reviewed which have been suggested to mediate this relationship, with recommendations being made for their use in intervention studies. Shortcomings of the family studies to date are discussed and these include: concentration on examination of issues around family life, studies being based on reports from single members of the family and the selection of subjects from clinical populations. Recommendations are made concerning methodological and conceptual issues that need addressing for future research.

Language: English

Keywords: Epilepsy / Quality of life / Family relations / Psychosocial problems / Reviews

Evans M, Cottrell D, Shiach C. Emotional and behavioural problems and family functioning in children with haemophilia: a cross-sectional survey. *Haemophilia*, 2000; 6(6): p.682-687
NIVEL: C 8405

The aim of this study was to examine the emotional and behavioural problems in children with haemophilia and their family functioning. A cross-sectional survey was conducted in which boys with haemophilia, aged between 4 and 15 years, were studied and compared with a group of their healthy school peers. A basic demographic questionnaire was used for both groups along with the Child Behaviour Checklist (CBCL) and the Family Assessment Measure (FAM). Seventeen of 24 families of boys with haemophilia participated (70.8% response). The comparison group consisted of 12 boys, i.e. 70.6% of the haemophilia sample. The groups did not differ in terms of the children's ages and family sizes but significantly fewer of the mothers of the boys with haemophilia worked outside the home. The two

groups were compared for scores on the CBCL and FAM. More problems were identified in the haemophilia group on both measures, i.e. there were more emotional, behavioural and family difficulties compared with the healthy group; however, because of the small sample sizes, the differences between the groups did not reach statistical significance. A larger study would be indicated in order to explore these differences further.

Language: English

Keywords: Haemophilia / Family relations / Psychosocial problems / Behaviour problems

Fernandes PT, Souza EA. Identification of family variables in parents' groups of children with epilepsy. *Arquivos de Neuro-psiquiatria*, 2001; 59(4): p.854-858
NIVEL : C 8355

OBJECTIVE: To evaluate the effectiveness of a support group for parents of children with epilepsy, in identifying the family variables linked to the parents' dynamics and children with epilepsy. **METHODS:** A number of pre-tests were applied to parents of 21 children with benign epilepsy of childhood recently diagnosed, from 5 to 15 years, who participated in the groups at HC/Unicamp. There was a presentation of an educational video, discussion and application of the post-test 1. After six months, the post-test 2 was applied. **RESULTS:** The beliefs were: fear of swallowing the tongue during the seizures (76.19%) and of a future mental disease (66.67%). Facing the epilepsy, fear and sadness appeared. 76.19% of the parents presented overprotection and 90.48%, expected a new seizure. In the post-test 1, the parents affirmed that the information offered had modified the beliefs. In the post-test 2, 80.95% did not report great doubts about epilepsy and 90.48% considered their relationship with their children better. **CONCLUSIONS:** The demystification of beliefs supplied from the groups influenced the family positively, prevented behaviour alterations and guaranteed effective care in the attendance to the child with epilepsy.

Language: English

Keywords: Epilepsy / Parents / Attitude / Family relations / Psychological stress

Galatzer A, Green E, Ofan R, Benzaquen H, Yosefsberg Z, Weintrob N, Karp M, Vardi P. Psychological impact of islet cell antibody screening. *Journal of Pediatric Endocrinology & Metabolism*, 2001; 14(Suppl 1): p.675-679

NIVEL: C 8504

This study was aimed at evaluating the psychological impact of autoantibody screening, a way of detecting individuals who are at risk for type 1 diabetes mellitus. Individuals who were antibody positive (AP) were identified through a large-scale screening program. The sample consisted of nine families in whom 10 AP youngsters (7 M, 3 F) were identified, ranging in age from 6-18 years (mean 11.8, median 10 yr). Seventeen parents and eight diabetic youngsters (mean age 15.2, median 16 yr) participated in the study. Reaction to autoantibody positivity was assessed with the Impact of Event scale (IES). The IES was answered twice: within a week from the disclosure of the AP status, and 3 months later. Parents scored higher than their diabetic children and AP children on both measures of the IES, Intrusion and Avoidance. Three months later both scores were significantly reduced in both the parents and the AP children; however, parents still scored significantly higher on both scores than the AP children. The results suggest that learning one's AP status induces significant anxiety, especially in parents of AP youngsters. Although this initial anxiety dissipates over time it still remains quite high after 3 months. The results highlight the importance of psychosocial counselling for all members of diabetes mellitus screening and prevention trials.

Language: English

Keywords: Diabetes mellitus / Screening / Anxiety / Parents

Gerhardt CA, Vannatta K, McKellop JM, Zeller M, Taylor J, Passo M, Noll RB. Comparing parental distress, family functioning, and the role of social support for caregivers with and without a child with juvenile rheumatoid arthritis. *Journal of Pediatric Psychology*, 2003; 28(1): p.5-15
NIVEL: C 8416

OBJECTIVE: To assess parental distress, family functioning, and social support among parents of children with a lifetime diagnosis of juvenile rheumatoid arthritis (JRA) and comparison families. It was hypothesised that parents of children with JRA would report greater distress, more family difficulties and fewer social support resources, that greater disease severity would be associated with more distress and that more social support would be associated with less distress. **METHODS:** Parents of 64 children with JRA (64 mothers, 46 fathers) completed questionnaires and in-home interviews along with 64 matched comparison families. Average time since diagnosis for children with JRA was 70 months. **RESULTS:** Families of

children with JRA generally reported levels of parental distress, family functioning, and social support similar to those for comparison families. More mothers of children with JRA exceeded the clinical cutoff on the SCL-90-R than comparison mothers. Although disease characteristics and social support did not distinguish subgroups of parents at greater risk for problems, family supportiveness and conflict were associated with caseness for mothers of children with JRA. CONCLUSIONS: Families of children with JRA exhibited substantial resilience over the long term. Further study of children recently diagnosed and with more severe forms of JRA is warranted to determine intervention needs, especially for mothers.

Language: English

Keywords: Rheumatoid arthritis / Parents / Psychological stress / Family relations / Social support

Glasscock R. A phenomenological study of the experience of being a mother of a child with cerebral palsy. *Pediatric Nursing*, 2000; 26(4): p.407-410
NIVEL: C 8397

OBJECTIVE: To explore the experiences and quality of life of mothers who have a child with cerebral palsy. METHODS: A convenience sample of 15 mothers whose children with spastic cerebral palsy receiving care at the high-risk and neurology clinics of a medical centre in a southern state participated in two audiotaped interviews. The mothers described how being the mother of a child from 1 to 5 years of age with cerebral palsy affects her life. Labov's (1982) transcription and Colaizzi's (1978) phenomenological methods were used to analyse transcripts of the interviews. An exhaustive description of the experience was written, and subsequently, in a second interview, was validated by the mothers. RESULTS: Four clustered themes emerged from the interviews: caregiver burden, family/social support, women's/mothers' roles, and socioeconomics. CONCLUSIONS: Mothers reported the following: (a) strong family relationships are counted on during difficult times; (b) caregiving stressors and day-to-day caregiving is difficult; (c) a positive caregiver role and interest in learning about cerebral palsy improve children's quality of life; (d) therapy and social services assist them with their children; (e) multiple roles and alterations in activities affect daily living; and (f) families financial status is affected.

Language: English

Keywords: Cerebral palsy / Mothers / Quality of life / Psychological stress

Graetz BW, Shute RH, Sawyer MG. An Australian study of adolescents with cystic fibrosis: perceived supportive and nonsupportive behaviors from families and friends and psychological adjustment. *Journal of Adolescent Health*, 2000; 26(1): p.64-69
NIVEL: C 8549

OBJECTIVE: To investigate supportive and nonsupportive behaviours exhibited by family members and friends toward adolescents with cystic fibrosis (CF), and to examine the relationships between these behaviours and adolescents' psychological adjustment. **METHODS:** Participants were 35 adolescents with CF attending the Women's and Children's Hospital in South Australia. Perceived supportive and nonsupportive behaviours were assessed using an adapted version of the Chronic Disease Support Interview. The psychological adjustment of the adolescents was assessed using the Youth Self Report Form. Repeated-measures analyses of variance were performed to compare the support provided by family members and friends. Multiple regression analyses assessed the contribution of supportive and nonsupportive behaviours for the prediction of psychological adjustment. **RESULTS:** Family members provided more tangible support than friends who, conversely, provided more companionship support. Overall, family members scored higher than friends on ratings for supportive behaviours. No differences were observed between family members and friends on ratings for nonsupportive behaviours. Rating of nonsupportive behaviours for family members was found to be the strongest predictor of psychological adjustment. **CONCLUSIONS:** Family members and friends provide different types of support. Family members provide more tangible help with treatment tasks and adolescents provide more companionship. Overall, this study demonstrated the importance of addressing nonsupportive as well as supportive behaviours when investigating the impact of support on the psychological adjustment of adolescents with a chronic illness.

Language: English

Keywords: Cystic fibrosis / Adolescents / Social support / Family / Friendship / Behaviour problems / Psychosocial problems

Gritti A, Di Sarno AM, Comito M, De Vincenzo A, De Paola P, Vajro P. Psychological impact of liver transplantation on children's inner worlds. *Pediatric Transplantation*, 2001; 5(1): p.37-43
NIVEL: C 8370

The purpose of this study was to evaluate the psychosocial status of children who have suffered from severe liver disease and undergone orthotopic liver transplantation (OLT). Eighteen children (mean age 6.8 yr, range 4.4-10.8 yr) participated in this study. Mean age at OLT was 3.4 yr. The assessment was psychoanalytically oriented and included individual sessions and testing procedures for children--the Children Apperception Test (CAT), the Weschsler Intelligence Scale for Children (WISC-R), the Weschsler Preschool and Primary Scale of Intelligence (WIPPSI), and the Human Figure Test--and a semi-structured interview with a separate questionnaire for parents. Patients were compared with an age- and gender-matched control group. The main findings in patients compared with controls were: IQ 91.6 (range 70-117) vs. 118 (range 94-135) ($p < 0.0001$); immaturity of ego and drives (72.2% vs. 27.7%; $p = 0.018$), fear of death (61.1% vs. 11.1%; $p = 0.04$), anxiety of loss (50% vs. 27.7%; $p = \text{NS}$), and depressive feelings (61.1% vs. 22.2%; $p = 0.04$); a mild defect of body image (44.4% vs. 33.3%; $p = \text{NS}$) associated with recurrent representations of motionless (72.2% vs. 38.8%; $p = \text{NS}$) and inexpressive (88.8% vs. 16.6%; $p < 0.0001$) human figures. Fantasies about OLT as a 'magic rebirth' or a 'body transformation' were detected in few patients (30%). Although a recurrent set of feelings, conflicts, and fantasies about OLT were expressed by children, individual specific psychological responses to this experience were often detected. In spite of the fact that approximately 50% of the parents mentioned emotional or behavioural disturbances of their child, only 3 parents were seriously concerned about this problem. The theme of transplantation was most often absent from communication between the child and their parents. These results suggest that psychic 'working through' of the chronic liver disease and OLT experience is difficult for children. Further studies are necessary to verify whether changes of parental attitude to OLT as a 'family secret' may facilitate integration of the OLT experience in the child's personality development.

Language: English

Keywords: Liver disease / Liver transplantation / Quality of life / Anxiety / Depression / Psychosocial problems

Gupta S, Mitchell I, Giuffre RM, Crawford S. Covert fears and anxiety in asthma and congenital heart disease. *Child: Care, Health and Development*, 2001; 27(4): p.335-348
NIVEL: C 8379

OBJECTIVE: 1) To compare anxiety and behavioural problems in children suffering 2 different medical conditions; one with a high mortality (congenital heart disease) and one with a very low mortality but high morbidity (asthma). 2) To investigate the influence of maternal anxiety, time since diagnosis and severity of disease. **METHODS:** Forty children with asthma (aged 6--17 years) were compared with 39 children with congenital heart disease in an Outpatient Asthma and Cardiology multidisciplinary Clinics at a tertiary care paediatric facility. Intake questionnaires and interviews determined these children to be without obvious psychosocial problems. Children filled in the Fear Survey Scale (FSSC-R) and Child Manifest Anxiety Scale (R-CMAS). Mothers were given the Child Behavior Checklist (CBCL) and State Trait Anxiety Scale (STAI-S and STAI-T). Normative means and SDs compared with means and SDs for both medical groups. The mother's scores on the STAI-S and STAI-T scales were correlated with the child's scores on the FSSC-R and the R-CMAS. **RESULTS:** Children with asthma and children with congenital heart disease had more medical fears, and more physiological anxiety than normative samples. Increased maternal anxiety was correlated in both groups with increased child anxiety, medical fears and behavioural problems in the child. Similarly, increased severity of asthma or cardiac problems was associated with more physiological anxiety and more fears. Less time since diagnosis of the disease adversely affected social interactions in both groups of children. **CONCLUSIONS:** Physiological anxiety, medical fears and maternal anxiety are important issues requiring attention in asthma and cardiac disease, even in the absence of obvious psychosocial problems. There may be specific problems with a recent diagnosis of a chronic illness.

Language: English

Keywords: Asthma / Congenital heart defects / Anxiety / Behaviour problems / Mothers

Hawley CA, Ward AB, Magnay AR, Long J. Parental stress and burden following traumatic brain injury amongst children and adolescents.

Brain Injury, 2003; 17(1): p.1-23

NIVEL: C 8501

OBJECTIVE: To get insight into the psychological and psychosocial stress experienced by parents of a child who has suffered traumatic brain injury (TBI), and to examine the relationship between self-reported problems, parental stress and general health. **METHODS:** Parents of 97 children admitted with a TBI (49 mild, 19 moderate, 29 severe) and parents of 31

uninjured children were interviewed and assessed. Structured interviews were carried out with families, and parents assessed on the Parenting Stress Index (PSI/SF) and General Health Questionnaire (GHQ-12) at recruitment, and repeated 12 months later. RESULTS: Forty parents (41.2%) of children with TBI exhibited clinically significant stress. Regardless of injury severity, parents of injured children suffered greater stress than control parents as measured by the PSI/SF ($p = 0.001$). There was a highly significant relationship between number of problems reported and level of parental stress ($p = 0.001$). Financial burden was related to severity of TBI. At follow-up, one third of parents of children with severe TBI scored ≥ 18 on the GHQ-12, signifying poor psychological health. CONCLUSIONS: The parents of a child with serious TBI should be screened for abnormal levels of stress. Parental stress and family burden may be alleviated by improved information, follow-up and support.

Language: English

Keywords: Acquired brain injury / Parents / Psychological stress / Health status

Hendriks AHC, Moor JMH de, Oud JHL, Franken WM, Savelberg MMHW. Behaviour problems of young motor disabled children at home and in the therapeutic toddler class. *European Journal of Special Needs Education*, 2001; 16(1): p.15-28
NIVEL: C 8552

The aims of this study were to examine behaviour problems of young children with motor disabilities at home and in a therapeutic toddler class and to assess parents' needs for help. Parents (aged 21-57 yrs) and teachers of 81 children (aged 1-4 yrs) diagnosed with cerebral palsy, spina bifida, psychomotor retardation, disorders of motor control, or undiagnosed conditions completed questionnaires concerning children's internalising behaviours, externalising behaviours, parental need for help in dealing with behaviours, and the effect of therapeutic toddler class. Results show that mothers reported that 21% of children displayed behavioural problems. Mothers more often reported externalising behaviour problems and behaviour problems in general than did teachers. Teachers reported more attention problems among children, such as high distractibility, poor concentration, and refusal to respond. As well, subjects reported that externalising behaviour problems at home occurred less frequently among children with the highest need for extra care-taking and low self-help skills.

Language: English

Keywords: Cerebral palsy / Spina bifida / Motor disorders / Pre-school children / Behaviour problems / Parents / Needs assessment

Holditch-Davis D, Docherty S, Miles MS, Burchinal M. Developmental outcomes of infants with bronchopulmonary dysplasia: comparison with other medically fragile infants. *Research in Nursing & Health*, 2001; 24(3): p.181-193
NIVEL: C 8499

The aim of this study was to explore the mental development and mother-infant interactions of infants with bronchopulmonary dysplasia (BPD) and to compare their development and interactions with those of other seriously ill infants who did not have neurological diseases. One-hour behavioural observations were made of the interactions of mothers with two groups of infants (23 with BPD, 39 medically fragile without BPD or neurological problems) at enrolment, every 2 months during hospitalisation, 1 month after discharge, and at 6 months' and 12 months' corrected age. Assessment of the home environment also was done at 6 and 12 months. Multiple regressions were calculated separately for child mental, adaptive, language, and motor outcomes. Predictors were: home environment assessment, measures of maternal interactive behaviours (positive attention, expression of negative affect, medicalised caregiving), infant group membership, and presence of intraventricular haemorrhage (IVH) in the infant. There were no significant differences between the two groups in any of the developmental outcomes or interactive variables, and the presence of IVH had no effect on these variables. Maternal positive attention and the home environment were correlated with mental development, and mother negative affect was related to adaptive behaviour for both groups. Differences in developmental and interactive behaviours between infants with BPD and other prematurely born infants found in other studies appear to be a result of chronic health problems and, thus, are not unique to infants with BPD.

Language: English

Keywords: Bronchopulmonary dysplasia / Infants / Child development / Parent-child relations

Hollidge C. Psychological adjustment of siblings to a child with diabetes. *Health & Social Work*, 2001; 26(1): p.15-25
NIVEL: C 8399

This aim of this study was to examine the psychological adjustment of well siblings of children with diabetes. A sample of 28 well siblings between the ages of eight and 12 were studied. Psychological adjustment was assessed by measuring self-concept, behavioural difficulties and competence, anxiety, and depression on standardised tests. A semistructured interview reported data gathered on the well siblings' emotional feelings and their communication patterns. The well siblings demonstrated significant internal psychological stressors and maintained high levels of behavioural competence. The internal stressors originated from anxiety and low self-concept. Recommendations based on the findings are offered to professionals who work with children with diabetes and their families.

Language: English

Keywords: Diabetes mellitus / Siblings / Coping / Psychological stress

Holmbeck GN, Coakley RM, Hommeyer JS, Shapera WE, Westhoven VC. Observed and perceived dyadic and systemic functioning in families of preadolescents with spina bifida. *Journal of Pediatric Psychology*, 2002; 27(2): p.177-189
NIVEL: C 8432

OBJECTIVE: To examine dyadic and systemic family functioning across several domains (conflict, cohesion, and stress) in families of preadolescents with spina bifida in comparison to families of healthy preadolescents.

METHODS: Mother-, father-, and child-reported questionnaire data and observational ratings of family behaviour were employed. Subjects were 8- and 9-year olds (n = 68 in each sample). **RESULTS:** Findings revealed significant group and socioeconomic status (SES) differences, particularly for the observational family data. Compared to families of healthy children, families in the spina bifida sample were less cohesive and children from this sample were more passive during family interaction tasks. Additional analyses suggested that some of these significant associations between group status and family functioning were mediated by verbal IQ, indicating that a significant portion (42%-55%) of the overall group effect was due to variations in child cognitive functioning. Lower SES families demonstrated higher levels of observed mother-child conflict, less observed and perceived family cohesion, and more life events. Lower SES families from the spina bifida sample appear to be particularly at risk for lower levels of family cohesion. **CONCLUSIONS:** Findings for the spina bifida sample support a resilience-disruption view of systemic functioning in families of children with paediatric conditions.

Language: English

Keywords: Spina bifida / School-age children / Family relations / Socioeconomic factors

Holmbeck GN, Johnson SZ, Wills KE, McKernon W, Rose B, Erklin S, Kemper T. Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: the mediational role of behavioral autonomy. *Journal of Consulting and Clinical Psychology*, 2002; 70(1): p.96-110

NIVEL: C 8433

The purpose of this study was to test a mediational model of associations between parental overprotectiveness (OP), behavioural autonomy, and psychosocial adjustment in families with 8- and 9-year-old preadolescents with spina bifida and a demographically matched sample of families with healthy children. Sixty-eight families of both groups were involved. Measures included questionnaire and observational assessments of parental OP; parent and child reports of behavioural autonomy; and parent, child, and teacher reports of preadolescent adjustment. On the basis of both questionnaire and observational measures of OP, mothers and fathers of children with spina bifida were significantly more overprotective than their counterparts in the healthy sample, although this group difference was partially mediated by children's cognitive ability. Across samples, mothers were more likely to be overprotective than fathers. Both questionnaire and observational measures of parental OP were associated with lower levels of preadolescent decision-making autonomy as well as with parents being less willing to grant autonomy to their offspring in the future. For the questionnaire measure of OP, and only for the spina bifida sample, the mediational model was supported such that parental OP was associated with less behavioural autonomy, which was, in turn, associated with more externalising problems. Findings are discussed in relation to the literature on parenting, autonomy development, and paediatric psychology.

Language: English

Keywords: Spina bifida / School-age children / Parent-child relations / Autonomy / Explanatory models

Horton TV, Wallander JL. Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology*, 2001; 46(4): p.382-399

NIVEL: C 8542

OBJECTIVE: To get insight into resilience factors like hope and social support in mothers of children with chronic physical conditions, based on a multivariate conceptual model proposed by J. L. Wallander et al (1989). Relationships among these variables were tested. **METHODS:** Subjects were 111 mothers of 5 to 18-year-old children who had cerebral palsy, spina bifida, or insulin-dependent diabetes mellitus. Tests used included the Hope Scale, Social Support Questionnaire-6, Brief Symptom Inventory, and Parents of Children With Disabilities Inventory. **RESULTS:** There were no differences in distress among mothers raising children with different conditions. Both hope and social support were associated negatively and uniquely with distress in these mothers. Perceptions of hope moderated the relationship between disability-related stress and maladjustment, suggesting a buffering effect when stress is high. However, hope did not appear to be a mediator of the relationship between social support and distress. **CONCLUSIONS:** These findings enhance the conceptual understanding of distress in maternal caregivers of children with a chronic physical condition. They also support improving sense of hope as is done in some problem-solving training programs to enhance coping in distressed individuals.

Language: English

Keywords: Cerebral palsy / Spina bifida / Diabetes mellitus / Mothers / Coping / Social support / Psychological stress

Hunfeld JA, Perquin CW, Bertina W, Hazebroek-Kampschreur AA , Suijlekom-Smit LW van, Koes BW, Wouden JC van der, Passchier J. Stability of pain parameters and pain-related quality of life in adolescents with persistent pain: a three-year follow-up. *The Clinical Journal of Pain*, 2002; 18(2): p.99-106

NIVEL: C 8353

OBJECTIVE: To test the hypothesis that pain parameters, pain-related quality of life, and impact of pain on the family would deteriorate over time in a group of adolescents whose reported persisting pain in a previous prevalence study. **METHODS:** A sample of 42 adolescents (aged 12-18 years) from a general population in the area of Rotterdam, The Netherlands, who indicated chronic pain in a previous prevalence study were included in this study. Three-year follow-up questionnaires, diaries, and interviews were used. **RESULTS:** The most prevalent pains were limb pain and headache. The pain intensity was mild (33 mm on a visual analogue scale), very

frequent (72% of all diary entries), and associated with relatively poor functional status and poor psychological and somatic functioning. The pain parameters, pain-related quality of life, and impact of pain on the family (i.e., restrictions in social life and problems in dealing with the stress of the adolescent's pain) remained surprisingly stable across the assessments. The interviews showed that pain had become part of the daily life of several adolescents, who structured their activities and sleeping hours to prevent aggravation of pain. In particular, adolescents with headache reported problems with cognitive activities, whereas those with limb pain and back pain reported problems with physical activities. **CONCLUSIONS:** For adolescents with persistent pain with no known organic cause, intensity and frequency of pain, quality of life, and impact of pain on the family did not change. Generally, they seemed to cope quite well with their pain. In view of these results, further studies should involve follow-up of adolescents with persistent pain into adulthood to establish the determinants of their pain and to find out whether they maintain their adaptive ways of living with their pain.

Language: English

Keywords: Chronic pain / Adolescents / Quality of life / Psychological stress / Family / Coping

Hunfeld JA, Perquin CW, Duivenvoorden HJ, Hazebroek-Kampschreur AA, Passchier J, Suijlekom-Smit LW van, Wouden JC van der. Chronic pain and its impact on quality of life in adolescents and their families.

Journal of Pediatric Psychology, 2001; 26(3): p.145-153

NIVEL: C 8349

OBJECTIVE: To get insight into the effects of chronic pain in adolescents on their quality of life and on that of their families. **METHODS:** One hundred twenty-eight youngsters (12-18 years) who had reported chronic pain kept a 3-week diary of their pain and completed a questionnaire on quality of life. Their mothers completed a questionnaire on the impact of their youngster's pain on the family. **RESULTS:** The most prevalent pains were limb pain, headache, abdominal, and back pain. The pain increased during the day, with the highest frequency around dinner time and the highest intensity around bedtime. Girls reported more intense and more frequent pain than boys. The higher the intensity and frequency of the pain, the lower the self-reported quality of life of the female or male adolescent, especially regarding psychological functioning (e.g. feeling less at ease), physical status (a greater incidence of other somatic complaints), and

functional status (more impediments to leisure and daily activities). Chronic pain also had a negative impact on family life. The mothers reported restrictions, particularly in social life, and problems dealing with the stress of the adolescent's pain. **CONCLUSIONS:** Chronic pain, not caused by somatic disease, was present to a higher degree in girls; the pain increased during the day and had a negative impact on quality of life of the adolescents and the family. There is a need for future research aimed at identifying risk factors for chronic pain and pain-associated quality of life in children and adolescents.

Language: English

Keywords: Chronic pain / Adolescents / Family / Quality of life / Activities of daily living / Psychological stress

Kirpalani HM, Parkin PC, Willan AR, Fehlings DL, Rosenbaum PL, King D, Nie AJ van. Quality of life in spina bifida: importance of parental hope. *Archives of Disease in Childhood*, 2000; 83(4): p.293-297
NIVEL: C 8377

OBJECTIVE: To evaluate the relative contributions of neonatal and current physical function, and of parental hope, to the health related quality of life (HRQL) of children and adolescents with spina bifida (SB). It was hypothesised that both parental hope and the neurophysical examination predict quality of life in children and adolescents with SB. **METHODS:** A previously validated disease and age specific health related quality of life (HRQL) instrument was posted to families of children (aged 5-12 years) and adolescents (aged 13-20 years) with SB. Parental hope was measured, the child's current physical function was determined and retrospective data on the neonatal neurophysical examination (NPE) were obtained. Regression analysis modelled HRQL firstly as a dependent variable on parental hope and NPE ("birth status"); and secondly on parental hope and current physical function ("current function"). **RESULTS:** Response rates were 71% (137 of 194) for families of children, and 54% (74 of 138) for families of adolescents. NPE data were available for 121 children and 60 adolescents. In children, the birth status model predicted 26% of the variability (R(2) hope 21%) compared with 23% of the variability (R(2) hope 23%) in the adolescents. The current function model explained 47% of the variability (R(2) hope 19%) in children compared with 31% of the variability (R(2) hope 24%) in the adolescents. **CONCLUSIONS:** In both age groups, parental hope was more strongly associated with the HRQL than neonatal or current physical deficits. A prospective study is required to determine

whether a causal relation exists between parental hope and HRQL of children and adolescents with SB.

Language: English

Keywords: Spina bifida / Quality of life / Attitude / Parents / Parent-child relations

Landolt MA, Ribi K, Laimbacher J, Vollrath M, Gnehm HE, Sennhauser FH. Brief report: Posttraumatic stress disorder in parents of children with newly diagnosed type 1 diabetes. *Journal of Pediatric Psychology*, 2002; 27(7): p.647-652
NIVEL: C 8435

OBJECTIVE: To determine rates of posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms in parents of children with newly diagnosed type 1 diabetes. **METHODS:** Parents of 38 children with newly diagnosed type 1 diabetes were assessed with the Posttraumatic Diagnostic Scale 6 weeks after diagnosis. **RESULTS:** Twenty-four percent of the mothers and 22% of the fathers met full diagnostic criteria for current PTSD. In addition, 51% of the mothers and 41% of the fathers met criteria for partial or subclinical PTSD. Co-occurrence of PTSD in couples was very low. Posttraumatic stress symptomatology did not correlate with age and gender of the child, socioeconomic status, family structure, or length of hospital stay. **CONCLUSIONS:** The findings support applicability of a posttraumatic stress model for investigating the psychological impact of type 1 diabetes on parents.

Language: English

Keywords: Diabetes mellitus / Parents / Posttraumatic stress symptoms

Lowes L, Lyne P. Chronic sorrow in parents of children with newly diagnosed diabetes: a review of the literature and discussion of the implications for nursing practice. *Journal of Advanced Nursing*, 2000; 32(1): p.41-48

This review deals with grief reactions of parents of diabetic children. The practice of health professionals who work with these parents is informed by two contrasting theoretical views of the progress of grief reactions; the time bound and the chronic sorrow perspectives. This review provides a critical appraisal of the evidence concerning grief reactions in parents of children with diabetes and evaluates the extent to which this supports the expectations

of the time bound theorists, that parents normally reach an end stage of the grieving process, or those of the proponents of chronic sorrow, who anticipate lifelong, recurring sadness. It concludes with a discussion of the implications of the debate for nursing practice.

Language: English

Keywords: Diabetes mellitus / Parents / Grief / Reviews

Magill-Evans J, Darrah J, Pain K, Adkins R, Kratochvil M. Are families with adolescents and young adults with cerebral palsy the same as other families? *Developmental Medicine & Child Neurology*, 2001; 43(7): p.466-472

NIVEL: C 8529

The aim of this study was to determine if adolescents and young adults with cerebral palsy (CP) and their families have similar or different life experiences compared to families of their peers without disability at two developmental stages: as the child enters and leaves adolescence (age ranges 13 to 15 years and 19 to 23 years). Families of 90 individuals with CP (42 females, 48 males) and 75 individuals without physical disabilities (34 females, 41 males) participated. They completed the Family Assessment Device, Life Situation Survey, Multidimensional Scale of Perceived Social Support, and Future Questionnaire. There were few differences in family functioning, life satisfaction, or perceived social support between the groups. Expectations of young adults with CP and parents of both adolescents and young adults regarding future independence and success were lower than the expectations of the control group. While the group results emphasise similarities between families during the two stages of adolescence, individual families and individual family members report specific challenges.

Language: English

Keywords: Cerebral palsy / Adolescents / Young adults / Quality of life / Social support / Family relations

Malhi P, Singh S. Effects of parental distress and family support on the psychological adaptation of children with juvenile rheumatoid arthritis. *Studia Psychologica*, 2002; 44(3): p.253-259

NIVEL: C 8342

The aim of this study was to investigate the mediating effects of parental emotional distress and family support on psychosocial functioning of children with juvenile rheumatoid arthritis (JRA). Thirty-five children (aged 6-14 yrs) with JRA and their parents were recruited for this study. Parental distress was measured by the Beck Depression Inventory and the trait form of the State Trait Anxiety Scale. Family support was assessed by the Family Relationship Index of the Family Environment Scale. The child's psychosocial functioning was measured by the Childhood Psychopathology Measurement Schedule. Results indicated that demographic and disease related factors were not correlated with the psychopathology scores of children. Higher levels of parental depression and anxiety were associated with higher psychopathology, and higher levels of family support were related to lower psychopathology scores among children with JRA. Multiple regression analysis, however, revealed that family conflict was the only significant predictor and accounted for 32% of variance in child's psychosocial adjustment. These findings are consistent with the stress-support-psychological adjustment relationship that has received empirical support in studies on children with chronic illnesses.

Language: English

Keywords: Rheumatoid arthritis / Psychological stress / Parents / Family relations / Social adjustment / Mental disorders

Malhotra S, Singh G. Psychological consequences of chronic physical illnesses in children and adolescents. *Indian Journal of Pediatrics*, 2002; 69(2): p.145-148
NIVEL: C 8404

This article gives an overview of the research concerning the adjustment to paediatric chronic illness under defined theoretical constructs. Apart from temperamental variation, family burden and functioning have been identified as factors operating in determining adjustment. Distress experienced by the family and disturbed family functioning directly influences the emotional outcome in physically disordered children. Comprehensive coordinated care services are required for integration of these patients into the community.

Language: English

Keywords: Chronic diseases, general / Quality of life / Coping / Psychological stress

Manuel JC. Risk and resistance factors in the adaptation in mothers of children with juvenile rheumatoid arthritis. *Journal of Pediatric Psychology*, 2001; 26(4): p.237-246
NIVEL: C 8384

OBJECTIVE: To examine the psychological adjustment of mothers of children with juvenile rheumatoid arthritis (JRA). It was hypothesised that psychosocial stressors were important over and above children's disease severity and that locus of control, maternal appraisal, family relations, maternal education, family income and extrafamilial social support would be of influence. **METHODS:** Mothers of 92 children with JRA completed surveys while waiting with their children for physician appointments or during JRA meeting breaks. **RESULTS:** Mothers reported higher mean levels of psychological symptoms than a normative group. Higher levels of psychosocial stress predicted increased psychological symptoms after accounting for disease severity and functional status. Maternal appraisal of the illness tended to moderate the relationship between illness stress and psychological symptoms, and maternal education moderated the relationship between daily hassles stress and psychological symptoms. **CONCLUSIONS:** These data indicate that mothers of children with JRA are at risk for psychological distress. Interventions that take into account the buffering effects of maternal education and appraisal may serve to decrease the effects of maternal stress.

Language: English

Keywords: Rheumatoid arthritis / Mothers / Psychological stress / Quality of life / Family relations / Social support / Socioeconomic factors

Markson S, Fiese BH. Family rituals as a protective factor for children with asthma. *Journal of Pediatric Psychology*, 2000; 25(7): p.471-480
NIVEL: C 8448

OBJECTIVE: To examine the potential for family rituals and routines to protect children with asthma against anxiety. Rituals and routines are for instance daily interaction patterns like dinnertime, regular activities during weekends and vacations and annual or religious celebrations. **METHODS:** Eighty-six families (43 children with asthma, 43 healthy comparison children) participated in the study. Children completed measures of anxiety (Revised Child Manifest Anxiety Scale) and health. Parents completed measures of stress (Parenting Stress Index), family rituals (Family Routines Questionnaire), and family health. **RESULTS:** Families that reported more

meaning in their family routines had children who reported lower levels of anxiety. Mother endorsement of family ritual meaning and father endorsement of family ritual routine were most strongly related to lower levels of anxiety. Support for the protective function of meaningful family rituals was stronger when a general health stress model was used rather than the presence or absence of asthma alone. CONCLUSIONS: Family rituals may serve a protective function for children with asthma under conditions of heightened parenting stress.

Language: English

Keywords: Asthma / Family / Anxiety / Psychological stress / Coping / Prevention

Mattie-Luksic M, Javornisky G, DiMario FJ. Assessment of stress in mothers of children with severe breath-holding spells. *Pediatrics*, 2000; 106(1 Pt 1): p.1-5
NIVEL: C 8390

OBJECTIVE: To examine maternal stress in parenting a child who exhibits breath-holding spells (BHS), and to identify the specific areas of stress impact, compared with mothers of children with a convulsive seizure disorder (SD) and mothers of control children. It was hypothesised that parenting a child who exhibits BHS is likely more stressful than parenting a healthy child, and also more stressful than parenting a child with a convulsive seizure disorder (SD), because it is often not recognised or misdiagnosed as behavioural rather than medical. METHODS: The Parenting Stress Index and questions regarding how mothers coped were individually administered to 34 mothers of children with BHS, 16 mothers of children with SD, and 16 mothers of children with no medical conditions (controls). RESULTS: Mothers of children with BHS or SD experience more overall stress and disruption in their attachment or understanding of their child, compared with control mothers. These groups of mothers (BHS and SD) also perceived their child as more distractible/hyperactive, less adaptive, and more demanding than did control mothers. However, mothers of the BHS group alone showed significant disruption in their sense of competence as a parent, maintaining self-identity, and receiving positive reinforcement from their child. Mothers of children with SD showed a similar trend, but it was not significant. These findings were not related to maternal health or feelings of depression/isolation, insufficient spousal support, child's mood, or other life stresses. CONCLUSIONS: Parenting a child with BHS or SD impacts a greater degree of life stress on mothers of these children than does

parenting control children, although the stress is greater for the BHS group than for the SD group.

Language: English

Keywords: Epilepsy / Parent-child relations / Psychological stress

McCusker CG, Kennedy PJ, Anderson J, Hicks EM, Hanrahan D.
Adjustment in children with intractable epilepsy: importance of seizure duration and family factors. *Developmental Medicine & Child Neurology*, 2002; 44(10): p.681-687
NIVEL: C 8366

The aims of this study were: 1) to examine the range and nature of adjustment difficulties experienced by children with epilepsy, 2) to elucidate which factors (epilepsy-related, pharmacological and psychosocial) were most associated with adjustment difficulties and 3) to explore associations between psychological factors and seizure frequency. Seventy-five families of children with intractable epilepsy but without a severe learning disability (mean age 7 years 1 month, SD 2 years 6 months; range 2 to 12 years) who attended a regional paediatric neurology service, were surveyed. A postal questionnaire was used which included standardised measures of child and family adjustment; forty-eight families responded (64%; 31 males, 17 females). There was no significant difference between responders and non-responders in terms of age, sex, number of other chronic illnesses and disabilities, age at epilepsy diagnosis, seizure type, nor number of antiepileptic drugs currently prescribed ($p > 0.05$). The importance of including multidimensional measures of outcome was highlighted by the finding that epilepsy-related, pharmacological, and psychosocial factors were differentially associated with specific adjustment difficulties. Two factors appeared to be most pervasively implicated across a range of adjustment problems: frequency of rectal diazepam administration and family patterns of relating to each other ($p < 0.05$). It appeared that duration of seizures (as indicated by frequency of rectal diazepam administration), rather than the frequency of seizures per se, was more pernicious in terms of poor adjustment. Intrafamilial relations (degree of conflict/cohesion) were not only associated with adjustment difficulties in the child, but also with the frequency of seizures themselves. Implications for psychological interventions in intractable epilepsy in childhood are highlighted.

Language: English

Keywords: Epilepsy / Social adjustment / Behaviour problems / Family relations

McMahon MA, Noll RB, Michaud LJ, Johnson JC. Sibling adjustment to pediatric traumatic brain injury: a case-controlled pilot study.

Journal of Head Trauma Rehabilitation, 2001; 16(6): p.587-594

NIVEL: C 8477

OBJECTIVE: To assess depressive symptoms, self-concept, and behaviour in non-affected siblings of children with severe paediatric traumatic brain injury (TBI). **METHODS:** A cross-sectional study with case controls was conducted in a children's hospital tertiary care centre. Subjects were 12 siblings of children consecutively admitted to an inpatient rehabilitation unit after a severe TBI. Case controls were randomly selected from the sibling's classmates. The main outcome measures which were used were the Child Behavior Checklist (CBCL), the Teacher's Report Form of the CBCL (TRF-CBCL), the Self-Perception Profile for Children and the Children's Depression Inventory (CDI). **RESULTS:** No statistical differences were found in depressive symptoms, self-concept, or behaviour between the siblings and their classmates 3 to 18 months after injury. Poorer functional outcomes in the child with a TBI were found to correlate significantly with lower self-concept and more symptoms of depression in the siblings. **CONCLUSIONS:** Further research is needed to evaluate the potential impact on sibling adjustment after paediatric TBI.

Language: English

Keywords: Acquired brain injury / Siblings / Self image / Depression / Behaviour problems

Mobarak R, Khan NZ, Munir S, Zaman SS, McConachie H. Predictors of stress in mothers of children with cerebral palsy in Bangladesh.

Journal of Pediatric Psychology, 2000; 25(6): p.427-433

NIVEL: C 8478

OBJECTIVE: To identify the stress experienced by mothers of young children with cerebral palsy in Bangladesh and to examine associated factors dealing with poverty. **METHODS:** Ninety-one mothers of children with cerebral palsy, aged 1.5 to 5 years, were recruited as they sought services at an urban and a rural centre for their children. Mothers were interviewed with the Self-Report Questionnaire and other family background and child behaviour measures. The children were examined by a paediatrician and by a psychologist. **RESULTS:** Out of 91, 38 (41.8%) mothers were at risk for psychiatric morbidity. Significantly associated factors included living in the rural area within a poor family, with a relatively older child. The strongest

predictor of maternal stress in multivariate analysis was child behaviour problems, especially those related to burden of caring. **CONCLUSIONS:** Ensuring practical help for mothers and advice on managing common behaviour problems are important components of intervention, as they may directly help to relieve stress on mothers of young disabled children in developing countries.

Language: English

Keywords: Cerebral palsy / Mothers / Psychological stress / Developing countries

O'Brien ME. Living in a house of cards: family experiences with long-term childhood technology dependence. *Journal of Pediatric Nursing*, 2001; 16(1): p.13-22
NIVEL: C 8578

The aim of this study was to examine families' experiences of providing long-term home care for children who are technology dependent. Interviews were conducted with 15 families. Families identified frequent change, uncertainty, and unpredictability in their lives, a phenomenon described as "living in a house of cards." Attempts to increase stability involved the use of vigilance, advocacy, and reframing. Areas of challenge, change, and growth included making sense of life, managing daily life with technology, and maintaining a functioning family. Increased understanding of family experiences with long-term childhood technology dependence can provide nurses with additional strategies for providing optimal care to this population.

Language: English

Keywords: Chronic diseases, general / Family / Quality of life / Home care

Oostrom KJ, Schouten A, Kruitwagen CL, Peters AC, Jennekens-Schinkel A, Dutch Study Group of Epilepsy in Childhood. Parents' perceptions of adversity introduced by upheaval and uncertainty at the onset of childhood epilepsy. *Epilepsia*, 2001; 42(11): p.1452-1460
NIVEL: C 8409

The purpose of this study was to examine the parent's perceptions of and reactions to the onset of "epilepsy only" and the implications for continuity of parenting. Content analysis was used to extract data on perceived (dis)continuity of parenting, from interviews held with parents of 69

schoolchildren in whom idiopathic or cryptogenic epilepsy ("epilepsy only") had recently been diagnosed. Almost half of the parents (42%) perceived neither themselves nor their child as having been thrown off balance by the onset of epilepsy. Quite a few parents (33%) perceived themselves rather than their child as having been thrown off balance. More parents of children with cryptogenic than with idiopathic epilepsy perceived themselves as being off balance. However, parents' perceptions of their children's reactions to the epilepsy-related changes were not influenced by any epilepsy variable. Rather, family trouble, long-standing behavioural problems, and adolescence contributed to the child's maladaptive reaction. Three extremely off-balance parents had children with seizures of "unclassifiable" epilepsy that later were found to be nonepileptic and psychogenic. It was concluded that the majority of the parents perceives their child as adapting well to the onset of epilepsy only. Children with seizure onset in adolescence and children with other adversities were perceived as adapting poorly to the additional adversity of epilepsy. Cryptogenic rather than idiopathic aetiology leaves parents in great suspense. In behavioural studies, it is advisable to treat children with unclassifiable epilepsy as a separate group.

Language: English

Keywords: Epilepsy / School-age children / Parents / Attitude / Quality of life / Behaviour problems / Learning problems

Pit- ten Cate IM, Kennedy C, Stevenson J. Disability and quality of life in spina bifida and hydrocephalus. *Developmental Medicine & Child Neurology*, 2002; 44(5): p.317-322
NIVEL: C 8541

The purpose of this study was to examine the impact of severity and type of condition and family resources on quality of life in children with spina bifida and hydrocephalus. A sample of children aged between 6 and 13 years with spina bifida (n=62), hydrocephalus (n=354), and spina bifida plus hydrocephalus (n=128) were identified via the register of the Association for Spina Bifida and Hydrocephalus (ASBAH). Parents completed standardised measures of Child Health Related Quality Of Life (CQOL), family needs survey (FNS), and caregiving self-efficacy scale (CSES) as well as questions on children's health and physical ability. Results showed there were no significant differences in the overall quality of life for the three disability conditions. The overall CQOL was over 1 SD lower for those with spina bifida and hydrocephalus than for children with other physical conditions. Sex and age were not related to overall CQOL. Specific aspects of CQOL

differentiated the three groups. Children with spina bifida had poorer CQOL scores on self-care, continence, and mobility/activities whilst those with hydrocephalus had poorer scores on school activities, worries, sight, and communication. Severity of condition and family resources, i.e. CSES and FNS, predicted 32% of the variance in CQOL. Associations were also found between overall CQOL and problems discernible at birth as well as epilepsy. Other factors, including those related to shunts, were not significantly related to CQOL. It was concluded that hydrocephalus is just as great a threat to CQOL as spina bifida. Beyond the general effect of condition severity on CQOL, family resources (as measured by the CSES and FNS) represent an additional influence on CQOL.

Language: English

Keywords: Spina bifida / Hydrocephalus / Quality of life / Activities of daily living / Family

Powers SW, Byars KC, Mitchell MJ, Patton SR, Standiford DA, Dolan LM. Parent report of mealtime behavior and parenting stress in young children with type 1 diabetes and in healthy control subjects. *Diabetes Care*, 2002; 25(2): p.313-318
NIVEL: C 8461

OBJECTIVE: To assess parent report of mealtime behaviour and experienced psychological stress by parents of preschool children with type 1 diabetes. It was hypothesised that children with type 1 diabetes would be seen as exhibiting more mealtime behaviour problems and that their parents would evidence greater parenting stress when compared with healthy subjects. It was also hypothesised that report of mealtime behaviour problems would be positively correlated with parenting stress. **METHODS:** A total of 40 children (aged 1-6 years) with type 1 diabetes were recruited from a paediatric hospital. Another 40 children matched for age, sex, marital status, and socioeconomic status were used as control subjects. Reliable and valid parent report measures, such as the Behavioral Pediatrics Feeding Assessment Scale and the Parenting Stress Index, were used for data collection. **RESULTS:** Parents of children with type 1 diabetes reported more behavioural feeding problems than parents of healthy control subjects. Additionally, parents of children with type 1 diabetes reported higher frequencies of parenting behaviours associated with poor nutritional intake and a greater number of parenting problems concerning mealtimes when compared with parents of healthy control subjects. Parents of children with type 1 diabetes also reported higher stress levels than parents of control

subjects. A moderate relationship between mealtime behaviour problems and general parenting stress was observed for families coping with type 1 diabetes. **CONCLUSIONS:** Mealtime problems reported in preschool children with type 1 diabetes are appropriate targets for behavioural intervention. Behavioural observation techniques and training in child behaviour management skills should be used in future research aimed at assessing and treating barriers to effective nutrition management in young children with type 1 diabetes.

Language: English

Keywords: Diabetes mellitus / Pre-school children / Behaviour problems / Parents / Psychological stress

Press J, Neumann L, Uziel Y, Bolotin A, Buskila D. Assessment of quality of life of parents of children with juvenile chronic arthritis.

Clinical Rheumatology, 2002; 21(4): p.280-283

NIVEL: C 8391

The purpose of this study was to assess the quality of life (QOL) of parents of children with juvenile chronic arthritis (JCA). The QOL, anxiety and depression of the parents of 28 children with JCA were evaluated and compared to those of the parents of 28 healthy children. Mothers of JCA children and mothers of healthy children reported similar QOL. The reported anxiety and depression levels were similar for mothers and fathers in both groups. The parents of children with pauciarticular-type JCA reported lower QOL and higher levels of anxiety and depression than the parents of children with other types, namely polyarticular and systemic JCA. These findings may be explained by the fact that the pauciarticular patients had shorter disease duration and were less frequently seen in the outpatient clinic. The QOL of mothers of children with JCA was found to be slightly impaired in the group of children with pauciarticular JCA. Future larger studies are needed to confirm these results, as the number of subjects in the three groups was rather low.

Language: English

Keywords: Rheumatoid arthritis / Parents / Quality of life / Anxiety / Depression

Reid DT, Renwick RM. Relating familial stress to the psychosocial adjustment of adolescents with Duchenne muscular dystrophy.

International Journal of Rehabilitation Research, 2001; 24(2): p.83-93

NIVEL: C 8381

The aim of this study was to investigate the relationships between familial stress and psychosocial adjustment in adolescents with Duchenne muscular dystrophy (DMD). The participants (36 caregivers and 32 adolescents) were all registered with the Muscular Dystrophy Association of Canada. The Offer Self-Image Questionnaire for Adolescents (Offer et al., 1982, 1989) was used to measure psychosocial adjustment of adolescents with DMD. Family stress was measured by the Questionnaire on Resources and Stress (Holroyd, 1987). All but a few of the participants were interviewed and completed self-report instruments in their own homes. The other families were interviewed in other settings (e.g., clinic, adolescent's school). The results indicate that, overall and in several specific areas, the adolescents demonstrate lower levels of psychosocial adjustment than their normal reference group. The results also indicate that familial stress is not related to sociodemographic variables, but is associated with psychosocial adjustment in the adolescent ($P = 0.0004$), and with intellectual function of the adolescent ($P = 0.001$). In fact, the results of a regression analysis show that the level of stress experienced by the family predicts the degree of psychosocial adjustment of the adolescent with DMD ($R^2 = 0.38$, $P = 0.0003$). These findings underscore the importance of a holistic approach with these families. Limitations of the study, and implications of the results, are discussed in terms of clinical practice and future research.

Language: English

Keywords: Duchenne muscular dystrophy / Adolescents / Social adjustment / Psychosocial problems / Psychological stress / Family

Sawyer MG, Spurrier N, Kennedy D, Martin J. The relationship between the quality of life of children with asthma and family functioning. *Journal of Asthma*, 2001; 38(3): p.279-284
NIVEL: C 8383

The aim of this study was to examine the relationship between the quality of life of children with asthma and several dimensions of family functioning. The quality of life of 84 children with asthma, aged 7-12 years, and their family functioning was assessed using standard questionnaires. A significant relationship was found between children's reports of their quality of life and several key dimensions of family functioning. The results suggest that independent of their frequency, the extent to which asthma symptoms upset and bother children varies depending on the level of the functioning of the children's families. Treatment approaches designed to improve family

functioning may reduce the extent to which children are bothered by their asthma symptoms and thus improve their quality of life.

Language: English

Keywords: Asthma / School-age children / Quality of life / Family relations

Sawyer MG, Spurrier N, Whaites L, Kennedy D, Martin AJ, Baghurst P. The relationship between asthma severity, family functioning and the health-related quality of life of children with asthma. *Quality of Life Research*, 2000; 9(10): p.1105-1115
NIVEL: C 8551

The aims of this study were 1) to compare the health-related quality of life (HRQL) of children with asthma with that of a large representative sample of children in the general community, and 2) to examine the relationship between the HRQL of children with asthma and their demographic characteristics, asthma severity and family functioning. A sample of 236 children with asthma and a sample of 4509 children from the general community were involved in this study. Children with asthma had a significantly poorer HRQL than other children in the community. Amongst the children with asthma, parents reported that children living in single-parent families had poorer physical health, mental health and social functioning than children in two-parent families. There was a significant relationship between the mental health of children with asthma and family functioning but no significant relationship between their physical health and family functioning. These findings suggest that the domains comprising the HRQL of children with asthma are related to both disease and non-disease factors. A better understanding of these relationships will facilitate the development of new interventions to help children with asthma.

Language: English

Keywords: Asthma / Quality of life / Family relations / Behaviour problems / Psychosocial problems

Sharpe D, Rossiter L. Siblings of children with a chronic illness: a meta-analysis. *Journal of Pediatric Psychology*, 2002; 27(8): p.699-710
NIVEL: C 8508

OBJECTIVE: To review the literature pertaining to the impact of pediatric chronic illness on sibling psychological functioning. METHODS: Fifty-one published studies and 103 effect sizes were identified and examined through

meta-analysis. RESULTS: The authors found (1) a modest, negative effect size statistic existed for siblings of children with a chronic illness relative to comparison participants or normative data; (2) heterogeneity existed for those effect sizes; (3) parent reports were more negative than child self-reports; (4) psychological functioning (i.e., depression, anxiety), peer activities, and cognitive development scores were lower for siblings of children with a chronic illness compared to controls; and (5) a cluster of chronic illnesses with daily treatment regimes was associated with negative effect statistics compared to chronic illnesses that did not affect daily functioning. CONCLUSIONS: More methodologically sound studies investigating the psychological functioning of siblings of children with a chronic illness are needed. Clinicians need to know that siblings of children with a chronic illness are at risk for negative psychological effects. Intervention programs for the siblings and families of children with a chronic illness should be developed.

Language: English

Keywords: Chronic diseases, general / Siblings / Psychosocial problems / Meta-analysis / Reviews

Sloper P. Predictors of distress in parents of children with cancer: a prospective study. *Journal of Pediatric Psychology*, 2000; 25(2): p.79-91
NIVEL: C 6498

The aim of this study was to examine levels of psychological distress in parents of children with cancer and relationships between distress and measures of illness variables, appraisal, psychosocial resources and coping strategies. Questionnaires were completed by 68 mothers and 58 fathers at 6 (Time 1) and 18 (Time 2) months postdiagnosis. High levels of distress for 51% of mothers and around 40% of fathers were apparent at both time points, with little change over time. For mothers, their appraisal of the strain of the illness, and their own ability to deal with it, and family cohesion were predictive of distress, both concurrently and prospectively, and, at Time 1, greater use of self-directed coping strategies was related to higher levels of distress. For fathers, risk factors of employment problems (Time 1) and the number of the child's hospital admissions (Time 2) were significant, along with appraisal and family cohesion. Continuation of high levels of distress over time points to the importance of identification of those at risk at an early stage and provision of ongoing support. Implications for such support are discussed.

Language: English

Keywords: Cancer / Parents / Psychological stress / Coping / Social support / Risk factors

Soliday E, Kool E, Lande MB. Family environment, child behavior, and medical indicators in children with kidney disease. *Child Psychiatry and Human Development*, 2001; 31(4): p.279-295
NIVEL: C 8445

This study was aimed at examining the effects of family environment on child behaviour symptoms and medical indicators in children with kidney diseases. Parents (n = 41) of children with nephrotic syndrome, chronic renal insufficiency, or kidney transplant completed family environment and child behaviour questionnaires. Medical indicators (utilisation and medications) were collected from medical records. A model including child age, diagnostic group, and family environment variables successfully predicted all outcomes except internalising behaviour. Higher family conflict predicted more externalising symptoms and higher number of prescribed medications; higher family cohesion predicted fewer hospitalisations. Nontraditional family structure predicted higher number of prescribed medications. Results are discussed as they relate to a stress and resistance framework, need for research on direction of effect, and clinical recommendations.

Language: English

Keywords: Kidney disease / Family relations / Hospitalisation / Drug utilisation / Behaviour problems

Sukhodolsky DG, Scahill L, Zhang H, Peterson BS, King RA, Lombroso PJ, Katsovich L, Findley D, Leckman JF. Disruptive behavior in children with Tourette's syndrome: association with ADHD comorbidity, tic severity, and functional impairment. *Journal of the American Academy of Child and Adolescent Psychiatry*, 2003; 42(1): p.98-105
NIVEL: C 8492

OBJECTIVE: To examine whether comorbidity of Tourette's syndrome (TS) with attention-deficit/hyperactivity disorder (ADHD) is associated with disruptive behaviour and how this influences social, adaptive, and family functioning. **METHODS:** The sample included 207 children (144 boys and 63 girls) between the ages of 7 and 18 years. Forty-two children received a diagnosis of TS-only, 52 received a diagnosis of ADHD-only, 52 children

had TS+ADHD, and there were 61 unaffected control children. Best-estimate DSM-IV diagnoses were assigned on the basis of structured interviews and clinical ratings. Dependent measures included parent and teacher ratings of disruptive behaviour, parent ratings of social and family functioning, and the Vineland Adaptive Behavior Scales. RESULTS: Children with TS-only did not differ from unaffected controls on the parent ratings of aggression and delinquent behaviour or on the teacher ratings of conduct problems. By contrast, children with TS+ADHD were rated significantly above unaffected controls and similar to children with ADHD-only on these indices of disruptive behaviour. Hierarchical regression analyses revealed that aggression and delinquency scores added unique contributions to impairment in social and family functioning, controlling for age, gender, and diagnostic status. CONCLUSIONS: Comorbid ADHD is highly associated with disruptive behaviour and functional impairment in children with TS. When disruptive behaviour problems are present, there is an additional burden on children's social and family functioning.

Language: English

Keywords: Tourette syndrome / Behaviour problems / Attention Deficit

Hyperactivity Disorder / Comorbidity / Family relations / Social adjustment

Svavarsdottir EK, McCubbin MA, Kane JH. Well-being of parents of young children with asthma. *Research in Nursing & Health*, 2000; 23(5): p.346-358
NIVEL: C 8380

The aim of this study was to examine how family caregiving activities in families of young children with asthma are related to parents' well-being. This was examined by identifying the most time-consuming and difficult caregiving demands experienced by parents and by investigating moderating influences of resiliency factors like sense of coherence (SOC) and family hardiness (FH). Seventy-six families (75 mothers and 62 fathers) of young children (infant to 6 years) with asthma participated in this study. The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin, M., & McCubbin, 1993, 1996) was the conceptual framework for the study. The major hypothesis was that SOC and FH, separately and in combination, moderate both family system and caregiving demands on general well-being. With hierarchical regression analysis, SOC and FH explained 56% of the variance in mothers' well-being; family demands, SOC, and FH explained 67% of the variance in fathers' well-being. No moderating relationships were found for SOC or FH. Resiliency factors (SOC and FH) and family demands

had direct relationships to the well-being of parents of young children with asthma.

Language: English

Keywords: Asthma / Infants / Pre-school children / Parents / Quality of life / Psychological stress

Taylor HG, Yeates KO, Wade SL, Drotar D, Stancin T, Burant C. Bidirectional child-family influences on outcomes of traumatic brain injury in children. *Journal of the International Neuropsychological Society*, 2001; 7(6): p.755-767

NIVEL: C 8441

The aim of this longitudinal study was to assess behaviour problems, injury-related family burden, and parent psychological distress regarding children with severe traumatic brain injury (TBI) over the first year post injury. Forty children with severe TBI, 52 with moderate TBI, and 55 with orthopaedic injuries not involving brain insult participated. Parents rated children's preinjury behaviour soon after injury. Postinjury child behaviour and family outcomes were assessed at 6- and 12-month follow-ups. Findings from path analysis revealed both direct and indirect effects of TBI on child behaviour and family outcomes, as well as cross-lagged child-family associations. Higher parent distress at 6 months predicted more child behaviour problems at 12 months, controlling for earlier behaviour problems; and more behaviour problems at 6 months predicted poorer family outcomes at 12 months, controlling for earlier family outcomes. Support for bidirectional influences is tentative given that limited sample size precluded use of structural equation modelling. The findings nevertheless provide impetus for considering the influences of person-environment interactions on outcomes of TBI.

Language: English

Keywords: Acquired brain injury / Behaviour problems / Parents / Psychological stress / Family relations

Taylor V, Fuggle P, Charman T. Well sibling psychological adjustment to chronic physical disorder in a sibling: how important is maternal awareness of their illness attitudes and perceptions? *Journal of Child Psychology and Psychiatry and Allied disciplines*, 2001; 42(7): p.953-962

NIVEL: C 8372

The aims of this study were: 1) to investigate the psychological adjustment of healthy siblings of children with chronic diseases, 2) to examine how accurate mothers are in reporting on well siblings' attitudes and perceptions, and 3) how the mothers' accuracy is influenced by maternal variables like distress, burden of care and satisfaction with social support. Sixty-two well siblings and mothers of children with a range of chronic physical disorders completed standardised questionnaires. The majority of siblings did not appear to have adjustment problems, although the sample had slightly increased rates of emotional symptoms compared to the general population. Mothers rated well siblings as having more negative attitudes and perceptions about the physical disorder than reported by siblings themselves. A multiple regression analysis indicated that better sibling adjustment was associated with higher maternal awareness of their attitudes and perceptions. These findings support Varni and Wallander's (1998) model that emphasises the role of relationship and attitude variables in child adjustment to chronic physical disorder. The implications of these findings for clinical practice are discussed.

Language: English

Keywords: Chronic diseases, general / Siblings / Psychosocial problems / Family relations

Van Horn M, DeMaso DR, Gonzalez-Heydrich J, Erickson JD . Illness-related concerns of mothers of children with congenital heart disease.

Journal of the American Academy of Child and Adolescent Psychiatry, 2001; 40(7): p.847-854

NIVEL: C 8557

OBJECTIVE: To examine illness-related concerns of mothers of children with congenital heart disease (CHD) and to assess the relationships among mothers' concerns, medical severity, and mother's emotional state.

METHODS: Thirty-eight mothers of children with CHD aged 3 to 16 completed semistructured interviews and rating scales during hospitalisation and 2 to 4 weeks after discharge. Mothers rated their distress about illness-related concerns, as well as their own depressed mood and anxiety. Mothers and two cardiologists rated the medical severity of each child's disease.

RESULTS: Mothers' concerns were reliably grouped into five categories: medical prognosis, quality of life, psychosocial functioning, effects on family, and financial issues. During hospitalisation, mothers were most concerned about medical prognosis. Distress about most concerns decreased postdischarge, as did mother's anxiety and depressed mood. Mothers'

perceptions of medical severity were associated with distress about psychosocial issues postdischarge. Mother's anxiety was not associated with number of concerns reported, or with distress about those concerns. Maternal depressed mood was associated with fewer illness-related concerns, but greater distress about those concerns. **CONCLUSIONS:** Illness-related concerns can be meaningfully categorised and are not necessarily a function of disease severity or mother's emotional state. An awareness of common concerns will improve clinical care by enabling practitioners to anticipate and address concerns in a proactive way. The results may inform the development of supportive mental health interventions for families of children with CHD.

Language: English

Keywords: Congenital heart defects / Mothers / Psychological stress / Anxiety / Depression

Visconti KJ, Saudino KJ, Rappaport LA, Newburger JW, Bellinger DC. Influence of parental stress and social support on the behavioral adjustment of children with transposition of the great arteries. *Developmental and Behavioral Pediatrics*, 2002; 23(5): p.314-321
NIVEL: C 8341

The aim of this study was to examine the joint role of parental stress and social support in the emotional adjustment of children with d-transposition of the great arteries (d-TGA). Questionnaires were administered to 143-153 parents when children were 1 and 4 years of age. Parent ratings of child behaviour problems were collected at 4 years (n = 152). The findings indicate a favourable outcome for parents and children with congenital heart disease (CHD). Compared with normative samples, parents experienced less stress and more social support, and they rated children as showing fewer behaviour problems. Parents with more stress at both ages reported more behaviour problems. Families with less social support reported more stress at both 1 and 4 years. Social support, however, did not moderate the relationship between stress and child behaviour problems. Early detection of distressed families may assist in alleviating stress and reducing behaviour problems.

Language: English

Keywords: Congenital heart defects / Parents / Psychological stress / Social support / Behaviour problems

Wade SL, Taylor HG, Drotar D, Stancin T, Yeates KO, Minich NM. A prospective study of long-term caregiver and family adaptation following brain injury in children. *Journal of Head Trauma Rehabilitation*, 2002; 17(2): p.96-111
NIVEL: C 8515

OBJECTIVE: To examine long-term adaptation in families of children with traumatic brain injury (TBI), compared to families of children with orthopaedic injuries. METHODS: Families of children with severe TBI (n = 53), moderate TBI (n = 56), and orthopaedic injuries (n = 80) were assessed at baseline, 6 months, and 12 months post injury and at an extended follow-up an average of 4.1 years post injury. Caregiver and family outcomes were examined using mixed model analysis. RESULTS: Patterns of adaptation over time varied across groups but indicated long-standing injury-related stress and burden in the severe TBI group. CONCLUSIONS: Severe TBI results in persistent caregiver stress for a substantial proportion of families.

Language: English

Keywords: Acquired brain injury / Family / Family relations / Psychological stress

Weinger K, O'Donnell KA, Ritholz MD. Adolescent views of diabetes-related parent conflict and support: a focus group analysis. *Journal of Adolescent Health*, 2001; 29(5): p.330-336
NIVEL: C 8516

OBJECTIVE: To get insight into the sources of conflicts between adolescents with diabetes and their parents, from the adolescents' perspective. METHODS: A focus group approach was used. Twenty-four adolescents (10 boys and 14 girls, age 13-15 years; 97% white) participated in three same-sex focus groups at two diabetes summer camps. The focus group leader used a prepared set of open-ended questions to guide the 90-minute sessions. Sessions were tape-recorded, transcribed, and analysed by a set procedure for qualitative analysis to identify the adolescents' perspectives on parent-adolescent sources of diabetes-related conflict and support. RESULTS: Adolescents reported the following sources of diabetes-related conflict: parental worry and intrusive behaviours; parental lack of understanding and blaming behaviours, and the parents focus on the future vs. the adolescent focus on the present. With regard to diabetes-related support, the teens identified parental understanding of the demands of diabetes and parental provision of reassurance about their child's illness and normative functioning. CONCLUSIONS: Adolescents' perceptions of

parental worry, lack of understanding, and resulting intrusive and blaming behaviours are major areas of conflict that need to be addressed in the management of type 1 diabetes.

Language: English

Keywords: Diabetes mellitus / Adolescents / Parent-child relations / Psychological stress

Wiegner S, Donders J. Predictors of parental distress after congenital disabilities. *Developmental and Behavioral Pediatrics*, 2000; 21(4): p.271-277

NIVEL: C 8519

The aim of this study was to investigate the relationship between child functional independence, family dynamics, psychosocial factors, and level of distress in parents of children with congenital disabilities like cerebral palsy, spina bifida and limb deficiencies. The Vineland Adaptive Behavior Scales, the Family Assessment Device (FAD), and the Brief Symptom Inventory (BSI) were administered to 60 parents of children with cerebral palsy, 34 parents of children with spina bifida, and 27 parents of children with limb deficiencies. Stepwise multiple regression analyses indicated that the Roles scale from the FAD and the presence of a significant new psychosocial stressor within the previous 6 months were statistically significant predictors of the level of parental distress as assessed by the BSI. Exploration of the extent to which families have adaptive distributions of responsibilities for dealing with domestic tasks, as well as with unrelated life stressors, may be helpful in identifying those parents of children with congenital disabilities who are at risk for distress.

Language: English

Keywords: Cerebral palsy / Spina bifida / Paralysis / Parents / Psychological stress / Family relations / Activities of daily living

Williams PD, Williams AR, Graff JC, Hanson S, Stanton A, Hafeman C, Liebergen A, Leuenberg K, Setter RK, Ridder L, Curry H, Barnard M, Sanders S. Interrelationships among variables affecting well siblings and mothers in families of children with a chronic illness or disability. *Journal of Behavioral Medicine*, 2002; 25(5): p.411-424

NIVEL: C 8347

The purpose of this study was to examine interrelationships among psychosocial variables known to affect the health and development of well siblings and parents in families with a chronically ill child, based on a structural equation model (SEM). Using dyads of 252 well children and parents, socioeconomic status (SES) and family cohesion were associated with the parent-reported behaviour of the well sibling. SES also influenced the mood of the mother that in turn influenced family cohesion. The well sibling's knowledge about the illness of the brother or sister, attitude toward the illness, mood, self esteem, and feelings of social support were interrelated and related to the behaviour of the well sibling. The SEM suggests that interventions may be directed at several points in these interactions including boosting knowledge levels of the well sibling, improving family cohesion, and assuring adequate "income" support to the family through income transfers or in-kind services.

Language: English

Keywords: Chronic diseases, general / Siblings / Parents / Family relations / Psychosocial problems / Socioeconomic factors / Explanatory models

Williams J, Lange B, Sharp G, Griebel M, Edgar T, Haley T, Frindik P, Casey S, Dykman R. Altered sleeping arrangements in pediatric patients with epilepsy. *Clinical Pediatrics*, 2000; 39(11): p.635-642

NIVEL: C 8517

The purpose of this study was to examine altered sleeping arrangements in the home environment following the diagnosis of epilepsy in children, a diagnosis which could lead to parental fear concerning seizure occurrence. Questionnaires concerning demographics, medical history, and sleeping arrangements were completed by parents of 179 children with epilepsy and by parents of 155 children with diabetes for comparison purposes. Based on parental response, 40 (22%) children with epilepsy changed to less independent sleeping arrangements. Logistic regression suggested that parental concern over seizure occurrence was highly associated with this change ($p < 0.001$). In contrast, 13 (8%) of the children with diabetes changed to a less independent sleep pattern. Results suggest changes in sleeping arrangements may alert the paediatrician to possible parental anxiety that may need to be addressed.

Language: English

Keywords: Epilepsy / Diabetes mellitus / Parents / Anxiety

Wood BL, Klebba KB, Miller BD. Evolving the biobehavioral family model: the fit of attachment. *Family Process*, 2000; 39(3): p.319-344
NIVEL: C 8490

The Biobehavioral Family model (BBFM) is useful in studying relational patterns in families of ill children. This model posits that family relational patterns and biobehavioural reactivity interact so as to influence the physical and psychological health of the children. The revised 1999 BBFM incorporates parent-child attachment as a pivotal construct. The aim of this study was to assess the value of incorporating attachment in the model and to test key family psychophysiological pathways. It was predicted that, in asthmatic children, child perception of parental relationship quality, triangulation of child in marital conflict, and parent-child security of relatedness will be associated with hopelessness and vagal activation (one mechanism of airway compromise in asthma). In this study, 22 children with asthma (11 males/11 females, aged 8 to 16), watched, alone, an emotionally challenging movie, then engaged in family discussion tasks (problem solving, loss, conflict, cohesion) and completed the Children's Perception of Interparental Scale, the Relatedness Questionnaire, The Multidimensional Scale of Anxiety in Children, and the Hopelessness Scale for Children. Heart rate variability, measured at baseline and throughout the movie and family tasks, was used to compute respiratory sinus arrhythmia (RSA)--an inferential measure of vagal activation. The child's perception of parental conflict showed trends of association with triangulation and insecure father-child relatedness. Triangulation and hopelessness also were associated with insecure father-child relatedness, all of which were associated with vagal activation. Insecure mother-child relatedness was correlated only with hopelessness. Anxiety was not related to any variables. These findings lend support to the 1999 BBFM, and suggest a key role for parent-child attachment.

Language: English

Keywords: Asthma / Family relations / Quality of life / Anxiety / Explanatory models

Young B, Dixon-Woods M, Findlay M, Heney D. Parenting in a crisis: conceptualising mothers of children with cancer. *Social Science & Medicine*, 2002; 55(10): p.1835-1847

The aim of this study was to investigate the experiences of mothers living with a child with cancer. Using empirical data from semi-structured

interviews with 20 mothers of a child with cancer, in one area of the UK, the authors draw on sociological literatures on motherhood, childhood, caring, and chronic illness to suggest a more helpful and informative way of understanding their experiences. It is suggested that mothers, although not ill themselves, experience many of the consequences of chronic illness. Biographical disruption begins for them when they first notice something wrong with their child, and intensifies with diagnosis, altering their sense of self and their social identity. The diagnosis brings with it a set of new responsibilities and role expectations, including an obligation of 'proximity'-being physically close to their child at all times to provide 'comfort' and 'keep-watch'. For mothers, caring evokes an intense emotional interdependence with their sick child, and involves a range of technical tasks and emotional work, including acting as 'brokers' of information for their child and managing their cooperation with treatment. Managing these obligations was achieved at high cost to the mothers themselves, and resulted in severe role strain by compromising their ability to function in other roles, including their role as the mother of their other children. Against the backdrop of a severe and life-threatening illness, everyday concerns about their child's diet or appropriate discipline take on a new significance and carry a heightened potential for generating conflict and distress for mothers. In presenting their accounts, mothers draw on prevailing cultural discourses about motherhood, childhood and cancer, and these clearly influence the context in which they care for their child, and shape their reflexive constructions of their experiences. Caring for a child with cancer had many adverse implications for the quality of life of the women who were studied. Mothers of a child with cancer warrant study in their own right, and such study benefits from interpretive perspectives.

Language: English

Keywords: Cancer / Mothers / Parent-child relations / Quality of life / Psychological stress

1.3 Questionnaires and measures on quality of life

Arunkumar G, Wyllie E, Kotagal P, Ong HT, Gilliam F. Parent- and patient-validated content for pediatric epilepsy quality-of-life assessment. *Epilepsia*, 2000; 41(11): p.1474-1484
NIVEL: C 8442

OBJECTIVE: To assess the parent-and patient-validated content of quality-of-life measurement for use in children with epilepsy. METHODS: The

parents of 80 consecutive children and adolescents with epilepsy were asked to list in order of importance their concerns about living with or caring for their children with epilepsy. Patients were 3 months to 18 years of age (mean, 10 years) and identified at the outpatient clinic or during hospital stay. To minimise investigator bias, parents and children listed their concerns in a private setting without staff involvement. RESULTS: Twenty-six distinct domains were generated by the parents and children. Concerns listed by more than 20 of parents included medication adverse effects (58), cognitive effects of epilepsy (46), prospects for the future (41), safety (35), independence (31), and brain damage caused by seizures (30). Concerns ranked by parents as most important included safety (18), brain damage from seizures (12), enigma of epilepsy (12), cognitive effects of epilepsy (11), and prospects for the future (10). Concerns listed by more than 20 of children included social problems (35), cognitive effects of epilepsy (29), driving (29), sports (27), medication adverse effects (25), and schooling (21). Concerns ranked by children as most important included issues related to medication adverse effects (13), cognitive effects of epilepsy (10), hatred of epilepsy (8), social embarrassment (6), fear of seizures (6), injury (6), and dislike of hospital visits (6). CONCLUSION: The effect of epilepsy on health-related quality of life in paediatric patients is defined by a limited number of domains. A 20-item inventory was chosen from the 26 domains generated by the parents and children. This study provides insight into parents' and children's perception of seizures and the impact of epilepsy on everyday life.

Language: English

Keywords: Epilepsy / Quality of life / Activities of daily living / Questionnaires

Asmussen L, Olson LM, Grant EN, Landgraf JM, Fagan J, Weiss KB.
Use of the Child Health Questionnaire in a sample of moderate and low-income inner-city children with asthma. *American Journal of Respiratory and Critical Care Medicine*, 2000; 162(4 Pt 1): p.1215-1221
NIVEL: C 8571

The aim of this study was to examine the psychometric performance of the Child Health Questionnaire (CHQ-PF50), an instrument to gauge paediatric, health-related quality of life from the patient's (or parent's) perspective, in a sample of children with asthma, overrepresenting those at high risk for poor outcomes. Seventy-four adult caregivers of children with asthma completed the CHQ. Internal consistency reliability was consistently high for all but one scale. Intraclass correlation coefficients ranged from a low of 0.37 to a

high of 0.84. Tests of validity found CHQ scales better at distinguishing levels of disease severity as defined by symptom activity than medication use or pulmonary function tests. Performance of the CHQ-PF50 in a sample of low-income to moderate income inner-city parents of children with asthma presented mixed results. The instrument addresses a broad range of concepts but some scales may be more salient than others in assessing health status of children at highest risk for asthma morbidity. Future efforts must compare condition-specific and generic instruments to evaluate their relative strengths and weaknesses, as well as potential links between them.

Language: English

Keywords: Asthma / Quality of life / Activities of daily living/ Questionnaires

Berry C, Shalowitz M, Quinn K, Wolf R. Validation of the Crisis in Family Systems-Revised, a contemporary measure of life stressors.

Psychological Reports, 2001; 88(3 Pt 1): p.713-724

NIVEL : C 8568

The objectives of this study were to test the validity of the Crisis in Family Systems-Revised, a measure of life stressors, using the same validation technique as in the original validation, and to provide further evidence of construct validity by assessing its relationship to socioeconomic status and residential location. Interviews were conducted with 124 parents in three outpatient paediatric asthma clinics affiliated with an academic medical center. The design was cross-sectional and correlational. Total count of life stressors accounted for 19% of the variance in scores on the Center for Epidemiologic Studies-Depression. Respondents using Medicaid and living in the city experienced more objective stressors, but the proportions of stressors rated as negative or positive (Valence), and ongoing (Chronicity) were fairly constant across subsamples, as was the Difficulty rating. Psychologists and health and mental health services researchers are in need of constructs relevant to contemporary society and its issues and tools to measure these constructs. Life stressors appears to be such a construct and the Crisis in Family Systems-Revised a measure with considerable utility.

Language: English

Keywords: Asthma / Family / Psychological stress / Socioeconomic factors / Questionnaires

Bijttebier P, Vercruyse T, Vertommen H , Gool SW van, Uyttebroeck A, Brock P. New evidence on the reliability and validity of the Pediatric

Oncology Quality of Life Scale. *Psychology and Health*, 2001; 16(4): p.461-469

The aim of this study was to replicate previous studies on the psychometric properties of the Pediatric Oncology Quality of Life Scale (POQOLS), a 21-item parent-report inventory for the assessment of physical restriction, emotional distress and discomfort from medical treatment in children with cancer. The research questions were focused on the scale's internal consistency, its relation with demographics, and its ability to discriminate between patient groups (criterion validity). The parents of 73 paediatric oncology patients (aged 2.83-19.75 yrs) completed the POQOLS. Child patients were drawn from the population of a university hospital and had diagnoses of leukaemia, lymphoma, or solid tumour. The results support the psychometric quality of the POQOLS. Three of the core aspects of quality of life are tapped using sufficiently short and internally consistent subscales. Data also indicate that the instrument is free from relations with demographics and shows good discriminant ability to differentiate between patient groups according to time since diagnosis, treatment status, and diagnosis.

Language: English

Keywords: Cancer / Leukaemia / Quality of life / Questionnaires

Bullinger M, Schmidt S, Petersen C, DISABKIDS Group. Assessing quality of life of children with chronic health conditions and disabilities: a European approach. *International Journal of Rehabilitation Research*, 2002; 25(3): p.197-206
NIVEL: C 8471

Methods to assess the quality of life of children with chronic conditions are still in development. The design of such an assessment tool for different age groups and different levels of disabilities is the objective of a European-Union-funded study: the DISABKIDS project. In addition, it addresses the psychosocial determinants of quality of life in children with disabilities. A major aim of the project, which is described in this article, is to develop and test instruments for children and adolescents with disabilities (as well as for their families) in seven countries, to assess the impact of the chronic health conditions on quality of life and to provide a tool for systematic monitoring of the quality of care given to children with disabilities. Assessment and monitoring will allow identification of unmet health care needs and, it is

hoped, ultimately, the fostering of the development of effective intervention strategies.

Language: English

Keywords: Chronic diseases, general / Quality of life / Assessment

Camfield C, Breau L, Camfield P. Impact of pediatric epilepsy on the family: a new scale for clinical and research use. *Epilepsia*, 2001; 42(1): p.104-112
NIVEL: C 8572

OBJECTIVE: To create a brief, global instrument that measures the psychosocial impact of paediatric epilepsy on the family. **METHODS:** Mothers rated their child's quality of life on a visual analogue scale (1-6) and completed the Impact of Pediatric Epilepsy Scale (IPES), which assesses the impact on academic achievement, participation in activities, health, relationships with family and with peers and siblings, social activities, self esteem, and the caregiver's hopes for their child's future adapted from the scale developed by Jacoby. External validation was determined by comparison of the IPES with physicians' reports of the characteristics of the child's epilepsy and neurological limitations and parents' ratings on the Family Environment Scale or Parenting Stress Index. In addition, each school-aged child completed the Piers-Harris Children's Self-Concept Scale, Brother-Sister Questionnaire, and Loneliness Scale. Teachers of children completed the Academic Performance Rating Scale. Seven days later, retest reliability of the IPES was evaluated. **RESULTS:** Ninety-seven mothers of children aged 2-16 years completed the IPES and the appropriate family and age-related questionnaires. Internal validation on the IPES yielded a Cronbach's α for the scale of 0.92. A significant Pearson's correlation indicated that total scores were consistent over time ($r = 0.81$). Spearman's correlations for the individual items were also significant, ranging from 0.48 to 0.78. Significant Spearman's correlations also indicated that quality of life was negatively related to impact on each of the 11 items of psychosocial function. Children with IPES scores above the median differed in some psychosocial aspects from those who scored below. Their parents were more stressed, their siblings were more respectful, they had lower self esteem, and they experienced more emotional problems. Total impact was also significantly related to seizure frequency, total number of medications taken, number of visits to a physician in the previous year, and number of nights spent in hospital for neurological reasons. **CONCLUSIONS:** The IPES is an accurate, acceptable, and quick measurement tool that reflects the way in

which childhood epilepsy has an impact on the child and on family life. It may be helpful in routine clinical care and may be useful in the research setting to find ways to improve the lives of children with epilepsy.

Language: English

Keywords: Epilepsy / Quality of life / Family relations / Psychological stress / Social participation / Self esteem / Peer relations

Eiser C, Morse R. The measurement of quality of life in children: past and future perspectives. *Developmental and Behavioral Pediatrics*, 2001; 22(4): p.248-256
NIVEL: C 8561

Quality of life (QoL) is central to paediatric practice. Where it is possible to manage but not cure a disease, it is important to determine how far treatment and disease compromise the child's QoL. In this way, informed judgments can be made about whether or not treatment is appropriate, and, where there is a choice, which choice might be the best option for the child. In this review, different approaches to measuring child QoL are considered, a methodological review of measures currently available is reported, the quality of these measures is evaluated, and finally the implications for the future development and use of QoL measures are considered. Computer searches identified 269 potentially relevant articles, of which 137 were included in the review. Of these, 43 were primarily concerned with the development of a new measure of QoL, 79 reported subsequent development of these same measures, and 15 used a battery approach to measure QoL. All currently available measures have limitations (e.g., limited psychometric data, lack of parallel forms for children and proxy raters, and insufficient attention to children's ability to complete paper-and-pencil measures). However, recommendations are made on the basis of those considered to be most satisfactory. It is essential that attempts be made to use QoL measures in research (e.g., evaluation of clinical trials and alternative treatments) to gain experience that will guide development of a second generation of more sophisticated measures. Despite the practical difficulties identified, measurement of QoL remains of central interest to all those concerned with the well-being of children.

Language: English

Keywords: Chronic diseases, general / Quality of life / Questionnaires / Reviews

Eiser C, Morse R. A review of measures of quality of life for children with chronic illness. *Archives of Disease in Childhood*, 2001; 84(3): p.205-211

NIVEL: C 8560

OBJECTIVE: To identify currently available generic and disease specific measures of quality of life (QoL) for work with children and to make recommendations about the future development and application of QoL measures. **METHODS:** Systematic searches were conducted to identify measures of QoL. Research papers were coded on the basis of predefined inclusion and exclusion criteria. **RESULTS:** Of the 137 papers included in the review, 43 involved the development of a new measure. These included 19 generic and 24 disease specific measures. Almost half the measures were developed in the USA. Measures were identified which were appropriate for children across a broad age range, and included provision for completion by different respondents (child only, parent only, or both). There were no clear distinctions between measures of QoL, health, or functional status.

CONCLUSIONS: A small number of measures which fulfil basic requirements was identified and could be used to assess QoL in clinical trials or following interventions. However, there remain a number of problems in measuring QoL in children. These include limited availability of disease specific measures; discrepancies between child and parent ratings; limited availability of measures for self completion by children; lack of precision regarding the content of domains of QoL; and the cultural appropriateness of measures developed elsewhere for children in the UK.

Language: English

Keywords: Chronic diseases, general / Quality of life / Questionnaires / Reviews

Eiser C, Vance YH, Seamark D. The development of a theoretically driven generic measure of quality of life for children aged 6-12 years: a preliminary report. *Child: Care, Health and Development*, 2000; 26(6): p.445-456

NIVEL: C 8601

OBJECTIVE: To develop and validate a generic computer-delivered measure of quality of life (QoL) suitable for children aged 6-12 years: the Exqol. The theoretical model adopted is based on an assumption that poorer QoL is the result of discrepancies between an individual's actual ('like me') and ideal self ('how I would like to be'). **METHODS:** The Exqol consists of 12 pictures, each of which is rated twice; first in terms of 'like me' and

second as 'I would like to be'. The Exqol is delivered using a Macintosh Powerbook and takes approximately 20 min to complete. Data are reported for 58 children with asthma (Mage = 8.95 years) and 69 healthy children (Mage = 7.49 years). In order to determine validity of the Exqol, children with asthma also completed the Childhood Asthma Questionnaire (CAQ) and their mothers completed a measure of child vulnerability and caregiver QoL. RESULTS: Higher discrepancies were found for children with asthma compared with healthy children ($P < 0.05$). For children with asthma, significant correlations were found between discrepancy scores and two of the four subscales of the CAQ. Children who rated their asthma to be more severe also had higher discrepancy scores ($P < 0.05$). CONCLUSIONS: The Exqol has acceptable internal reliability and validity and distinguishes between children with asthma and healthy children. These data provide preliminary support for the theoretical assumption that QoL reflects perceived discrepancies between an individual's actual and ideal self. Methodological refinements to the Exqol are suggested.

Language: English

Keywords: Chronic diseases, general / Asthma / Quality of life / Questionnaires

Gee L, Abbott J, Conway SP, Etherington C, Webb AK. Development of a disease specific health related quality of life measure for adults and adolescents with cystic fibrosis. *Thorax*, 2000; 55(11): p.946-954
NIVEL: C 8567

OBJECTIVE: To develop and validate a disease specific health-related quality of life (HRQoL) measure for adults and adolescents with cystic fibrosis. METHODS: Areas of concern to adults and adolescents with CF were identified by unstructured interviews, self-administered questionnaires, consultation with multidisciplinary specialist staff, a review of the relevant literature, and examination of other HRQoL measures. Items for the questionnaire were generated on the basis of this process. Continued evaluation and development of the Cystic Fibrosis Quality of Life (CFQoL) questionnaire was undertaken by a process of statistical analysis and continued feedback from patients. The full testing and validation of the CFQoL questionnaire took place over four phases: (1) initial item generation and testing of a preliminary questionnaire, (2) testing and validation of the second version of the questionnaire, (3) test-retest reliability of a third and final version of the questionnaire, and (4) sensitivity testing of the final version of the questionnaire. RESULTS: Nine domains of functioning were identified using principal components analysis with varimax rotation.

Internal reliability of the identified domains was demonstrated using Cronbach alpha coefficients (range 0.72-0.92) and item to total domain score correlations. Concurrent validity (range $r = 0.64-0.74$), discriminatory ability between different levels of disease severity, sensitivity across transient changes in health (effect size range, moderate $d = 0.56$ to large $d = 1.95$), and test-retest reliability ($r = 0.74-0.96$) were also found to be robust.

CONCLUSIONS: The CFQoL questionnaire is a fully validated disease specific measure consisting of 52 items across nine domains of functioning which have been identified by, and are of importance to, adolescents and adults with cystic fibrosis. This measure will be useful in clinical trials and longitudinal studies.

Language: English

Keywords: Cystic fibrosis / Adolescents / Quality of life / Activities of daily living / Questionnaires

Goldbeck L, Storck M. Das Ulmer Lebensqualitäts-Inventar fuer Eltern chronisch kranker Kinder (ULQIE): Entwicklung und psychometrische Eigenschaften. (ULQIE: A quality-of-life inventory for parents of chronically ill children.) *Zeitschrift für Klinische Psychologie und Psychotherapie*, 2002; 31(1): p.31-39
NIVEL: C 8597

The objective of this study was to develop and test the "Ulmer Lebensqualitäts-Inventar fuer Eltern chronisch kranker Kinder (ULQIE; Ulm quality inventory for life inventory for parents of chronically ill children), a short self-report instrument. The questionnaire was constructed according to the principles of classical test theory. It assesses physical and daily functioning, satisfaction with the situation in the family, emotional distress, self-development, and well-being. Its subscales were developed by factor analysis. The 29-item instrument was administered to 122 parents (52% mothers, 48% fathers) of chronically ill children (65% males, 35% females; mean age 5.5 yrs) in Germany. Subjects completed the ULQIE within 2 weeks of diagnosis and again 10-12 weeks later. For validation purposes, subjects also completed a questionnaire on physical well-being during the follow-up assessment. The results of the varimax rotation and Cronbach alpha-analyses showed satisfactory psychometric properties and internal consistency. Data on the ULQIE's validity are reported. The findings indicate that the questionnaire can be recommended for measuring parental quality of life within the context of psychosocial support programs for chronically ill children.

Language: German

Keywords: Chronic diseases, general / Parents / Quality of life / Questionnaires

Goldbeck L, Schmitz TG. Comparison of three generic questionnaires measuring quality of life in adolescents and adults with cystic fibrosis: the 36-item short form health survey, the quality of life profile for chronic diseases, and the questions on life satisfaction. *Quality of Life Research*, 2001; 10(1): p.23-36
NIVEL: C 8598

OBJECTIVE: To evaluate the psychometric properties of different generic quality of life (QL) measures and to extract secondary dimensions of QL in patients with cystic fibrosis (CF), in order to define a disease-specific QL pattern. METHODS: The short-form-36 health survey (SF-36), the quality of life profile for chronic diseases (PLC), and the questions on life satisfaction (FLZ(M)) were simultaneously employed in a cross-sectional study with 70 adolescents and adults with CF. The different concepts of the measures were compared. Internal consistency (Cronbach's alpha), convergent and construct validity (correlation patterns, common factor analysis), and external validity (correlations with symptom and pulmonary function scores, with intensity of therapy; comparisons with healthy peers) of the three instruments were investigated. RESULTS: Similar reliability, but different validity of the questionnaires are demonstrated. Seventy-three percent of the total variance across the three measures could be explained with a seven-factor-solution: (1) physical functioning (19.3% of total variance), (2) mental health (19.3%), (3) social integration (7.5%), (4) role function/pain (7.5%), (5) economic/material living conditions (7.5%), (6) partnership/family (6.7%) and (7) anxiety (5.2%). CONCLUSIONS: The different validity of the instruments has to be considered in choosing a questionnaire appropriate to the purpose of measuring. Shortcomings of each instrument can be overcome by multimethod designs and by developing disease-specific scales.

Language: English

Keywords: Cystic fibrosis / Adolescents / Quality of life / Questionnaires

Hartmaier SL, DeMuro-Mercon C, Linder S, Winner P, Santanello NC. Development of a brief 24-hour adolescent migraine functioning questionnaire. *Headache*, 2001; 41(2): p.150-156
NIVEL: C 8562

The objective of this study was to develop a brief questionnaire to assess short-term decrements in social, psychological and cognitive functioning in adolescents with acute migraine. One hundred twenty-three potential items were generated by literature review and by interviewing adolescents suffering migraine and specialists. To reduce the items, 127 adolescents were asked to identify which items affected their daily functioning in the 24 hours following onset of a migraine, and to rate them on a 5-point scale from "not very important" to "extremely important." Reduction to an 18-item questionnaire was performed by evaluating subject-perceived importance (number of times an item was chosen, times mean importance score) in combination with principal components factor analysis. Five domains were identified: (1) activities, (2) social functioning, (3) cognitive functioning, (4) migraine headache symptoms, and (5) emotional functioning. Questions regarding school loss and school performance during a migraine were added to the final questionnaire as a separate outcome measure. The correlation between the five domains as measured by the Spearman correlation coefficient ranged from 0.17 to 0.49 suggesting some, but minimal, overlap. Cronbach alpha for individual domains ranged from 0.50 to 0.84. The questionnaire was pilot-tested in 12 adolescent migraineurs to determine ease of administration and comprehension and revised to improve clarity.

Language: English

Keywords: Migraine / Adolescents / Quality of life / Activities of daily living / School / Questionnaires

Heimlich TE, Westbrook LE, Austin JK, Cramer JA, Devinsky O. Brief report: Adolescents' attitudes toward epilepsy: further validation of the Child Attitude Toward Illness Scale (CATIS). *Journal of Pediatric Psychology*, 2000; 25(5): p.339-345
NIVEL: C 8564

OBJECTIVE: To get insight into the attitudes and feelings of adolescents with epilepsy about their illness using the Child Attitude Toward Illness Scale (CATIS) and to provide further psychometric validation of the CATIS. **METHODS:** Participants were 197 adolescents aged 11 to 17 years who completed the CATIS at two points and two external validation scales. Test-retest and internal consistency reliability and construct validity were computed. Analysis of variance was used to examine differences in attitudes according to gender, age, and epilepsy severity. **RESULTS:** Girls, older adolescents, and those with more severe epilepsy had more negative attitudes toward having epilepsy than boys, younger adolescents, and those with

moderate or mild epilepsy, respectively. Psychometric analyses yielded excellent internal consistency reliability and good test-retest reliability. The CATIS was moderately correlated with self esteem and mastery, supporting its construct validity. CONCLUSIONS: The CATIS is a useful and psychometrically sound tool to assess adolescents' attitudes toward having chronic illness.

Language: English

Keywords: Epilepsy / Adolescents / Attitude / Quality of life / Questionnaires

Henry B, Aussage P, Grosskopf C, Goehrs JM. Development of the Cystic Fibrosis Questionnaire (CFQ) for assessing quality of life in pediatric and adult patients. *Quality of Life Research*, 2003; 12(1): p.63-76
NIVEL: C 8599

The aim of this study was to develop and validate 2 versions of the Cystic Fibrosis Questionnaire (CFQ). The 2 versions are: the CFQ 14+ for teenagers and adults, and the CFQ Child P, a parent-proxy evaluation for children aged 8-13. They include three modules for assessing QOL, symptoms and health perception. Nine QOL dimensions were identified: physical functioning, energy/well-being, emotions, social limitations, role, embarrassment, body image, eating disturbances and treatment burden. Items were derived from 33 interviews with patients and parents. Item reduction and assessment of internal consistency, convergent and discriminant validity were based on a large cross-sectional survey among 393 patients and parents. A second study was conducted among 124 patients and 85 parents to test reproducibility and responsiveness, confirm the subscale structure and assess scalar properties using Rasch analysis. All psychometric properties were successfully demonstrated and both the CFQ 14+ and the CFQ Child P French questionnaires are now well validated. German and Spanish validated adaptations are available, an English validation is in progress. It was concluded that the CFQ 14+ and CFQ Child P are well validated, multilingual measures which allow QoL assessment in children, teenagers and adults with CF.

Language: English

Keywords: Cystic fibrosis / Quality of life / Activities of daily living / Psychosocial problems / Questionnaires

Hoare P, Mann H, Dunn S. Parental perception of the quality of life among children with epilepsy or diabetes with a new assessment questionnaire. *Quality of Life Research*, 2000; 9(6): p.637-644
NIVEL: C 8594

The aim of this study was to evaluate the usefulness of a newly designed questionnaire to assess the quality of life among children with epilepsy or diabetes. Factor analysis identified one factor, the impact on the parents and the family, which was responsible for over a third of the variance in the two illness groups. Two other factors, impact on development and impact on health, were also found in the epilepsy group. The questionnaire discriminates well between children with epilepsy or diabetes, showing that the former is more affected than the latter. Children with more severe epilepsy are seen by parents to have a worse quality of life than children whose epilepsy is well controlled.

Language: English

Keywords: Epilepsy / Diabetes mellitus / Quality of life / Questionnaires

Kolk AM, Schipper JL, Hanewald GJ, Casari EF, Fantino AG. The Impact-on-Family Scale: a test of invariance across culture. *Journal of Pediatric Psychology*, 2000; 25(5): p.323-329
NIVEL: C 8589

OBJECTIVE: To investigate the suitability of the Impact-on-Family Scale for cross-cultural use. **METHODS:** The Italian version of the scale was administered to mothers of children with chronic illnesses. Factorial invariance was examined to investigate whether the four factors found with the original United States (U.S.) scale could be replicated. **RESULTS:** The results clearly demonstrate the replicability of the first three factors, Financial Burden, Familial/Social Impact, and Personal Strain. In addition, internal consistency and the homogeneity of the items of the corresponding scales are satisfactory. However, the fourth factor, Mastery, could not be replicated, and the reliability of the corresponding scale is poor. Italian mothers scored significantly lower on the Financial Burden and on the Familial/Social Impact dimension, compared to the American sample. **CONCLUSIONS:** Three of the four factors of the Impact-on-Family Scale are useful for cross-cultural comparisons between U.S. and Italian samples.

Language: English

Keywords: Chronic diseases, general / Family / Psychological stress / Questionnaires

Kromer ME, Prihoda TJ, Hidalgo HA, Wood PR. Assessing quality of life in Mexican-American children with asthma: impact-on-family and functional status. *Journal of Pediatric Psychology*, 2000; 25(6): p.415-426
NIVEL: C 8603

OBJECTIVE: To assess the validity of two questionnaires, the Impact on Family (IOF) and the Functional Status II (R) (FSIIR), in children with asthma. **METHODS:** Hundred and fifteen Hispanic parents of children with asthma were interviewed and the IOF and FSIIR scores and reliability coefficients were compared for the following subgroups: English or Spanish language and high or low educational level. The construct validity of the IOF Total score and FSIIR scores were assessed by examining the relationship between these scores and other health status variables. **RESULTS:** The IOF Total score and FSIIR Illness score demonstrated acceptable construct validity and reliability for language and education subgroups, although several of the IOF subscales had low reliability. **CONCLUSIONS:** IOF Total score and FSIIR Illness score can be recommended for use by Spanish- and English-speaking Mexican-American respondents.

Language: English

Keywords: Asthma / Family / Quality of life / Health status / Questionnaires

Last BF, Grootenhuis MA, Destree-Vonk A, Heymans HSA. De ontwikkeling van een levensloopvragenlijst voor jong-volwassenen (LVJV). (The development of a life course questionnaire for young adults.) *Gedrag & Gezondheid*, 2000; 28(1): p.23-30

The aim of this study was to develop a systematic questionnaire to investigate the course of life. That was considered relevant for examining the influence of chronic illness in children reaching adulthood on their course of life. Therefore, 'The Course of Life questionnaire: Levensloopvragenlijst voor Jong-Volwassenen: LVJV' was developed. The questionnaire aims to measure retrospectively: school development, autonomy development, psychosexual development, social development, anti-social behaviour, smoking and drinking. Results of a pilot study in a student population are presented. The LVJV appears to be an instrument which is simple to administer and has good face-validity. Test-retest reliability of the questionnaire is good. Concurrence between the data and available nationally registered data about drinking, smoking and sexual behaviour shows that it is possible to collect such information retrospectively in a valid way.

Language: Dutch

Keywords: Chronic diseases, general / Young adults / Child development / Questionnaires

Merlijn VP, Hunfeld JA, Wouden JC van der, Hazebroek-Kampschreur AA, Passchier J. Shortening a quality of life questionnaire for adolescents with chronic pain and its psychometric qualities.

Psychological Reports, 2002; 90(3 Pt 1): p.753-759

NIVEL : C 8592

The aim of this study was to develop a shortened list of the 71-item scale Quality of Life Headache-Youth, to be also suitable for other pain locations to enhance compliance. For this, a sample of 98 adolescents from an open population with chronic benign pain was recruited. This article presents the psychometric qualities of the shortened version, named the Quality of Life Questionnaire for Adolescents with Chronic Pain. The original version could be reduced to 44 items which showed suitable internal consistency and construct validity against COOP/WONCA charts.

Language: English

Keywords: Chronic pain / Adolescents / Quality of life / Questionnaires

Osman LM, Baxter-Jones AD, Helms PJ, EASE Study Group. Parents' quality of life and respiratory symptoms in young children with mild wheeze.

European Respiratory Journal, 2001; 17(2): p.254-258

NIVEL: C 8573

The Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ), measures the impact of child asthma symptoms on family activity (CGAct) and parental anxiety (CGEmot). It has not been validated for families of children <7 years, with wheezing illness. Therefore, the aim of this study was to assess the sensitivity of the PACQLQ to symptom change in preschool children with wheezing illness. The families of 62 children were involved in this study. The median age of children was 3 years (range 0.8-6 years). At entry and 3-month follow-up, parents recorded child respiratory symptoms in a 1-month diary and completed the PACQLQ. On average, children in the study had 7 symptomatic days per month. On entry, mothers ≤ 30 yrs had worse scores than those > 30 ($p < 0.02$), and mothers in less affluent socioeconomic groups had worse scores than those in higher groups ($p = 0.05$). Change in symptom scores and symptom free days between entry and follow-up was associated with change in PACQLQ

scores ($r = 0.54-0.57$, $p < 0.001$). Thirty-three parents had absolute change in PACQLQ of < 0.5 over three months (which has been previously defined as not being clinically significant). Compared to parents with higher PACQLQ change, parents with PACQLQ scores < 0.5 , did not differ in frequency of child symptoms or in social-demographic factors, but had better quality of life scores on entry to the study ($p < 0.01$). It is concluded that the Paediatric Asthma Caregiver's Quality of Life Questionnaire is sensitive to group measures of child symptom change over 3 months, among preschool children, and this supports its use as an outcome measure in clinical trials. The absolute impact of child symptoms on parent quality of life varies among parents.

Language: English

Keywords: Asthma / Pre-school children / Parents / Quality of life / Questionnaires

Quittner AL, Sweeny S, Watrous M, Munzenberger P, Bearss K, Gibson Nitza A, Fisher LA, Henry B. Translation and linguistic validation of a disease-specific quality of life measure for cystic fibrosis. *Journal of Pediatric Psychology*, 2000; 25(6): p.403-414
NIVEL: C 8593

OBJECTIVE: To develop and validate an English version of a French disease-specific measure of quality of life for children, adolescents, and adults with cystic fibrosis (CF). **METHODS:** Following a backward and forward translation of the measure, 60 participants, including 20 children, 20 parents, and 20 adolescents/young adults completed the Cystic Fibrosis Questionnaire (CFQ) and a series of cognitive probes evaluating their understanding of the items and response choices. **RESULTS:** Semantic and conceptual problems with the items were identified and modified for the second set of cognitive interviews. Response distributions across items and ages were adequate, and the predicted associations between disease severity and quality of life were obtained. **CONCLUSIONS:** The English version of the CFQ appears to be a linguistically valid measure of quality of life for patients with CF. A national validation study is now under way to test the psychometric properties of the measure.

Language: English

Keywords: Cystic fibrosis / Quality of life / Questionnaires

Rich M, Lamola S, Gordon J, Chalfen R. Video intervention/prevention assessment: a patient-centered methodology for understanding the adolescent illness experience. *Journal of Adolescent Health*, 2000; 27(3): p.155-165
NIVEL: C 8582

OBJECTIVE: To develop and test the applications of the Video Intervention/Prevention Assessment (VIA), a mixture of video technology and qualitative research methods, to assess the needs of adolescents with chronic illnesses. **METHODS:** In this assessment method adolescents with chronic diseases are interviewed for condition-specific verbal reports (CSVRs) of their medical and psychosocial histories. Standardised health-related quality of life (HRQL) instruments are administered. Trained to use video camcorders, participants record visual narratives of their illness experiences. They document their daily lives, interview families and friends, and record personal monologues regarding their observations, behaviours, understandings, and beliefs about their disease. On completion of the visual narratives, HRQL is again evaluated. Verbal, scaled, and visual data are analysed from three perspectives: medical, psychosocial, and anthropological. Data from the CSVRs, HRQLs, and visual narratives are triangulated to validate and enrich findings. Investigating the illness experience from the adolescent patient's perspective, the VIA method was pilot-tested with children and adolescents with asthma. **RESULTS:** As a research tool, VIA found environmental risk factors, medication adherence problems, and outcome-affecting illness beliefs and psychological states that were not identified by standard clinical tools. As an intervention, VIA showed that it may be an effective tool for health-related environmental surveys. Participants' condition-specific quality of life showed measurable improvement after the self-examination process of VIA. As communication, VIA made apparently counterproductive patient behaviours understandable by showing them in context with the adolescent's experience of illness and health care. VIA can enhance medical history-taking and management strategies, improve adolescents' self-management skills, and educate clinicians, families, and students of the health care professions about the realities of the adolescent living with a chronic health condition.

Language: English

Keywords: Chronic diseases, general / Asthma / Adolescents / Quality of life / Sick role / Patient compliance / Assessment

Ronen GM, Rosenbaum P, Law M, Streiner DL. Health-related quality of life in childhood disorders: a modified focus group technique to involve children. *Quality of Life Research*, 2001; 10(1): p.71-79
NIVEL: C 8591

OBJECTIVE: To develop a child-centred qualitative research methodology to facilitate direct exploration of health-related quality of life (HRQL) issues and to identify the quality of life elements in pre-adolescent children with a chronic medical condition. **METHODS:** Purposeful stratified sampling of children, aged 6-12, who function in a regular school class, with active epilepsy who were assembled in small focus groups. The groups met in four phases and were led by moderators who probed preset open questions and activities. **RESULTS:** The study demonstrated that this modified focus groups process was a powerful exploratory experience eliciting meaningful and important issues in quality of life beyond what parents and health professionals expected, and helped identify HRQL elements in childhood epilepsy. **CONCLUSION:** Modified focus groups are appropriate and suitable to explore quality of life issues in pre-adolescent children with a chronic medical condition. The process is feasible and trustworthy.

Language: English

Keywords: Epilepsy / School-age children / Quality of life / Assessment

Rutishauser C, Sawyer SM, Bond L, Coffey C, Bowes G. Development and validation of the Adolescent Asthma Quality of Life Questionnaire (AAQOL). *European Respiratory Journal*, 2001; 17(1): p.52-58
NIVEL: C 8569

The purpose of this study was to develop and validate the "Adolescent Asthma Quality of Life Questionnaire (AAQOL)", which is specifically developed for adolescents with asthma. One-hundred and eleven adolescents with frequent-episodic or persistent asthma aged 12-17 years were recruited from three tertiary paediatric asthma clinics. The standardised multi-step method consisted of: 1) item selection including semistructured interviews (n=14); 2) item reduction and validation (n=66); and 3) assessment of reproducibility (n=31). Item reduction was performed applying the clinical impact method. The 32 item AAQOL covers six domains: symptoms, medication, physical activities, emotion, social interaction and positive effects. There was high internal consistency for the six domains ($\alpha=0.70-0.90$) and for the total score ($\alpha=0.93$). Test-retest reliability was high for all domain scores ($r=0.76-0.85$) and the total score ($r=0.90$), indicating high

reproducibility of the AAQOL. There was high correlation with the paediatric Asthma Quality of Life Questionnaire ($\rho=0.81$) which focuses primarily on symptoms and emotional well-being. There was weak to moderate correlation with clinical parameters of asthma severity ($\rho=0.25-0.65$). The 32-item Adolescent Asthma Quality of Life Questionnaire is a valid, developmentally age-appropriate and dimensionally comprehensive asthma-specific quality of life measure for use in adolescents.

Language: English

Keywords: Asthma / Adolescents / Quality of life / Activities of daily living / Questionnaires

Schneider JW, Gurucharri LM, Gutierrez AL, Gaebler-Spira DJ. Health-related quality of life and functional outcome measures for children with cerebral palsy. *Developmental Medicine & Child Neurology*, 2001; 43(9): p.601-608
NIVEL: C 8566

The aim of this study was to examine and to compare different measures of health-related quality of life (HRQL) in children with cerebral palsy (CP). The scores of a generic HRQL measure, the Child Health Questionnaire (CHQ), a disease-specific HRQL measure for children with CP, the Caregiver Questionnaire (CQ), and a paediatric functional measure, the Wee-Functional Independence Measure (WeeFIM) were compared. Participants included 30 caregivers of children with CP. The caregivers' children were a mean age of 8 years 6 months (17 females, 13 males). The ethnic origin of the children was 18 African-American, 8 white, 3 Hispanic, and 1 Middle Eastern. Significant correlations were found between the CQ and WeeFIM total and subscale scores ($r=0.388$ to 0.641). There was no correlation between the CHQ and CQ total summary scores, but significant correlations were found between the CHQ subscales related to parent time and family cohesion and the CQ total and subscale scores ($r=0.386$ to 0.481). The lack of correlation between the CHQ and WeeFIM indicates HRQL and function are different constructs that cannot be inferred from each other. The fair relationship found between the CQ and WeeFIM suggests that the constructs measured in these two assessments overlap. The lack of correlation between the total summary scores of the CHQ and CQ suggests the CQ may be a more specific measure of HRQL for this population that reflects the impact of the child's condition on the caregiver.

Language: English

Keywords: Cerebral palsy / Quality of life / Parents / Psychological stress / Activities of daily living / Questionnaires

Sherman EM, Slick DJ, Connolly MB, Steinbok P, Camfield C, Eyril KL, Massey C, Farrell K. Validity of three measures of health-related quality of life in children with intractable epilepsy. *Epilepsia*, 2002; 43(10): p.1230-1238
NIVEL: C 8602

OBJECTIVE: To assess the validity of three parent-rated measures of health-related quality of life (HRQOL) in paediatric epilepsy: (a) the Impact of Childhood Illness Scale (ICI), (b) the Impact of Child Neurologic Handicap Scale (ICNH), and (c) the Hague Restrictions in Epilepsy Scale (HARCES). **METHODS:** Retrospective data were examined for 44 children with intractable epilepsy. Validity was assessed by evaluating differences across epilepsy severity groups as well as correlations between HRQOL scales and neurologic variables (seizure severity, epilepsy duration, current/prior antiepileptic medications) and psychosocial measures (emotional functioning, IQ, social skills, adaptive behaviour). Scale overlap with a global QOL rating also was assessed. **RESULTS:** The HRQOL measures were moderately to highly intercorrelated. The scales differed in terms of their associations with criterion measures. The HARCES was related to the highest number of neurologic variables and the ICNH to the fewest. All three scales were related to psychosocial functioning and to global quality of life. **CONCLUSIONS:** The results of this study suggest that the three measures are likely adequate measures of HRQOL for use in intractable childhood epilepsy. The measures were highly intercorrelated, and they were all broadly related to criterion measures reflecting specific domains of HRQOL as well as global QOL. Some differences between scales emerged, however, that suggest care in choosing HRQOL instruments for children with epilepsy.

Language: English

Keywords: Epilepsy / Quality of life / Social adjustment / Questionnaires

Tauler E, Vilagut G, Grau G, Gonzalez A, Sanchez E, Figueras G, Vall O, Ferrer M, Alonso J. The Spanish version of the Paediatric Asthma Quality of Life Questionnaire (PAQLQ): metric characteristics and equivalence with the original version. *Quality of Life Research*, 2001; 10 (1): p.81-91

NIVEL: C 8590

OBJECTIVE: To develop an equivalent Spanish version of the Paediatric Asthma Quality of Life Questionnaire (PAQLQ), and to assess its measurement characteristics. **METHODS:** The forward and back-translation method was used for the adaptation. A longitudinal study (assessments at the 1st and 5th weeks), with patients from the emergency and outpatient departments of three Spanish hospitals, was designed to test the properties of the new adapted version. At each visit, a trained interviewer administered the PAQLQ, a Global Index of Change and a General Health Perception scale. The Peak Expiratory Flow Rate (PEFR) was also recorded daily, together with symptoms, during the prior week. **RESULTS:** Ninety-nine patients (66.7% males, 42.4% suffering an exacerbation, mean age of 11.3 years) with the following types of asthma were evaluated: mild intermittent (31.3%), mild persistent (36.4%), moderate persistent (29.3%) and severe persistent (3%). At the 1st visit, the mean pre-bronchodilator %PEFR was 87.3%. The Cronbach's alpha ranged from 0.86 to 0.95. As expected, correlations between the PAQLQ scores, and the Asthma Control Score (0.53-0.67), the General Health Perception (0.34-0.55), and the %PEFR (0.44-0.55) were moderate. The PAQLQ scores remained unchanged in stable patients while increased significantly in those showing improvements. **CONCLUSIONS:** After a standard cross-cultural adaptation process, the Spanish version of the PAQLQ has shown to be equivalent to the original, with similar internal consistency reliability, validity and sensitivity to clinical changes.

Language: English

Keywords: Asthma / Quality of life / Questionnaires

Varni JW, Seid M, Knight TS, Uzark K, Szer IS. The PedsQL 4.0 Generic Core Scales: sensitivity, responsiveness, and impact on clinical decision-making. *Journal of Behavioral Medicine*, 2002; 25(2): p.175-193
NIVEL: C 8595

This article describes the results of 3 studies aimed at examining the validity of the PedsQL 4.0 (Pediatric Quality of Life Inventory) Generic Core Scales in paediatric patients with diverse acute or chronic health conditions. The PedsQL 4.0 Generic Core Scales consist of 23 items applicable for healthy school and community populations and paediatric populations with acute and chronic health conditions. The 4 PedsQL 4.0 Generic Core Scales (Physical, Emotional, Social, School) were administered to 209 children and 269

parents (289 subjects accrued overall) recruited from paediatric cardiology, orthopaedics, and rheumatology clinics. Sensitivity, responsiveness, and the impact on clinical decision-making were determined. The PedsQL was differentially sensitive to increasing degrees of cardiac disease severity in the cardiology clinic setting and responsive to clinical change over time in the paediatric orthopaedics clinic setting. In the paediatric rheumatology clinic setting, the PedsQL demonstrated an impact on clinical decision-making, resulting in subsequent increases in HRQOL.

Language: English

Keywords: Chronic diseases, general / Quality of life / Questionnaires

Verrips GH, Vogels AG, Ouden AL den, Paneth N, Verloove-Vanhorick SP. Measuring health-related quality of life in adolescents: agreement between raters and between methods of administration. *Child: Care, Health and Development*, 2000; 26(6): p.457-469
NIVEL: C 8565

The aim of this study was to determine inter-rater agreement between parents and adolescents in assessing Health-Related Quality of Life (HRQoL) using the TNO AZL Children's Quality Of Life (TACQOL) questionnaire. A second aim was to determine intermethod agreement comparing mailed questionnaires with telephone interviews and face-to-face interviews. A random sample from a Dutch cohort of 14-year-old very low birth weight children and their parents were invited to participate in a face-to-face (n = 150) or telephone interview (n = 150). Participants were also sent a questionnaire by mail. The response rate was 83%. Inter-rater and intermethod agreement were generally good in observable HRQoL domains, and moderate in less readily observable, and possibly less stable, domains such as moods, pain and physical symptoms, and social functioning. In measuring children's HRQoL using the TACQOL, the results and their interpretation are dependent on the source of information and the method of administration.

Language: English

Keywords: Chronic diseases, general / Adolescents / Quality of life / Questionnaires

Vitale MG, Levy DE, Moskowitz AJ, Gelijns AC, Spellmann M, Verdisco L, Roye DP Jr. Capturing quality of life in pediatric

orthopaedics: two recent measures compared. *Journal of Pediatric Orthopaedics*, 2001; 21(5): p.629-635
NIVEL: C 8563

The aim of this study was to evaluate and compare 2 standardised measures to assess the health status and needs of children with orthopaedic problems. The Child Health Questionnaire and the American Academy of Orthopaedic Surgeons Pediatric Outcomes Data Collection Instrument, two new paediatric health status measures, were assessed for their ability to detect differences in health states in a paediatric orthopaedic population. The instruments have a range of scales designed to measure various aspects of physical and psychosocial health. Two hundred forty-two patients with wide-ranging diagnoses were enrolled in this cross-sectional study. The instruments exhibited ceiling effects in some domains but generally performed as they were intended in this large cohort. Using secondary factor analysis, it was shown that the domains of the instruments appropriately distinguish physical and psychosocial health. Several domains from each instrument discriminated between diagnosis groups and patients with varying numbers of comorbidities. Both of these measures show significant promise and have an important role in helping define the outcomes of children with orthopaedic problems.

Language: English

Keywords: Musculoskeletal diseases / Health status / Quality of life / Activities of daily living / Questionnaires

Wenninger K, Aussage P, Wahn U, Staab D, German Cystic Fibrosis Questionnaire study group. The revised German Cystic Fibrosis Questionnaire: validation of a disease-specific health-related quality of life instrument. *Quality of Life Research*, 2003; 12(1): p.77-85
NIVEL: C 8596

OBJECTIVE: To validate the German adaptation of the Cystic Fibrosis Questionnaire (CFQ), a disease-specific health related quality of life (HRQOL) instrument for patients with cystic fibrosis (CF) developed in France. **METHODS:** On the basis of results from a first dataset (n = 197 CF adolescent and adult patients), revisions were made and retested in a second sample of 103 patients. **RESULTS:** The final revised version showed good construct validity. The same nine HRQOL domains as in the French original CFQ-14+ emerged from the analyses as structurally robust scales. The internal consistencies of the HRQOL scales ranged from 0.71 to 0.94. The

instrument's clinical validity was supported by severely ill patients reporting lower HRQOL than less severely ill patients on most scales.

CONCLUSIONS: It is concluded that the evidence supports the validity and reliability of the instrument. An important future area of application is the use in comparative multi-center international studies.

Language: English

Keywords: Cystic fibrosis / Quality of life / Questionnaires

2 Social Participation

2.1 Social participation from the patient's perspective

Al-Dawood KM. Schoolboys with bronchial asthma in Al-Khobar City, Saudi Arabia: are they at increased risk of school absenteeism? *Journal of Asthma*, 2002; 39(5): p.413-420
NIVEL: C 8457

The aim of this study was to determine the mean period of school absenteeism (MPSA) among asthmatic Saudi schoolboys of Al-Khobar City and to determine the factors associated with the absenteeism. A cross-sectional study was conducted, in which a self-administered questionnaire was distributed, which was completed by the parents of 1482 schoolboys who satisfied the selection criteria of the study. The prevalence rate of questionnaire-diagnosed asthma (QDA) was 9.5% (141/1482). The MPSA among questionnaire-diagnosed asthmatic boys (QDAs) was 13.6 +/- 3.4 days compared to 3.7 +/- 2.2 days among non questionnaire-diagnosed asthmatic boys (non QDAs). Among QDAs, the MPSA was associated significantly and positively with those who were younger, and with decreasing levels of socioeconomic class, histories of pets at home, presence of a currently smoking family member (father or both parents), visit to a hospital emergency room, and admission to hospital. It was significantly and negatively associated with concomitant use of prophylactic medication(s), including those used appropriately. The QDAs from middle and lower socioeconomic classes showed less use of prophylactic medication(s) but more histories of visits to an emergency room and of admissions to hospital. The multiple linear regression equation for the total period of school absenteeism (TPSA) during the 1995 academic year was generated. Asthmatic school children have a higher MPSA compared to their non asthmatic classmates. The risk of suffering the impacts of this disease is

shown to be particularly increased among QDAs belonging to less socioeconomically advantaged families.

Language: English

Keywords: Asthma / School absenteeism / Socioeconomic factors

Alderfer MA, Wiebe DJ, Hartmann DP. Social behaviour and illness information interact to influence the peer acceptance of children with chronic illness. *British Journal of Health Psychology*, 2001; 6: p.243-255
NIVEL: C 8536

The aim of this study was to examine the contribution of social behaviour to the peer acceptance of children with chronic illness. It was predicted that children with illness would receive less acceptance than children without illness, and that prosocial behaviour would improve acceptance, while aggressive behaviour would hamper it. Based upon attribution and cognitive bias theories, the authors also predicted that prosocial behaviour would be more beneficial and aggressive behaviour less damaging to the acceptance of children with illness compared to healthy children. Hundred and forty-nine preadolescents (aged 11-13 yrs) indicated social acceptance of hypothetical children portrayed in vignettes as either chronically ill or healthy with prosocial, aggressive, or no social behaviour. A 13-item social intentions scale gauged acceptance. Results show that the hypotheses were supported. Although children described as ill received lower acceptance ratings than healthy children, prosocial/ill children were more accepted than aggressive/ill children. Social behaviour interacted with physical status to affect acceptance. The potential processes by which peers judge acceptance of children with illness are discussed.

Language: English

Keywords: Chronic diseases, general / Social adjustment / Behaviour problems / Peer relations

Anderson CJ, Vogel LC. Work experience in adolescents with spinal cord injuries. *Developmental Medicine & Child Neurology*, 2000; 42(8): p.515-517
NIVEL: C 8419

The purpose of this study was to get insight into the work experiences of adolescents with spinal cord injuries (SCI) compared to peers without disabilities. This could be a way to identify those who are less well prepared

for employment than their peers, in order to make efforts to alleviate the differences. Twenty-eight adolescents with SCI and 25 age-matched individuals without disabilities (controls) took part in the study. A structured telephone questionnaire was used to assess their experience of household chores, volunteer jobs, and paid work. The mean age at interview was 16.2 years for those with SCI and 16.0 years for control participants. There was no significant difference between the individuals with SCI and the control participants in chores or volunteer work experiences, but the individuals with SCI were significantly less likely to have paid work experience than control participants ($\chi^2 = 13.670$, $p < 0.001$). Of the older adolescents, aged >15 to 19 years, five of 15 individuals with SCI and 16 of 16 control participants had paid work (Fisher exact test $p < 0.001$). Of individuals with SCI, those with milder injuries and those injured at a younger age were more likely to have work experience.

Language: English

Keywords: Paralysis / Adolescents / Employment / Activities of daily living

Beckung E, Hagberg G. Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 2002; 44(5): p.309-316
NIVEL: C 8420

This study focused on children with cerebral palsy. In a representative series of 176 children, aged 5 to 8 years, associations were studied between additional neuroimpairments, activity limitations, and participation restrictions in the domains of mobility, education, and social relations as proposed in the International Classification of Functioning Disability and Health (ICF). Learning disability occurred in 40%, epilepsy in 35%, visual impairment in 20%, and infantile hydrocephalus in 9% of the children. Additional neuroimpairments were most frequently seen in children with tetraplegia and dystonic CP and in those with antecedents of brain malformations or severe perinatal compromise. Activity limitations were studied with the Gross Motor Function Classification System (GMFCS) and a system for grading bimanual fine motor function (BFMF) was developed. There was a strong correlation of 0.74 between the GMFCS and BFMF ($p < 0.001$). Learning disability, activity limitations, and participation restrictions were all clinically strongly associated with each other ($p < 0.001$). Restriction in mobility was best predicted by the GMFCS, learning disability, and the BFMF; in education by learning disability and the GMFCS; and in social relations by learning disability, the GMFCS, and

BFMF. Motor function and learning disability were important predictors for participation restrictions in children with CP. The ICF has the capacity to be a model to help plan interventions for specific functional goals and to ascertain the child's participation in society.

Language: English

Keywords: Cerebral palsy / Comorbidity / Activities of daily living / Academic achievement / Motor skills / Learning problems / Social support

Boer J de, Claessens M. *Kinderen en jongeren met een chronische ziekte: een onderzoek naar knelpunten in zorg en maatschappelijke participatie. (Chronically ill children and adolescents: bottlenecks in health care services and social participation.)* Utrecht: CG-Raad, 2001
NIVEL: R 10407

The aim of this study was to get insight into the problems experienced by chronically ill children and adolescents and their parents, with respect to health care services and social participation. Focus group interviews were held with 5 groups; children, adolescents and parents of children of different age-groups. Problems with respect to family burden, peer relations, regular education, leisure activities, information supply and continuity of care were reported by many participants. Recommendations are given to improve quality of care, information supply and support services for regular and special education.

Language: English

Keywords: Chronic diseases, general / Patient satisfaction / Psychosocial problems / School / Leisure / Peer relations / Quality of care

Brodin J, Fasth A. *Habilitation, support and service for young people with motor disabilities: a Swedish perspective. International Journal of Rehabilitation Research*, 2001; 24(4): p.309-316
NIVEL: C 8426

'Full participation in society' and 'equal opportunities' are key concepts in Scandinavian habilitation and rehabilitation policy. This study aimed at getting insight into the life situation, e.g. activities of daily living, support needs and social participation, of adolescents with motor disabilities. This study was based on a questionnaire answered by 477 young persons aged between 16 and 25 years, primarily with motor disabilities. The results show that they have fewer opportunities than young people in general to

participate in social life. A conclusion is that improvements need to be made regarding the quality and quantity of habilitation support.

Language: English

Keywords: Cerebral palsy / Spina bifida / Motor disorders / Adolescents / Activities of daily living / Social support / Needs assessment

Caldwell LL, Finkelstein JW, Demers B. Exploring the leisure behavior patterns and experiences of youth with endocrinological disorders: implications for therapeutic recreation. *Therapeutic Recreation Journal*, 2001; 35(3): p.236-249
NIVEL: C 8362

The purpose of this study was to determine whether therapeutic recreation intervention is necessary in the lives of adolescents with endocrinological disorders such as short stature (SS), delayed puberty (DP), and diabetes mellitus (DM), by examining their leisure behaviour patterns and experiences. All adolescents in the study were diagnosed with an endocrinological problem. Of the 178 adolescents (aged 11-19 yrs old) who agreed to participate in the study, 83 were male and 91 were female. It was found that the leisure behaviours and experiences of adolescents with SS, DP, and DM were similar to those of a clinical comparison group. Recency of the discovery of the problem was related to increased parental control and this parental control was greater for those diagnosed with SS/DP and DM. These findings are discussed in relationship to recent studies on youth with endocrinological disorders and make recommendations for therapeutic recreation.

Language: English

Keywords: Dwarfism / Diabetes mellitus / Leisure

Calsbeek H, Rijken M, Bekkers MJ, Kerssens JJ, Dekker J, Berge Henegouwen GP van. Social position of adolescents with chronic digestive disorders. *European Journal of Gastroenterology & Hepatology*, 2002; 14(5): p.543-549
NIVEL: C 8611

OBJECTIVE : To examine the social position of adolescents with a chronic digestive disorder. METHODS : Five diagnostic groups, including inflammatory bowel disease (IBD), chronic liver diseases, congenital digestive disorders, coeliac disease and food allergy (total n = 758, aged 12-

25 years), were each compared with a population-based control group in a multicentre study using a cross-sectional design. Social position was assessed by a mailed questionnaire measuring 24 aspects, categorised as education, leisure activities, friendship, labour participation, financial situation, partnership and sexuality. RESULTS : Eight aspects of social position were found to be affected negatively by one or more chronic digestive diseases: absence from school due to illness, going out, having a paid job, needing re-education in order to get a job, getting benefits as main income source, encountering bottlenecks in establishing financial commitments, having self-confidence in making a pass at someone, and restrictions in making love. Adolescents with chronic liver disease and IBD were found to experience more restrictions in social position. Adolescents with food allergy and congenital digestive disorders appear to experience some restrictions, but to a lesser degree, and adolescents with coeliac disease do not appear to have any problems regarding social position compared with controls. CONCLUSIONS : The social position of adolescents is affected negatively by having a chronic digestive disease, in particular chronic liver disease and IBD. Negative consequences occur in education, leisure activities, labour participation, financial situation, partnership and sexuality.

Language: English

Keywords: Inflammatory bowel disease / Liver disease / Congenital digestive disorders / Coeliac disease / Food allergy / School absenteeism / Peer relations / Employment / Leisure

Diette GB, Markson L, Skinner EA, Nguyen TT, Algatt-Bergstrom P, Wu AW. Nocturnal asthma in children affects school attendance, school performance, and parents' work attendance. *Archives of Pediatrics & Adolescent Medicine*, 2000; 154(9): p.923-928
NIVEL: C 8483

OBJECTIVE: There are few studies of the impact of nocturnal awakening from asthma on children with the disease, including problems with daytime functioning. This study was conducted to determine whether nocturnal awakenings from asthma have an effect on school absenteeism and school performance in children and work absenteeism in their parents. METHODS: Cross-sectional survey was conducted in three managed care organisations in the United States. Participants were parents of 438 children with asthma, aged 5 to 17 years, who were enrolled in managed care organizations.. Main outcome measures were: parent's reports of number of days their child missed school and parent missed work and how often the child's education

suffered because of asthma in the past 4 weeks. RESULTS: Overall, more than 40% of children had nocturnal awakenings from asthma in the past 4 weeks. Multivariate analyses were performed that adjusted for child age, race, overall symptom severity, and use of reliever medications. Compared with children who did not awaken from asthma, there were greater odds of missed school days in children who awakened 1 to 3 nights (odds ratio [OR], 3.6; 95% confidence interval [CI], 2.1-6.2), 4 to 7 nights (OR, 4.4; 95% CI, 2.0-10.0), and more than 7 nights (OR, 14.7; 95% CI, 5.9-37.0). Similarly, there were greater odds of education suffering in children who awakened 1 to 3 nights (OR, 2.3; 95% CI, 1.4-3.7), 4 to 7 nights (OR, 2.1; 95% CI, 0.9-4.6), and more than 7 nights (OR, 2.3; 95% CI, 1.0-5.4), and parents missing work in children who awakened 1 to 3 nights (OR, 4.0; 95% CI, 2.2-7.1), 4 to 7 nights (OR, 6.5; 95% CI, 2.7-16), and more than 7 nights (OR, 3.2; 95% CI, 1.3-7.9). Greater overall symptom severity and high use of reliever medication were also associated with missed school, education suffering, and parent absenteeism. CONCLUSIONS: Nighttime awakenings in children with asthma may affect school attendance and performance, as well as work attendance by parents. Nighttime symptoms have independent prognostic value, even when overall asthma symptom severity is accounted for. By addressing whether there are nighttime awakenings in children with asthma, clinicians may be able to tailor the therapeutic regimen to counter these symptoms.

Language: English

Keywords: Asthma / Academic achievement / School absenteeism / Parents / Employment

Duijn NP van, Brouwer HJ, Gooskens RHJM. Kinderen met hoofdpijn: een onderschat probleem. (Children with headache: an underestimated problem.) *Medisch Contact*, 2000; 55(26): p.971-974

The aim of this study was to get insight into the problems of children with headache in their daily life. A representative sample of 2691 parents was asked whether they had children between 6-16 years of age who suffer from headache. This happened to be the case in 46 % of the children, of whom 9 % suffered frequently and severely, with consequences for their daily life activities, like school absenteeism and withdrawal from sportive and recreational activities.

Language: Dutch

Keywords: Headache / Migraine / Activities of daily living / School absenteeism

Fekkes M, Kamphuis RP, Ottenkamp J, Verrips E, Vogels T, Kamphuis M, Verloove-Vanhorick SP. Health-related quality of life in young adults with minor congenital heart disease. *Psychology and Health*, 2001; 16(2): p.239-250

The aims of this study were to investigate the social impediments experienced by young adults with minor congenital heart disease (CHD) and to compare the health status and health-related quality of life of these CHD-patients with a matched group (age, sex) from the general population. Young adults with minor CHD, not in need of surgical correction, were sent a questionnaire. Results showed that a substantial part of the CHD-patients experienced social impediments, i.e. at school (19%), during free time (15%), in choosing (13%) or performing a job (9%), with medical examinations for job/insurance (19%), and taking out a life insurance policy (8%). Those CHD-patients that experienced social impediments reported a health status and health-related quality of life comparable with the general population. Remarkably, CHD-patients without social impediments reported a better health-related quality of life for 6 of the 12 scales, when compared with the general population. This last result might be explained by coping mechanisms resulting in a higher appreciation of health status which is expressed in a higher health related quality of life.

Language: English

Keywords: Congenital heart defects / Young adults / Quality of life / Social participation / Vocational education / Employment

Fotland H. Childhood cancer and the interplay between illness, self-evaluation and academic experiences. *Scandinavian Journal of Educational Research*, 2000; 44(3): p.253-273
NIVEL: C 8359

The objective of this retrospective study was to investigate how cancer and its treatment affect children's academic development, academic self-concept, and self esteem. Eight children (aged 11-19 years) whose treatment for various cancers had been completed 1-2+ years previously and their parents, teachers, and health personnel completed interviews. The children's interviews focused on their academic experiences in hospital and local schools from the time when they fell ill. Results indicate that pupils with cancer clearly valued their own academic ability, that they strove to master academic requirements in spite of the illness-related restrictions, that school proved to be an important self-concept area for the children, and that their

self esteem was greatly influenced by their evaluation of their own academic status. It is concluded that the academic experiences of children with cancer have a major impact on the development of their self esteem.

Language: English

Keywords: Cancer / School / Academic achievement / Self esteem

Gabe J, Bury M, Ramsay R. Living with asthma: the experiences of young people at home and at school. *Social Science & Medicine*, 2002; 55(9): p.1619-1633

The aim of this study was to discover the meaning of asthma to adolescents with moderate to severe symptoms and the ways in which they employ coping strategies in everyday life at school and within the family. Based on in-depth interviews with 55 young people aged 11-16 living in West London, it shows that asthma restricted their lives at school and recreationally but that they were actively involved with their condition and its management. The study reveals that while prescribed medicines in the form of inhalers were used as the primary means of coping with asthma episodes, the young people were concerned about being dependent on such medicines, in line with more general ambivalence in late modern cultures about the long term use of prescribed medicines. It also demonstrates how social relations in particular contexts help to determine the extent to which asthma episodes can be managed.

Language: English

Keywords: Asthma / Adolescents / Sick role / Coping / School / Leisure / Quality of life

Gledhill J, Rangel L, Garralda E. Surviving chronic physical illness: psychosocial outcome in adult life. *Archives of Disease in Childhood*, 2000; 83(2): p.104-110
NIVEL: C 8473

This article reviews the literature about the psychosocial outcome of adult survivors of chronic physical illness, focusing on some of the more severe chronic disorders. Psychosocial outcome is divided into psychiatric and social outcome. Psychiatric morbidity deals with psychological symptoms or psychopathology. Another psychological marker is (low) self esteem. The measures of social outcome include educational attainment, occupational status, marital status, social relations and place of residence. Psychiatric

outcome is not severe in the majority of adult survivors. The evidence regarding social outcome suggests that there is mild impairment when compared to the general population. Recommendations for further research are given.

Language: English

Keywords: Chronic diseases, general / Young adults / Survivors / Academic achievement / Employment / Marital status / Mental disorders

Gray D, Parker-Cohen NY, White T, Clark ST, Seiner SH, Achilles J, McMahon WM. A comparison of individual and family psychology of adolescents with chronic fatigue syndrome, rheumatoid arthritis, and mood disorders. *Developmental and Behavioral Pediatrics*, 2001; 22(4): p.234-242
NIVEL: C 8406

The aim of this study was to get insight into the psychosocial problems and possible psychiatric comorbidity in adolescents with chronic fatigue syndrome (CFS) and to compare them with adolescents with rheumatoid arthritis and with mood disorders. Three groups of paediatric patients were selected by diagnosis-(1) CFS (n = 15), (2) juvenile rheumatoid arthritis (n = 15), and (3) mood disorders (n = 15)-across many psychological measures. CFS subjects had dramatic elevation of the Somatic Complaints subscale (mean T score = 75), whereas the mood disorders group had higher externalising scores (mean T score = 68) on the Child Behavior Checklist. The CFS subjects missed significantly more school compared with the two control groups. After the onset of CFS, 13 of 15 of the CFS patients required significant educational accommodation. Only 4 of the 15 CFS patients had an Axis I psychiatric diagnosis, as determined by the Computerized Diagnostic Interview for Children. Despite a low rate of psychiatric diagnosis in the CFS sample, these data attest to their psychosocial and school dysfunction.

Language: English

Keywords: Chronic fatigue syndrome / Rheumatoid arthritis / Mood disorders / Adolescents / Mental disorders / Psychosocial problems / School

Huberty TJ, Austin JK, Huster GA, Dunn DW. Relations of change in condition severity and school self-concept to change achievement-related behavior in children with asthma or epilepsy. *Journal of School Psychology*, 2000; 38(3): p.259-276

NIVEL: C 8360

The aim of this study was to examine the influence of gender, change in condition severity, and change in school self-concept on changes in academic-related behaviour in children with either asthma or epilepsy. Hundred-and-ten children with asthma and 117 children with epilepsy (all aged 8-12 years) were assessed at 2 times, 4 years apart, with the Adaptive Functioning section of the Teacher Report Form of the Child Behavior Checklist and the School Self-Concept subscale of the Piers-Harris Self-Concept Scale for Children. Overall, children with asthma improved more than the children with epilepsy. Change in condition severity was significantly related to Academic Performance for children with epilepsy, with those having high severity at both times doing less well. For the children with asthma, change in condition severity was related to changes in Academic Performance, Happy, Learning, and Total Adaptive Functioning. School Self-Concept was related to changes in Working Hard, Happy, Behaving Appropriately, Learning, and Total Adaptive Functioning only for children with epilepsy. With the exception of children with high-severity epilepsy over time, the majority of the children were near the population mean in achievement-related behaviour at follow-up.

Language: English

Keywords: Asthma / Epilepsy / Academic achievement / School / Social adjustment / Self esteem

Hutzler Y, Fliess O, Chacham A, Auweele Y van den. Perspectives of children with physical disabilities on inclusion and empowerment: supporting and limiting factors. *Adapted Physical Activity Quarterly*, 2002; 19(3): p.300-317

NIVEL: C 8333

The purposes of this study were to examine the personal experiences of children with physical disabilities in physical education (PE) and identifying supporting and limiting mechanisms to their inclusion and empowerment. A computerised analysis of individual profiles was performed based on in-depth interviews with 8 females and 2 males (aged 9-15 years), who were included in regular PE classes. Disabilities of subjects (Ss) were spastic diplegia (4 Ss), spastic hemiplegia (4 Ss), spinal motor atrophy (1 S), and limb-girdle muscular dystrophy (1 S). Two individual profiles served as examples for situations faced during inclusive settings and typical reaction patterns. A comparative qualitative analysis of interview themes generated 5

main categories of themes: assistive devices, physical activity, peers, important adults, and self. Experiences during physical activity were identified as supporting or limiting empowerment within each category, based on selected criteria. An almost equal distribution of supporting and limiting factors was observed.

Language: English

Keywords: Paralysis / Activities of daily living / Autonomy

Huurte T, Aro H. The psychosocial well-being of Finnish adolescents with visual impairments versus those with chronic conditions and those with no disabilities. *Journal of Visual Impairment & Blindness*, 2000; 94(10): p.625-637
NIVEL: C 8586

In previous research it was found that the psychosocial development and social support of adolescents with and without visual impairments did not differ. However, many adolescents with visual impairments report problems in their social relationships. The authors decided to investigate whether these results were specific to adolescents who are blind or to those with low vision. The psychosocial well-being of 115 adolescents with visual impairments was compared with that of 44 adolescents with chronic conditions and 607 adolescents with no disabilities. It was found that the adolescents with visual impairments, especially those who were blind, had more difficulties in their relationships with friends than did the other two groups, but had fewer problems with psychological well-being than did the adolescents with chronic conditions.

Language: English

Keywords: Vision disorders / Blindness / Adolescents / Quality of life / Peer relations

Jopla. *Vriendschap, relaties en seksualiteit: een literatuurstudie en onderzoek onder jongeren met een lichamelijke handicap en chronische ziekte. (Friendship, relationship and sexuality: a literature study and study on young people with physical handicaps and chronic illnesses.)* Utrecht : JOPLA, 2001
R 10357

The aim of this project was to get insight into the way adolescents and young adults with a chronic illness or physical disability form and maintain

friendships and sexual relations . The project consisted of a literature study and a pilot study. The results suggest that self concept is an important factor in the adolescent's ability to form and maintain relations. Moreover, attitudes towards illness and self concept are more important than illness severity.

Language: Dutch

Keywords: Chronic diseases, general / Adolescents / Young adults / Friendship / Peer relations

Kendall L, Lewin RJ, Parsons JM, Veldtman GR, Quirk J, Hardman GE. Factors associated with self-perceived state of health in adolescents with congenital cardiac disease attending paediatric cardiologic clinics. *Cardiology in the Young*, 2001; 11(4): p.431-438
NIVEL: C 8407

The purpose of this study was to determine the ways in which adolescents with congenital cardiac disease believed that the condition had affected their life, and how these views were related to their perceived health. Interviews were conducted with a series of 37 adolescents, 17 girls and 20 boys, aged from 11 to 18, as they attended the clinics of 4 paediatric cardiologists in a teaching hospital in the United Kingdom. Transcripts of the interviews were analysed for recurring themes. A questionnaire was formed consisting of a set of questions for each theme, and additional items eliciting "perceived health", and administered to a second series of 74 adolescents, 40 boys and 34 girls, who were again aged from 11 to 18 years. Slightly less than half (46%) perceived their health as either "good" or "very good", and one-third (33%) rated it as "average". The majority (66%) felt themselves to be "the same" as, or only very slightly "different" from, their peers. The assessment of the seriousness of their condition by the adolescents, the degree to which they saw themselves as different from others, and their perceived health, were not related to the "complexity of the underlying medical condition" as rated by their physician. It was the psychosocial themes, such as exclusion from activities or the effect of the condition on relationships, that were most strongly related to the perception of their health by the adolescents. Improved education of parents, teachers and peers, and attendance at classes for cardiac rehabilitation, might help to ameliorate some of these problems.

Language: English

Keywords: Congenital heart defects / Adolescents / Sick role / Psychosocial problems

Kort AC de, Rulkens MP, IJzerman MJ, Maathuis CG. The Come Back Programme: a rehabilitation programme for patients with brain injury with psychosocial problems despite previous rehabilitation. *International Journal of Rehabilitation Research*, 2002; 25(4): p.271-278
NIVEL: C 8465

In 1994 the Come Back Programme (CBP) started in a rehabilitation centre, Groot Klimmendaal, in Arnhem, The Netherlands. The CBP is a rehabilitation programme for (young) adults with brain injury (BI) having problems with their psychosocial functioning despite having undergone a rehabilitation programme previously. The main goal of the CBP is to regain maximal independence in psychosocial functioning. The objectives of this study were to assess problems young adults experience after brain injury, despite having undergone a rehabilitation programme previously, and whether the CBP can improve psychosocial functioning. The study was retrospective, through investigating medical records and via a structured questionnaire sent to patients who participated in the CBP between 1994 and 1998 (n = 25). Follow-up was at least 1 year after the CBP. There was an 80% response (n = 20). The mean age at BI was 22 years. The patients had severe BI (mean duration of coma 4.7 weeks) and 17 had traumatic BI. Prior to the CBP negative consequences were seen on independence of living, employability, relationships and contact with friends. Little to no effect was seen on contact with family and leisure activities. After the CBP, positive effects were found on employability and independence of living but not on premorbid levels. The effect on the other aspects were absent or not clear. Most patients wanted support at follow-up. The authors concluded that the CBP had a positive effect on independence of living and employability. A 'second' rehabilitation programme can be useful if psychosocial problems are present. Long-lasting support and structural control seem necessary and are recommended.

Language: English

Keywords: Acquired brain injury / Young adults / Psychosocial problems / Social adjustment / Activities of daily living / Employment / Rehabilitation

Kumagai T, Ito M, Yamazaki Y, Sekijima K, Sakakibara K, Matsutomo Y, Hijikigawa F, Yamada H. Long-term prognosis of patients with West syndrome in Japan: social aspects. *Brain & Development*, 2001; 23(7): p.695-697
NIVEL: C 8608

This study was aimed at getting insight into quality of life and social aspects of patients with West syndrome, during the course of their childhood until reaching young adulthood. Long-term social prognosis of 120 Japanese patients with West syndrome at the age of 25.4 years in average was surveyed using a structured questionnaire. The survey revealed that ADL score remained null in one-fifth of cases; the majority entered in special education course for disabled children; only eleven cases were employed as a full-time worker. As to QOL, 60% of cases were spending daily life with joy. In summary, social prognosis of West syndrome is generally gloomy, but a proportion of patients can lead an independent social life, and an enriched social environment is the most influential factor for better prognosis

Language: English

Keywords: West syndrome / Quality of life / Activities of daily living / Special education / Employment

Kupferberg S, Morris MK, Bakeman R. Spontaneous facial expressivity in children with acquired brain injury. *Journal of Head Trauma Rehabilitation*, 2001; 16(6): p.573-586
NIVEL: C 8610

OBJECTIVES: Children with acquired brain injury (ABI) often have difficulties in social interaction. Specific child behaviours, like facial expressivity, can have adverse social outcomes. Existing literature on facial expression in adults reflects that brain injured patients can have difficulties in facial expressivity. Because no comparable studies have been attempted in children, the aim of this study was to investigate spontaneous facial behaviour during social interaction and to explore possible links between ABI, facial expressivity, and caregiver-reported social competence.

METHODS: The design consisted of between-group comparisons using t tests, within-group comparisons using correlational analyses, correlational analyses of independent variables and outcome measures. Sixteen school-aged children with ABI and 32 normally developing children of comparable age and gender participated. Main outcome measure were aspects of facial expressivity derived from coding scheme designed for this study.

RESULTS: Children with ABI were less expressive overall and tended to shift expressions less often than normally developing children. Several measures of expressivity were correlated with measures of social competence. **CONCLUSIONS:** Brain injury inhibits production of some

aspects of spontaneous facial expression. Results are suggestive of links between facial behaviour and social skills.

Language: English

Keywords: Acquired brain injury / Social skills

Loveland KA, Stehbens JA, Mahoney EM, Sirois PA, Nichols S, Bordeaux JD, Watkins JM, Amodei N, Hill SD, Donfield S, the Hemophilia Growth and Development Study. Declining immune function in children and adolescents with hemophilia and HIV infection: effects on neuropsychological performance. *Journal of Pediatric Psychology*, 2000; 25(5): p.309-322

NIVEL: C 8469

OBJECTIVE: To get insight into the neuropsychological performance (IQ, verbal skills, psychomotor skills, memory and academic achievement) in children and adolescents with haemophilia who are infected with the human immunodeficiency virus (HIV). **METHODS:** Participants were 333 males with haemophilia, ages 6-19 years at entry. A baseline and four annual neuropsychological evaluations were given. A longitudinal growth curves analysis of data was performed to detect changes associated with declining immune function. The cohort was stratified into four groups: (1) HIV- (n = 126); (2) HIV+, average of first two and last two CD4 counts \geq 200, (n = 106; High CD4 group); (3) HIV+, average first two counts \geq 200, average last two counts $<$ 200 (n = 41; CD4 Drop group); and (4) HIV+, average first two and last two counts $<$ 200 (n = 60; Low CD4 group). **RESULTS:** There were significant differences among the four groups over time in nonverbal intelligence, perceptual/performance skills, nonverbal memory, academic achievement, and language. The Low CD4 group consistently showed the greatest decrement in performance. On measures showing a practice effect for repeated measurements, the Low CD4 group participants' scores remained stable over time, suggesting opposing effects of practice and HIV-related declines. Lowered academic performance relative to IQ was found in all groups. **CONCLUSIONS:** Declines in neuropsychological functioning are directly related to declines in immune functioning in HIV+ children, adolescents, and young adults with haemophilia. Haemophilia itself may be a risk factor for academic underachievement.

Language: English

Keywords: Haemophilia / Hiv / Cognition disorders / Intelligence / Motor skills / Educational achievement

McCauley E, Feuillan P, Kushner H, Ross JL. Psychosocial development in adolescents with Turner syndrome. *Developmental and Behavioral Pediatrics*, 2001; 22(6): p.360-365
NIVEL: C 8446

This study was aimed at examining the psychosocial adjustment of a sample of adolescent girls with Turner syndrome, a genetic condition in which part or all of the second X chromosome is missing. Subjects included 122 girls with a diagnosis of Turner syndrome (TS) and a control group of 108 girls with no genetic disorder or chronic illness. Subjects were 13 to 18 years of age. A battery of questionnaires assessing social, academic, school, and behavioural functioning was administered. TS girls were seen as having significantly more problems in terms of social relationships and school progress and were more likely to meet criteria for attention-deficit hyperactivity disorder than control girls. The TS girls were also rated by a parent as less socially competent (e.g., fewer friends, less time with friends) than the control group. Social difficulties appear to be an area of vulnerability for TS girls.

Language: English

Keywords: Turner syndrome / Adolescents / Educational achievement / Social adjustment / Personality development / Peer relations / Attention Deficit Hyperactivity Disorder

Meijer SA, Sinnema G, Bijstra JO, Mellenbergh GJ, Wolters WHG. Peer interaction in adolescents with a chronic illness. *Personality and Individual Differences*, 2000; 29(5): p.799-813
NIVEL: C 8612

The aims of this study were: (1) to describe peer interaction of adolescents with a chronic illness in comparison with norms of healthy adolescents; (2) to examine the relationship of peer interaction with the illness characteristics functional limitations and pain. Peer interaction of 98 adolescents with a chronic illness was assessed with measures of social activities (Child Behavior Check List), social self esteem (Dutch version of Self Perception Profile for Adolescents), self-reported social skills (Scale of Interpersonal Behaviour for Adolescents, SIG-A) and social anxiety. Results showed that diagnosis is related to social activities, but not to other aspects of peer interaction. Chronically ill girls had a lower level of social activities compared to healthy subjects. In addition, girls with cystic fibrosis displayed more assertive behaviour than healthy girls, while chronically ill boys displayed less inadequate social skills than healthy boys. Functional

limitations were not associated with peer interaction. However, pain was associated with restricted social activities in boys. It was concluded that in general, chronically ill adolescents were well adjusted socially and that functional limitations and pain do not seem to be risk factors for social adjustment problems.

Language: English

Keywords: Chronic diseases, general / Adolescents / Peer relations / Social skills / Social adjustment

Meijer SA, Sinnema G, Bijstra JO, Mellenbergh GJ, Wolters WH. Social functioning in children with a chronic illness. *Journal of Child Psychology and Psychiatry*, 2000; 41(3): p.309-317
NIVEL: C 8613

The aims of this study were: (1) to describe peer interaction of children with a chronic illness in comparison with normative data of healthy children; (2) to examine whether peer interaction was related to the illness characteristics physical restrictions and pain. A sample of 107 children with a chronic illness was involved in this study. Peer interaction was assessed with measures of social activities (CBCL), parent-reported social skills (CABS), child-reported social skills (MESSY), social self esteem (SPPC), and social anxiety (SASK). Results showed no differences between diagnosis groups, suggesting that the social consequences of chronic illness are not diagnosis specific. Compared with healthy norms, chronically ill children reported less aggressive behaviour. The parent-report measures suggested a similar trend. Children with chronic illness also tended to display more submissive behaviour than healthy norms, as perceived by their parents. With regard to illness characteristics, both physical restrictions and pain were associated with restricted social activities, but not with other measures of social peer interaction. Children who display submissive behaviour and children who are restricted in their social activities should receive extra attention because they are especially vulnerable for problems in their social development.

Language: English

Keywords: Chronic diseases, general / School-age children / Peer relations / Social skills / Social adjustment

Meyer A, Machnick MA, Behnke W, Braumann KM. Teilnahme von asthmakranken Kindern am Schulsport: eine Erhebung an Hamburger

Schulen. (Participation of asthmatic children in gymnastic lessons at school.) *Pneumologie*, 2002; 56(8): p.486-492
NIVEL: C 8476

INTRODUCTION: Exercise is a predominant stimulus leading to bronchial obstruction in asthmatic children. Therefore physicians, teachers and parents still have a negative attitude towards physical exercise of asthmatic children in school. This study was aimed at investigating the attendance of girls and boys with asthma during sport-lessons at school. METHODS: Two hundred and fifty-nine teachers who give lessons in sports in 46 different schools (high school, primary and secondary school) in Hamburg were asked about their knowledge of the disease and how often and in which manner asthmatic children participated in their sport-lessons. RESULTS: Teachers estimated that in each class (average: 25 - 30 children) approximately 1 asthmatic is present. 60 % of these asthmatics take part likewise their healthy peers. 40 % either take part only sometimes (12,6 %) or specific elements (25,2 %) or not at all (12,2 %). Most of the teachers assessed their knowledge about the disease as medium good. In contrast, only 4,7 % of them had a specific plan that allows asthmatics to participate in sport-lessons without getting obstructive. CONCLUSION: Asthmatic children are underestimated in school and participate in only 60 % equally to their healthy peers at sport-lessons. The knowledge about this most frequent chronic disease in children could be increased. Better training of teacher-students and teachers is recommended.

Language: English

Keywords: Asthma / School

Reiter-Purtill J, Gerhardt CA, Vannatta K, Passo MH, Noll RB. A controlled longitudinal study of the social functioning of children with juvenile rheumatoid arthritis. *Journal of Pediatric Psychology*, 2003; 28(1): p.17-28
NIVEL: C 8376

OBJECTIVE: To get insight into the social functioning, relationships and difficulties of children with juvenile rheumatoid arthritis (JRA), compared to nonchronically ill controls, and to examine the impact of disease severity or disease activity over time on the social functioning of children with JRA. METHODS: Peer-, teacher-, and self-reports of social functioning were obtained from 57 children with JRA and 63 controls. Social reputation and social acceptance were examined cross-sectionally and longitudinally.

RESULTS: Cross-sectional analyses indicated no significant differences between children with JRA and controls on measures of social functioning. For children with more severe disease, like ratings declined over the 2-year period relative to children with mild disease. Children with active disease were chosen fewer times over the 2-year period as a best friend than children in remission. **CONCLUSIONS:** Because children with severe or active JRA may be at risk for difficulties with social acceptance over time, they are appropriate targets for interventions that ameliorate or prevent these difficulties.

Language: English

Keywords: Rheumatoid arthritis / Social adjustment / Social support / Friendship / Psychosocial problems

Sekerel BE, Saraclar Y, Ones U, Guneser S, Akcakaya N, Tanac R, Anlar Y, Turkish National Allergy and Clinical Immunology Society. Childhood asthma perception in Turkey under real-life environment (CAPTURE) study. *Pediatric Allergy and Immunology*, 2001; 12(5): p.266-273

NIVEL: C 8510

The aim of this study was to get insight into the perceptions of childhood asthma by patients, their relatives and their physicians. This was considered important because the experiences of patients and their relatives influence the success of any treatment. A questionnaire-based survey was performed to obtain data on the perception of the impact of asthma in daily life among children (age-range 6-14 years) and adolescents (age-range 15-20 years). A total of 756 patients (384 children, 372 adolescents) were randomly selected from 11 Turkish cities and interviewed face-to-face. Of the total study population, 71.3% received regular follow-up and 75.9% currently took asthma medication. Almost 50% reported that asthma affected their lives significantly. Even though half of the patients had symptoms at least once a week, one-third were not receiving regular prophylactic treatment. Exercise produced asthma symptoms in 45.5% of children and 27.4% of adolescents. The finding that asthma continues to be a major health problem clearly indicates an urgent need for further management programs in Turkey.

Language: English

Keywords: Asthma / Activities of daily living / Professional-patient relations / Psychosocial problems

Schouten A, Oostrom KJ, Pestman WR, Peters AC, Jennekens-Schinkel A; Dutch Study Group of Epilepsy in Childhood. Learning and memory of school children with epilepsy: a prospective controlled longitudinal study. *Developmental Medicine & Child Neurology*, 2002; 44(12): p.803-811

NIVEL: C 8346

The aims of the study were to determine whether learning and memory are compromised in school children with recently diagnosed epilepsy and to examine the relationships between learning and memory and psychosocial and epilepsy variables. Word span and learning of locations were assessed within 48 hours after diagnosis of epilepsy and three and 12 months later, in 69 school children with epilepsy (average age 9.1 years, SD 2.7; 33 males, 36 females) and 66 classmates. Results showed that patients and controls performed similarly in registration, recall, and retention. Patients recalled slightly less than controls when probed under conditions of increased demand on working memory. Maladaptive reactions of parents and children to the onset of epilepsy and not reaching 6-months of seizure remission contributed to poor performance. Individually, those patients who required special assistance at school, under-performed occasionally in one or the other component of memory. Although the proportion of under-performers was stable over time, the children composing the group did change. It was concluded that school children with new onset idiopathic or cryptogenic epilepsy are inordinately vulnerable when processing memory tasks. The vulnerability is neither persistent nor memory-specific.

Language: English

Keywords: Epilepsy / Cognition disorders / Learning problems / Academic achievement

Simeonsson RJ, McMillen JS, Huntington GS. Secondary conditions in children with disabilities: spina bifida as a case example. *Mental Retardation and Developmental Disabilities*, 2002; 8(3): p.198-205

NIVEL: C 8340

The aim of this review is to examine the concept of secondary conditions and its application in studies of childhood disability. Specifically, in this article the focus is on children with spina bifida as a representative group. The "International Classification of Functioning, Disability and Health" (World Health Organization) provides a classification of body function/structure, activities, participation and the environment to document

dimensions of human functioning in context. The ICF is of value in the study of secondary conditions in 2 ways: as a conceptual framework for defining impairments, activity limitations and participation restrictions, and the mediating role of the environment in their expression; and as a taxonomy for coding these dimensions of disability. The ICF can yield a profile of a child's difficulties, and documentation of environmental barriers experienced by that child. Research studies with children and adolescents with spina bifida reveal that physical and mental impairments and limitations in performing activities and participating in communal life are experienced as secondary conditions. The significance of secondary conditions is that they are preventable. Identifying the mechanisms associated with their manifestation is thus an important priority for the development of effective prevention programs.

Language: English

Keywords: Spina bifida / Activities of daily living / Social participation

Weglage J, Grenzebach M, Pietsch M, Feldmann R, Linnenbank R, Denecke J, Koch HG. Behavioural and emotional problems in early-treated adolescents with phenylketonuria in comparison with diabetic patients and healthy controls. *Journal of Inherited Metabolic Disease*, 2000; 23(5): p.487-496
NIVEL: C 8523

The aim of this study was to determine the pattern and degree of emotional and behavioural problems in patients with phenylketonuria (PKU), compared with diabetic patients, and to examine the relationship of these problems with quality of biochemical control. This comparative study covered 42 PKU patients aged 10-18 years (mean 14.7 years) and 42 diabetic patients matched for sex, age and socioeconomic status. Patients' groups were compared with a control sample of healthy controls (n = 2900) from an epidemiological study. The Child Behavior Check List (CBCL) was used according to Achenbach, intelligence quotient (IQ) test according to Weiss, and blood phenylalanine concentrations and HBA1 concentrations were monitored. Internalising problems such as depressive mood, anxiety, physical complaints or social isolation were significantly elevated in both phenylketonuric and diabetic patients, whereas externalising problems were not. The two patient groups did not differ significantly either in the degree or in the pattern of their psychological profile. In both groups no significant correlations could be computed between the psychological characteristics and the biochemical control, the IQ, and the socioeconomic status. No

patient was undergoing psychiatric treatment or psychotherapy. Our results strongly support a psychological perspective for the development of behavioural and emotional problems in both phenylketonuric and diabetic patients. Thus, medical treatment should be accompanied by psychological support for the families.

Language: English

Keywords: Phenylketonuria / Diabetes mellitus / Adolescents / Behaviour problems / Social adjustment / Psychosocial problems

Williams J, Phillips T, Griebel ML, Sharp GB, Lange B, Edgar T, Simpson P. Factors associated with academic achievement in children with controlled epilepsy. *Epilepsy & Behavior*, 2001; 2(3): p.217-223
NIVEL: C 8352

The objective of this study was to investigate a number of factors which are associated with academic underachievement in children with epilepsy. Multiple aetiologies for academic underachievement have been suggested by past research including lower self esteem, inattention, memory inefficiency, and lower socioeconomic status. A sample of 65 children (mean age = 10 years, 5 months) with well-controlled epilepsy was assessed on the four primary factors, as well as academic achievement and intelligence. A stepwise regression analysis was employed with academic achievement as the dependent variable and measures of self esteem, attention, memory, and socioeconomic status as independent variables. When intelligence was controlled, attention was the only variable associated with achievement scores. Seizure variables including seizure type and duration of epilepsy were not associated with differences in academic performance. Findings support the importance of measuring attention skills in children with epilepsy and suggest that reduced auditory attention skills may be associated with decreased academic performance in these children.

Language: English

Keywords: Epilepsy / Academic achievement / Socioeconomic factors / Cognition disorders / Self esteem

Wray J, Sensky T. Congenital heart disease and cardiac surgery in childhood: effects on cognitive function and academic ability. *Heart*, 2001; 85(6): p.687-691.
NIVEL: C 8486

OBJECTIVE: To evaluate changes in cognitive and academic functioning following cardiac surgery in children with congenital heart disease.

METHODS: A prospective cross sectional study was conducted in which patients were assessed immediately before treatment and 12 months later. Three groups of children aged 3.5-17 years were involved: a group with congenital heart disease awaiting surgery, another awaiting bone marrow transplantation, and a healthy comparison group. The main outcome measures used were intelligence quotient and measures of academic attainment, evaluated with the British Ability Scales. **RESULTS:**

Preoperatively, children with cyanotic lesions showed deficits in comparison with those with acyanotic lesions. Postoperatively, children with cyanotic lesions showed a deterioration in performance and achieved significantly lower scores than those with acyanotic lesions. While there were significant differences between the congenital heart disease and bone marrow transplantation groups preoperatively, these were no longer apparent at follow up. **CONCLUSIONS:** In contrast to previously published findings, the present results suggest that cardiac surgery does not result in early postoperative improvements in cognitive function for children with congenital heart disease. The nature of the cardiac lesion continues to affect cognitive and academic performance, even after surgery.

Language: English

Keywords: Congenital heart defects / Cognition disorders / Intelligence / Academic achievement / Postoperative complications

Yeatts KB, Shy CM. Prevalence and consequences of asthma and wheezing in African-American and White adolescents. *Journal of Adolescent Health*, 2001; 29(5): p.314-319

NIVEL: C 8351

PURPOSE: To get insight into the consequences for daily life activities and school attendance of health care utilisation for wheezing symptoms and asthma in a multiracial school-based population. **METHODS:** Wheezing symptoms and physician-diagnosed asthma were measured in 2059 eighth graders with the International Study of Asthma and Allergies in Children video questionnaire. The sample site population consisted of 40% African-American, 53% White, and 49% girls. Thirty-two percent of the children were on the free school lunch program. Adolescents self-reported their wheezing symptoms and physician diagnosis in response to the video wheezing scenes. They also answered questions on activity limitations, school attendance, and sleep disturbances owing to their wheezing

symptoms. Multiple logistic regression was used to calculate odds ratios and adjust for potential confounders. RESULTS: Nine percent of the adolescents reported physician-diagnosed asthma with current symptoms and 27% reported current wheezing with no diagnosis of asthma. Physician-diagnosed asthmatics and wheezers were 2.6 (95% confidence interval [CI] 1.9, 3.6) and 1.8 (95% CI 1.4, 2.2) times more likely, respectively, to miss school days because of wheezing symptoms than asymptomatic adolescents. Diagnosed asthmatics were 7.8 (95% CI 5.5, 11.2) times and wheezers 4.7 (95% CI 3.5, 6.1) times more likely to have sleep disturbances than asymptomatic adolescents. Diagnosed asthmatics were 49 (95% CI 30.0, 79.8) times and wheezers 4.8 (95% CI 3.0, 7.5) times as likely to report a clinic visit for wheezing than asymptomatic adolescents. African-Americans had similar prevalence of wheezing, compared with Whites, although African-Americans were 1.4 (95% CI 1.1, 1.9) times as likely to have physician-diagnosed asthma. Girls were twice as likely to report physician-diagnosed asthma and wheezing symptoms as were boys. CONCLUSIONS: Adolescents with wheezing experienced functional consequences comparable to those of adolescents with physician-diagnosed asthma. Although wheezers may have less severe asthma than diagnosed asthmatics, the functional consequences of wheezing are likely to impair school performance and limit activity.

Language: English

Keywords: Asthma / Activities of daily living / School absenteeism / Health care utilisation

2.2 *Social participation from the family's perspective*

Anthony KK, Gil KM, Schanberg LE. Brief report: Parental perceptions of child vulnerability in children with chronic illness.

Journal of Pediatric Psychology, 2003; 28(3): p.185-190 (Erratum in:

Journal of Pediatric Psychology, 2003; 28(5): following page 373)

NIVEL: C 8335

OBJECTIVE: To investigate the extent to which parental perceptions of child vulnerability predict school absence, social anxiety and problems in social adjustment in children with chronic illness. METHODS: Sixty-nine child-parent dyads were recruited from paediatric rheumatology and pulmonary clinics. Parents completed a self-report measure of parental perceptions of child vulnerability. Children completed measures of social adjustment. Parents also provided written permission to obtain school

attendance records. Physicians provided a global assessment of children's disease severity. RESULTS: Increased parental perceptions of child vulnerability were related to increased social anxiety in children, even after controlling for child age and disease severity. Lower levels of parental education related to both increased perceptions of child vulnerability and increased school absences. CONCLUSIONS: Health providers should assess parental beliefs and parenting practices in assessing the adjustment of children with chronic illness. Moreover, interventions aimed at enhancing child adjustment to chronic illness might best target parents as well as children.

Language: English

Keywords: Chronic diseases, general / Parents / Attitude / School absenteeism / Social adjustment

Balen R. Listening to children with cancer. *Children & Society*, 2000; 14: p.159-167
NIVEL: C 8532

The aim of this study was to explore issues concerning the provision of an activity week experience for a group of British paediatric cancer patients. This research suggested that the activity week appeals to children who are confident, active and able to separate from parents and whose parents are keen to encourage independence and new experiences. Children diagnosed and treated at a younger age and further away from treatment are more likely to express concerns about homesickness and safety and to not apply for the week. In this article, issues of protection, independence and disability are discussed with reference to the importance of parental attitude on children's psychological accommodation to disease and treatment.

Language: English

Keywords: Cancer / Leisure / Family

Gustafsson D, Olofsson N, Andersson F, Lindberg B, Schollin J. Effect of asthma in childhood on psycho-social problems in the family. *Journal of Psychosomatic Research*, 2002; 53(6): p.1071-1075
NIVEL: C 8436

OBJECTIVE: To describe the psychosocial effects on families having a child with asthma, and at determining whether a relation exists between the medical severity of disease and psychosocial problems. METHODS: The

findings are based on a questionnaire with the following domains: economy, work, free time, health, environment, and family, as well as a health-related medical questionnaire. They are built on psychosocial problems and on medical records. RESULTS: The frequency of psychosocial problems was high regarding single questions in the evaluated psychosocial domains. A relation was found between high drug consumption and severe psychosocial problems. However, no positive correlation was detected among visits at the hospital's emergency department, absence from school due to asthma or disturbed sleep, and psychosocial problems. On the contrary, a negative correlation was found between absence from school due to asthma and psychosocial problems. CONCLUSION: It is concluded that for single questions in each psychosocial domain, the problem rate is high, but when taking into account the mean value of different psychosocial problems in each domain, the reported problem rate is fairly low. This method permits selection of the psychosocial domains with the most severe problems in each family. It can, therefore, be used to direct help from the medical service. There was also a relation found between the medical severity of asthma and the extent of the psychosocial problems caused by the disease.

Language: English

Keywords: Asthma / Family / Psychosocial problems / School absenteeism

Kliebenstein MA, Broome ME. School re-entry for the child with chronic illness: parent and school personnel perceptions. *Pediatric Nursing*, 2000; 26(6): p.579-582
NIVEL: C 8398

PURPOSE: The purpose of this study was to identify specific concerns of parents and school personnel with respect to children with chronic illness who return to school. METHODS: Telephone interviews were conducted with 21 parents. Twenty-four questionnaires were completed by school personnel, social workers, principals, psychologists, teachers, and school nurses. Content analysis was used to explore the data for recurrent themes. RESULTS: Five areas of concern were evident in the survey responses of parents and school personnel: (a) how parents informed the school about the child's illness (breaking the news), (b) the processes related to the child's actual re-entry into the school (making the transition), (c) the ongoing monitoring of the child's health status both parents and teachers felt necessary (watching the child), (d) the need to teach school personnel about unexpected health problems (teaching the teachers), and (e) school personnel's expectations for the child (working with the child). Specific

examples of positive and negative experiences related to these themes are provided.

Language: English

Keywords: Chronic diseases, general / School / Parents

Palermo TM. Impact of recurrent and chronic pain on child and family daily functioning: a critical review of the literature. *Developmental and Behavioral Pediatrics*, 2000; 21(1): p.58-69

NIVEL: C 8358

The aim of this review was to get insight into the current status of research on the impact of recurrent and chronic pain on everyday functioning of children and families and to organise the research findings around the specific life contexts (e.g., school, peers) that may be affected by pain. Although findings demonstrate that many different aspects of child and family life are affected by pain, the prevalence and severity of children's functional limitations associated with pain remain unknown. Few treatment studies for paediatric recurrent and chronic pain have focused on enhancing children's functioning. It has been shown, however, that functional outcomes can be improved by cognitive-behavioural interventions. Recommendations for research on functional outcomes and implications for clinical practice are discussed.

Language: English

Keywords: Chronic pain / Activities of daily living / Family / School / Social adjustment / Psychological stress / Reviews

2.3 *Questionnaires and measures on social participation*

Adams CD, Streisand RM, Zawacki T, Joseph KE. Living with a chronic illness: a measure of social functioning for children and adolescents. *Journal of Pediatric Psychology*, 2002; 27(7): p.593-605

NIVEL: C 8600

OBJECTIVE: To develop and validate a measure of social functioning in children and adolescents with chronic medical conditions, Living with a Chronic Illness (LCI), which is designed to distinguish social difficulties related to the illness from those social difficulties associated with other factors (e.g., limited income). METHODS: Parents (n = 108) and youths (n = 115) completed the LCI, along with other psychological measures (e.g.,

Youth Self-Report). Teachers completed the Teacher Report Form and provided grade and absence data. Health care utilisation data were obtained from medical charts. RESULTS: Statistical analyses supported the internal consistency and initial validity of LCI scores. Correlational results strongly point to the distinction made between illness-related and non-illness-related social difficulties and suggest that the LCI has some relation to existing measures (e.g., Child Behavior Checklist), while still providing a unique perspective on children's social functioning. Univariate and regression analyses revealed significant relations between LCI scores and health care utilisation. CONCLUSIONS: These findings support the initial psychometric properties and clinical utility of the LCI scores. Strengths and limitations of this study are discussed, as well as potential clinical applications for the LCI questionnaire.

Language: English

Keywords: Chronic diseases, general / School absenteeism / Social participation / Peer relations / Behaviour problems / Questionnaires

Silver CH. Ecological validity of neuropsychological assessment in childhood traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 2000; 15(4): p.973-988
NIVEL: C 8570

The aim of this review is to give an overview of empirical research on the degree to which neuropsychological testing predicts children's real-world functioning following traumatic brain injury (TBI). Only moderate correlations between test scores and everyday functioning are offered. This line of research is hindered by several methodological issues: difficulty translating performance on standardised testing into real-world capacities, measurement of real-world functioning, developmental factors, and the influence of intervening variables in the natural environment. Ecologically valid assessment may require multiple data sources. More research is needed to respond effectively to questions about children's everyday functioning after traumatic brain injury.

Language: English

Keywords: Acquired brain injury / Assessment / Cognition disorders / Social adjustment / Academic achievement / Reviews

3 Self Management

3.1 Coping

3.1.1 Coping from the patient's perspective

Atkin K, Ahmad WIU. Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder. *Social Science & Medicine*, 2001; 53(5): p.615-626

The aim of this qualitative study was to explore the strategies which young people use to cope with sickle cell disorder or thalassaemia major, two haemoglobin disorders with serious implications for health and survival. By focusing on coping strategies, the authors explore how young people attempt to take control over their lives. The respondents, largely of South Asian and African Caribbean origin, aged between 10 and 19 years, valued maintaining a normal life and struggled to achieve this normalcy. Strategies were employed to minimise difference from peers but these strategies remained vulnerable. Coping occurred in a dynamic space, involving negotiation and engagement with both personal and structural factors. Threats to normalcy did not always reside in the condition; life transitions, changes in social relationships and racist, disablist or sexist marginalisation also threatened coping strategies.

Language: English

Keywords: Thalassaemia / Sickle cell disease / Coping / Ethnic minorities

D'Auria JP, Christian BJ, Henderson ZG, Haynes B. The company they keep: the influence of peer relationships on adjustment to cystic fibrosis during adolescence. *Journal of Pediatric Nursing*, 2000; 15(3): p.175-182. NIVEL: C 8576

The aim of this study was to explore the influence of peer relationships on adjustment to cystic fibrosis (CF) during the transition to adolescence. Interviews, based on a grounded theory approach, were conducted with 15 adolescents with CF. Discovering the course was the core category that captured the influence of peers on adjustment to CF. Four subcategories were identified: (1) losing ground, (2) being out of the loop, (3) finding a new company of friends, (4) fighting a never-ending battle. The downward progression of CF and increasing social interactions with peers with CF during hospitalisation helped them learn CF was a lifelong disease with

relentless demands. Interventions should focus on strategies for promoting peer support, a positive attitude, and hope to create a sense of belonging, social competence, and well-being.

Language: English

Keywords: Cystic fibrosis / Adolescents / Quality of life / Peer relations / Friendship

Fearnow-Kenney M, Kliever W. Threat appraisal and adjustment among children with cancer. *Journal of Psychosocial Oncology*, 2000; 18(3): p.1-17
NIVEL: C 8579

The aim of this study was to measure appraisals of threat among children with cancer. A qualitative measure appropriate for the experience of coping with childhood cancer was developed. Forty children with cancer completed the measure in response to a medically related event, a peer-related event, and a family related event. Child-rated hope and parent-rated measures of dependency, anxiety/depression, and peer relations served as outcome variables. Four factors of threat were created on the basis of previous research and intercorrelations of the nine subscales composing the current measure: threat to self, threat to others, threat of loss, and threat of physical harm to self. The results indicated that children's ratings of the four types of threat varied with the context of the stressful event (i.e., medical, peer, or family). Regression analyses provided initial support for a direct relationship between specific dimensions of threat and measures of adjustment. Implications for theory and applications are discussed.

Language: English

Keywords: Cancer / Coping / Psychological stress / Social adjustment

Frare M, Axia G, Battistella PA. Quality of life, coping strategies, and family routines in children with headache. *Headache*, 2002; 42(10): p.953-962
NIVEL: C 8410

OBJECTIVE: To identify the relationship between paediatric headache severity, coping, and quality of life (QoL) in the context of everyday family life. METHODS: A sample of 48 Italian families with children seeking treatment for primary headaches was interviewed using an adaptation of the Ecocultural Family Interview (EFI). The EFI is a parent interview that

explores the daily routines of family life in which the child and parent participate and the main concerns regarding how that routine is organised. RESULTS: As expected the Lisrel analyses consistently showed that QoL is affected by a child's coping abilities in a causal direction. Headache frequency and duration have a significant impact on a child's QoL. The family daily routine influences significantly both the child's coping ability and QoL. Surprisingly enough, children's coping strategies are not related to headache severity. CONCLUSIONS: More research is needed on the causal factors influencing child's ability to cope with pain, and in particular more attention should be devoted to the contextual and family factors related to paediatric headache.

Language: English

Keywords: Tension headache / Migraine / Coping / Quality of life / Family relations

Goldbeck L, Baving A, Kohne E. Psychosoziale Aspekte der β -Thalassämie: Krankheitserleben, Coping und Therapiemitarbeit. (Psychosocial aspects of beta-thalassemia: distress, coping and adherence.) *Klinische Pädiatrie*, 2000; 212(5): p.254-259

NIVEL: C 8401

OBJECTIVE: The aim of this study was to investigate the coping strategies, health related locus-of-control-beliefs and psychosocial influences on compliance of children, adolescents and young adults with thalassemia. METHODS: A battery of questionnaires was employed to 43 patients with thalassemia major (3 to 26 years old) treated in Germany according to the German multicenter study respectively their parents: the Ulm Thalassemia Inventory, the KIDCOPE, the Multidimensional Health Locus of Control Scales and the Giessen Complaint List. Clinical symptoms of haemosiderosis were correlated with psychosocial variables. RESULTS: The patients feel more distressed from their treatment than from their illness itself. They react to disease-related distress with a variety of coping strategies. Some of the most frequent coping strategies are maladaptive, indicating feelings of helplessness. Internal locus-of-control-beliefs were low and fatalistic locus-of-control-beliefs were high compared with other clinical groups. The self-reported adherence to the iron chelation treatment is correlated with age, gender, age at the start-point of the treatment and emotional distress. Complaints, coping strategies and locus of control are independent from adherence as well as from haemosiderosis. CONCLUSIONS: Patients with thalassemia major need more information about their disease and about the benefits of iron chelation therapy.

Additional psychosocial support should reduce emotional distress, strengthen coping competence and lead to a better integration of therapy in daily life.

Language: German

Keywords: Thalassemia / Coping / Psychosocial problems / Patient compliance

Grey M, Davidson M, Boland EA, Tamborlane WV. Clinical and psychosocial factors associated with achievement of treatment goals in adolescents with diabetes mellitus. *Journal of Adolescent Health*, 2001; 28(5): p.377-385
NIVEL: C 8350

OBJECTIVE: To evaluate a behavioural program of coping skills training for adolescents with Type 1 diabetes mellitus. The following questions were addressed: (a) What clinical and psychosocial factors are associated with achievement of metabolic control treatment goals after 1 year? and (b) What baseline clinical and psychosocial factors are associated with improvement in the quality of life after 12 months? **METHODS:** Eighty-one subjects (of 83 who began; aged 14.3 +/- 2.0 years at entry; 48 females, 33 males; 95% white; diabetes duration 8.9 +/- 3.9 years) with Type 1 diabetes completed 12 months of follow-up in a study of intensified treatment of diabetes. Assessments at baseline and at 12 months used the Diabetes Quality of Life for Youth scale, the Self-efficacy for Diabetes Scale, the Children's Depression Inventory, the Issues in Coping with Diabetes Scale, and the Diabetes Family Behavior Scale. Data were analysed using multiple and logistic regression. **RESULTS:** From a baseline of >9%, HbA1c levels decreased to a mean of 7.8 +/- 0.7%, with 30% of the subjects achieving the treatment goal of <or=7.2%. Logistic regression demonstrated that achievement of goal levels of HbA1c were associated with better metabolic control at study entry (p = .05), participation in coping skills training (p = .003), and more parental participation in guidance and control (p = .05). Multiple regression analysis demonstrated that participation in coping skills training with lower impact of diabetes on quality of life at baseline and less depression at baseline contributed significantly to the variance (0.57) in quality of life at 12 months. **CONCLUSIONS:** Providers need to pay particular attention to adolescents with poorer metabolic control and impact of diabetes on quality of life when they intensify their treatment because they are less likely to reach treatment goals. Furthermore, behavioural interventions such as coping skills training may help teens achieve their goals.

Language: English

Keywords: Diabetes mellitus / Adolescents / Coping / Quality of life / Self care

Kashikar-Zuck S, Goldschneider KR, Powers SW, Vaught MH, Hershey AD. Depression and functional disability in chronic pediatric pain. *The Clinical Journal of Pain*, 2001; 17(4): p.341-349
NIVEL: C 8556

OBJECTIVE: To describe pain characteristics, coping strategies, depression, and functional disability in children and adolescents with chronic pain and to examine potential factors that are associated with functional disability in a paediatric pain population. A secondary aim was to compare functional disability in two chronic pain conditions: localised musculoskeletal pain and chronic daily headaches. **METHODS:** The participants in this study were 73 paediatric pain patients with a variety of chronic pain conditions. Subjects in the second part of the study were a subset of patients (N = 44) from the pain clinic sample with chronic localised musculoskeletal pain and a subset of patients (N = 38) from the headache centre of the same hospital who had chronic daily headaches. Patients completed self-report measures of pain intensity, depression, coping strategies, coping efficacy, and functional disability. **RESULTS:** Results indicated that chronic pain had a substantial impact on the children's lives and that depression was strongly associated with functional disability. Maladaptive coping was correlated with depression and disability; however, maladaptive coping was not independently associated with functional disability. A comparison between the two groups found significant differences in pain intensity and functional disability. The localised musculoskeletal pain group reported higher levels of disability and more difficulty coping than the chronic daily headache group. **CONCLUSIONS:** The implications for treatment of chronic pain in children are discussed with an emphasis on greater attention to developmental issues and their relation to coping, emotional functioning, and disability in paediatric pain. Further research examining differences in coping and disability between different paediatric pain groups is also warranted.

Language: English

Keywords: Chronic pain / Coping / Depression / Activities of daily living

Meijer SA, Sinnema G, Bijstra JO, Mellenbergh GJ, Wolters WH.
Coping styles and locus of control as predictors for psychological

adjustment of adolescents with a chronic illness. *Social Science & Medicine*, 2002; 54(9): p.1453-1461

The aim of this study was to examine the influence of coping styles and locus of control on psychosocial adjustment in adolescents with a chronic illness. Psychosocial adjustment of 84 adolescents aged 13-16 years with a chronic illness was assessed with measures of social adjustment, global self esteem and behaviour problems. Linear regressions were performed with demographic factors (age and gender) and stress-processing factors (coping style and locus of control) as predictor variables. Results indicated that coping styles were related to most aspects of social adjustment. The coping styles 'seeking social support' and 'confrontation' were important predictors for positive social adjustment; the coping style 'depression' was a predictor for poor adjustment, low social self esteem and high social anxiety. Avoidance and locus of control were not strongly associated with psychosocial adjustment. Clinical implications of these findings were discussed in terms of preventive interventions for adolescents with a chronic illness.

Language: English

Keywords: Chronic diseases, general / Adolescents / Coping / Social adjustment

Murphy DA, Moscicki AB, Vermund SH, Muenz LR, The Adolescent Medicine HIV/AIDS Research Network. Psychological distress among HIV(+) adolescents in the REACH study: effects of life stress, social support, and coping. *Journal of Adolescent Health*, 2000; 27(6): p.391-398
NIVEL: C 8587

OBJECTIVE: To examine the effects of life events, social support, and coping on anxiety and depression among HIV-infected adolescents. It was hypothesised that higher levels of stressful events would be associated with higher levels of anxiety and depression, but that this association would be moderated by satisfaction with social support and by adaptive coping.
METHODS: HIV-infected adolescents from 16 locations in 13 U.S. cities (N = 230, median age 16.09 years, standard deviation 1.2, range 13-19; 77% females) were recruited into the Reaching for Excellence in Adolescent Care and Health (REACH) project. REACH is the first large-scale disease progression study of HIV(+) adolescents infected through sexual behaviour or injection drug use. The adolescent assessment was conducted by audio-computer assisted self-interview. Least squares regressions were used to test hypotheses. **RESULTS:** Life events with high impact were associated with

higher levels of depression and anxiety. Frequently reported events included: being prescribed medications (74%), family financial problems (61%), and parental alcohol abuse (20%). Contrary to expectations, the buffering hypotheses of social support and adaptive coping were not supported. Satisfaction with social support and adaptive coping methods were both associated directly with lower levels of depression, but no association was detected between these two measures and anxiety. **CONCLUSIONS:** Although life event distress was directly associated with psychological distress, neither social support nor adaptive coping seemed to moderate this association. However, both satisfaction with support and adaptive coping were associated directly with depression in HIV-infected adolescents.

Language: English

Keywords: Hiv / Adolescents / Psychological stress / Anxiety / Depression / Social support / Coping

Phipps S, Steele R. Repressive adaptive style in children with chronic illness. *Psychosomatic Medicine*, 2002; 64(1): p.34-42

OBJECTIVE: 1) To assess whether previously reported findings of high levels of repressive adaptation in children with cancer are unique to the cancer population or are generally characteristic of children with serious chronic illness and 2) to assess the utility of a new measure of anger expression in the adaptive style measurement paradigm. **METHODS:** Measures of defensiveness, trait anxiety, and anger expression were obtained from three groups of children: those with cancer (N = 130), those with chronic illnesses (diabetes, cystic fibrosis, and juvenile rheumatoid disorders; N = 121), and healthy control participants (N = 368). Based on their self-reports, participants were categorised according to the adaptive style paradigm as either high anxious, low anxious, defensive high anxious, or repressor. The prevalence of these categories was compared across groups. **RESULTS:** Children in the cancer and chronic illness groups both reported significantly higher levels of defensiveness and lower levels of anxiety than did the healthy control participants. Application of the adaptive style paradigm produced a significantly higher percentage of children identified as repressors in both cancer and chronic illness groups relative to healthy children. Children classified as repressors also reported significantly less expression of anger than did nonrepressors. **CONCLUSIONS:** An increased prevalence of repressive adaptation is not unique to children with cancer, but may be generally characteristic of children with serious chronic

illness. Use of anger in place of anxiety as the repressed affect produced a similar distribution of adaptive styles in the study populations.

Language: English

Keywords: Cancer / Diabetes mellitus / Cystic fibrosis / Rheumatoid arthritis / Coping / Personality

Phipps S, Steele RG, Hall K, Leigh L. Repressive adaptation in children with cancer: a replication and extension. *Health Psychology*, 2001; 20(6): p.445-451
NIVEL: C 8233

The aim of this study was to explore whether repressive adaptation in children with cancer is premorbid or reactive. The adaptive style was assessed longitudinally in 130 children with cancer at the time of diagnosis and at 6 months and 1 year after diagnosis. Comparison groups included healthy children and children with other serious but nonmalignant chronic illnesses. At diagnosis, children with cancer showed a higher incidence of a repressive adaptive style than healthy children, and the incidence of repressive adaptation remained stable over time. Children with other chronic illnesses also showed levels of repressive adaptive style comparable to the cancer group. These findings suggest a shift toward repressiveness in response to the diagnosis of cancer that is then maintained over time and necessitate further examination of the health consequences of adaptive style in this population.

Language: English

Keywords: Cancer / Coping / Personality

Reeve DK, Lincoln NB. Coping with the challenge of transition in older adolescents with epilepsy. *Seizure*, 2002; 11(1): p.33-39
NIVEL: C 8522

This study was aimed at investigating psychological adjustment and coping behaviour in adolescents with epilepsy. A patient group of 36 adolescents, aged 16-21 years, with epilepsy and a control group of 31 of their peers were involved in this study. A process model of coping was used. Participants completed a postal questionnaire containing measures of psychological adjustment (self esteem, affect, self-efficacy) and an adolescent coping questionnaire. Comparison of the two groups showed that the patient group exhibited significantly more non-productive coping than the control group.

The control group exhibited significantly more problem solving coping and displayed significantly more problem solving bias than the patient group. No significant differences were found between the patient and control group on measures of psychological adjustment. However, psychological adjustment was found to be associated with coping response in the patient but not the control group.

Language: English

Keywords: Epilepsy / Adolescents / Self esteem / Coping

Röder I. *Stress in children with asthma: coping and social support in the school context.* Leiden: Universiteit Leiden, 2000

NIVEL: B 4752

The aim of this study was to characterise children with asthma on their psychosocial functioning and their stress processing. This was done in two ways. First, children with asthma were described as a group, thus differences between children with asthma and children without asthma were examined. Secondly, individual differences within the group of children with asthma were described, thus correlates of psychosocial problems were examined. The following three research questions were formulated: (1) Do children with asthma show more psychosocial problems than their peers?; (2) Do children with asthma differ from their peers with respect to experiencing stress, coping strategies, and perceived social support?; (3) How can differences in psychosocial functioning between children with asthma be accounted for? Explanations for differences in psychosocial functioning are sought in several concepts that are part of the theoretical model for coping with chronic disease by Maes, Leventhal and De Ridder (1996): (1) perceived stress when confronted with disease-related and school-related stressors, (2) coping strategies when confronted with these stressors, (3) coping with asthma in daily life, and (4) quantity and quality of perceived social support. Demographic variables, such as age, gender, and parental educational level, as well as disease characteristics were also included in the study.

Language: English

Keywords: Asthma / Psychological stress / Coping / Social support / School

Schmidt S, Petersen C, Bullinger M. *Coping with chronic disease from the perspective of children and adolescents: a conceptual framework*

and its implications for participation. *Child: Care, Health & Development*, 2003;29(1): p.63-75
NIVEL: C 8443

The objective of this article is to delineate important issues in the study of coping with chronic conditions in childhood. More specifically, the aims are to contrast the coping of children with that of adults, to highlight developmental aspects, to give an overview on empirical approaches and theories and to formulate goal perspectives in health care. In future research, there is a need to focus the situational context and content of coping rather than to assess the effort employed and level of a particular coping strategy. Coping is not only a way of regulating emotions, but has an interpersonal meaning, depending on its interactional context. In the medical field, coping has a mediating function for participation and shared medical decision-making in health care processes.

Language: English

Keywords: Chronic diseases, general / Coping / Child development / Reviews

Spence LJ, Kaiser L. Companion animals and adaptation in chronically ill children. *Western Journal of Nursing Research*, 2002; 24(6): p.639-656
NIVEL: C 8581

In this article a stress-coping model is presented to examine the role animals may play in adaptation for children with chronic illnesses. The contribution of companion animals to the constructs within the model and the adaptation process is discussed. This model provides a potential theoretical framework for synthesizing literature and pursuing empirical work on the role of companion animals in chronic childhood illness.

Language: English

Keywords: Chronic diseases, general / Psychological stress / Coping

Thastum M, Zachariae R, Herlin T. Pain experience and pain coping strategies in children with juvenile idiopathic arthritis. *The Journal of Rheumatology*, 2001; 28(5): p.1091-1098
NIVEL: C 8488

OBJECTIVE: To examine the experiencing of and coping with pain by children with juvenile idiopathic arthritis (JIA) by comparing the reactions to

cold pressor pain and pain coping strategies of JIA patients, healthy children, and their parents. **METHODS:** 16 children with JIA were studied and one of their parents and 14 healthy children and one of their parents. Patients with JIA were selected from the patient population by fulfilling criteria for inclusion in a "high pain" group (n = 7) of patients with modest clinical arthritis activity, but who presented daily reports of pain in connection with everyday activities, and a "low pain" group (n = 9) who presented significant clinical arthritis activity, but who had only a few complaints of pain related to everyday activities. Dependent variables included pain threshold, discomfort, intensity and tolerance to cold pressor pain, and pain coping strategies. **RESULTS:** Patients with JIA exhibited significantly lower mean pain tolerance than healthy children. Disease duration correlated with both experimental and clinical pain measures, and JIA patients used significantly more Behavioural Distraction than healthy children. Correlations were found between children's and parents' use of Approach and Distraction related coping strategies. Correlations were also found for the coping strategy of Catastrophising in the JIA patient group. For experimental pain coping strategies, a significant correlation was found between the JIA patients' and their parents' use of Distraction. For the JIA patients Positive Self-statements and Behavioural Distraction were inversely correlated with the clinical pain measures. In both children and parents the experimental pain coping strategies of Catastrophising and Distraction were associated with the experimental pain response measures, and low pain JIA patients tended to use more Distraction pain coping strategies than high pain patients. **CONCLUSION:** The results indicate that JIA patients may differ from healthy children with regard to their responses to experimental pain as well as to their use of pain coping strategies. Pain coping strategies of JIA patients were associated with pain coping strategies of their parents, and use of pain coping strategies was associated with both experimental and clinical pain experience.

Language: English

Keywords: Rheumatoid arthritis / Chronic pain / Coping / Parents

3.1.2 Coping from the family's perspective

Azar R, Solomon CR. Coping strategies of parents facing child diabetes mellitus. *Journal of Pediatric Nursing*, 2001; 16(6): p.418-428
NIVEL: C 8425

This study addresses coping strategies of parents of children with diabetes mellitus. The research questions were whether mothers and fathers differ in their coping strategies, which kinds of strategies they use and whether the child's sex influences the strategies used. Thirty couples were involved in this study. The Ways of Coping Questionnaire (WCQ) was administered during a home interview. Results showed that both parents used planful problem solving, exercised positive reappraisal, and sought social support frequently, with mothers using more planful problem-solving strategies than fathers. Within the family, analyses showed that fathers were more likely to use distancing, independent of the child's sex, whereas mothers were more likely to frequently use all the coping strategies when the child was a girl. The implications of the results for nursing are discussed.

Language: English

Keywords: Diabetes mellitus / Parents / Coping / Sex differences

Charron-Prochownik D, Kovacs M. Maternal health-related coping patterns and health and adjustment outcomes in children with Type 1 diabetes. *Children's Health Care*, 2000; 29(1): p.37-45
NIVEL: C 8548

The aim of this study was to examine the relation between maternal health-related coping strategies and rehospitalisations and psychopathology of children with diabetes. Subjects in this longitudinal study were 42 mothers and their diabetic children (aged 8.8-17.9 years). A comprehensive assessment battery was used, including a semistructured psychiatric interview and self-rated questionnaires, and overall diabetes course and management were followed. Twenty children were rehospitalised for diabetes-related reasons within 2.5 years after study commencement. Results show that mothers reported moderate to high use of the 3 health-related coping patterns of family integration, social support, and understanding the medical situation. Findings suggest that mothers' coping patterns have no detectable impact on short-term health outcomes of children with diabetes.

Language: English

Keywords: Diabetes mellitus / Parents / Coping / Hospitalisation / Mental disorders

Chen JY, Chen SS, Jong YJ, Yang YH, Chang YY. A comparison of the stress and coping strategies between the parents of children with

Duchenne muscular dystrophy and children with a fever. *Journal of Pediatric Nursing*, 2002; 17(5): p.369-379
NIVEL: C 8429

This study aimed at comparing the stresses and coping strategies of the parents of children with a chronic condition with those of children with an acute illness, taking Duchenne muscular dystrophy (DMD) and fever as examples, respectively. This university hospital-based case control study included 31 parents with a DMD child and 30 parents of a child with a fever. The study was conducted in southern Taiwan. The study compared the differences of stress and coping strategies between the two groups using closed-ended questionnaires. The control group (fever group) showed higher "stress," "conflict," and "help needs." The DMD subjects had a tendency to use wish-fulfilling fantasy to cope. "Impact" was influenced by income and religion, and income and mother's age influenced coping strategies. Professionals need to manage the parent's conflict, to provide information and resources, and to support the parent's emotional reactions to caring for a child with acute and chronic illness.

Language: English

Keywords: Duchenne muscular dystrophy / Parents / Psychological stress / Coping / Sick role

D'Angelo LJ, Abdalian SE, Sarr M, Hoffman N, Belzer M, Adolescent Medicine HIV/AIDS Research Network. Disclosure of serostatus by HIV infected youth: the experience of the REACH study. *Journal of Adolescent Health*, 2001; 29(Suppl 3): p.72-79
NIVEL: C 8588

OBJECTIVE: To examine the ways HIV-infected youths disclose their serostatus to parents and sexual partners and how this is influenced by sociodemographic, clinical and risk behaviour factors. **METHODS:** Baseline data on 317 HIV infected adolescents in national 15 site study were examined. Data sources included direct and computer-assisted interview, laboratory studies, and chart reviews. Examination of parental disclosure was restricted to subjects without parental permission requirements. Concordance in parental disclosure/support used McNemar's test. Associations between disclosure to parent(s) and subject characteristics were examined using logistic regression analysis. Repeated measure analysis was used for sexual partner disclosure. **RESULTS:** Subjects of both genders more often disclosed their HIV infection status to mothers than to their fathers (77% vs. 47%, $p < .001$). With disclosure, perceived support from

either parent was high. In multivariate analyses, factors associated with maternal disclosure were length of time since diagnosis (OR = 1.43; 95% CI: 1.06-1.92), and Hispanic ethnicity (OR = .37; 95% CI: .15-.95). No factors were significantly associated with paternal disclosure in multivariate analysis, although length of time since diagnosis showed a trend (OR = 1.31; 95% CI: 1.00-1.74). Factors associated with disclosure to sexual partners were partner's HIV+ status (OR = 2.09; 95% CI: 1.11-3.93) and "main partner" status (OR = 3.17; 95% CI: 1.84-5.46). CONCLUSIONS: Although subjects were more likely to reveal their status to their mothers, parental support was perceived as high after disclosure to either parent. Since "time since diagnosis" was associated with parental disclosure, support systems are necessary for youth until such a disclosure can occur.

Language: English

Keywords: Hiv / Adolescents / Parent-child relations / Peer relations

Gontard A von, Backes M, Laufersweiler-Plass C, Wendland C, Lehmkuhl G, Zerres K, Rudnik-Schoneborn S. Psychopathology and familial stress: comparison of boys with Fragile X syndrome and spinal muscular atrophy. *Journal of Child Psychology and Psychiatry*, 2002; 43(7): p.949-957

OBJECTIVE: To analyse and compare the specific effects of two exemplary conditions of childhood chronic illness and mental retardation on familial stress and coping. METHODS: Forty-nine boys with Fragile X syndrome (FXS) were compared with 46 boys with Spinal Muscular Atrophy (SMA) and 32 male controls. Intelligence was measured with the RAVEN or K-ABC tests. Psychopathology was assessed with the CBCL questionnaire and a structured psychiatric interview (Kinder-DIPS), parental stress with the QRS, coping with the F-COPES and social support with the F-SOZU questionnaires. RESULTS: The mean age of the FXS boys was 8.6, of the SMA boys 12.7 and of the controls 11.2 years. The mean IQ was 47 for the FXS, 112 for the SMA and 103 for the control groups. According to the CBCL, 89.8% of the FXS boys, 21.7% of the SMA and 15.7% of the controls had a total score in the borderline or clinical range. The rates were 63.3%, 34.8% and 21.9% for internalising and 67.3%, 10.9% and 18.8% for externalising behaviour, respectively. 81.6% of the FXS and 10.9% of the SMA patients had a DSM-IV or ICD-10 psychiatric diagnosis. The most common were ADHD (FXS: 36) and Separation Anxiety Disorder (SMA: 4). In total, parental stress was significantly higher in the FXS than in the SMA families (and in both compared to controls). There were no major inter-

group differences regarding social support and familial coping.

CONCLUSIONS: Children with FXS are severely mentally retarded and have a high rate of mainly externalising disorders. Despite good coping abilities and social support, this is associated with high familial stress. The SMA boys, with an intelligence in the upper normal range, are no more deviant than their healthy controls. Parental stress is lower in the SMA families with good coping abilities. In conclusion, families with mentally retarded children are in even greater need of help than those of children with severe chronic illness/physical handicap.

Language: English

Keywords: Spinal muscular atrophy / Mental retardation / Family / Psychological stress / Coping / Mental disorders

Hodgkinson R, Lester H. Stresses and coping strategies of mothers living with a child with cystic fibrosis: implications for nursing professionals. *Journal of Advanced Nursing*, 2002; 39(4): p.377-383

OBJECTIVE: To explore current stresses and coping strategies used by mothers of children with cystic fibrosis (CF) and to identify roles and strategies that nursing professionals could extend or adopt to support them.

METHODS: Semi-structured interviews were carried out with 17 mothers of children with CF who attended a regional cystic fibrosis hospital clinic.

Interviews were analysed using the Framework method of analysis.

RESULTS: The study suggests that major stresses for many mothers are feeling in the middle in terms of decision-making particularly concerning the genetic implications of CF, the burden of responsibility for parenting a child with a chronic illness, and coming to terms with a personal change in identity. The most commonly used coping strategy was seeking support from others including nursing professionals. Relationships with health professionals in secondary care were generally positive, with nurses often the first people mothers turned to when they had concerns and also key in interpreting medical information. Relationships with primary care health professionals appeared to be more limited with a role reversal described by some mothers who felt it their responsibility to educate and inform primary care professionals about CF. **CONCLUSIONS:** This study suggests that nursing professionals in primary and secondary care need to look beyond the care of the child to the needs of the mother. It provides evidence to suggest that nursing professionals in primary and secondary care have a number of important roles to play as holders of hope, bridge builders and in providing

continuity of care for such families. It also suggests strategies to strengthen nurse-patient relationship.

Language: English

Keywords: Cystic fibrosis / Mothers / Psychological stress / Coping / Professional-family relations / Nursing

Hoekstra-Weebers JEHM. *Parental adaptation to pediatric cancer.*

Enschede: Febodruk BV, 2000

NIVEL : B 4873

This thesis was aimed at exploring the psychosocial effects on parents at their children's diagnosis and treatment of cancer. The following aspects were studied: psychological and physical complaints and psychological stress, the frequency of using seven different coping styles, the extent to which the parents are happy with their the relationship and the social support they receive. Also, several variables were studied in their capacity to forecast the psychosocial functioning and the coping ability of the parents. It concerned demographic characteristics, other stressors, illness variables, personality, coping styles and social support. Finally, the effect of a psychological intervention meant to help the parents in coping with the diagnosis and the treatment, has been studied.

Language: English

Keywords: Cancer / Parents / Psychological stress / Coping / Mental disorders / Psychosocial problems / Social support

Kerr SM, McIntosh JB. Coping when a child has a disability: exploring the impact of parent-to-parent support. *Child: Care, Health and Development*, 2000; 26(4): p.309-322

NIVEL: C 8554

OBJECTIVE: To examine the impact of parent-to-parent support for families of a child with a congenital limb deficiency. METHODS: A qualitative approach was used in which data were collected retrospectively from in-depth interviews with parents of 63 children. The audio-taped interviews were transcribed and then analysed using constant comparative procedures. RESULTS: The early weeks and months following the birth of their baby was a difficult and emotional time for most parents. Feelings of isolation were common and there was a lot of concern about what the future would hold. Although a certain amount of support was derived from contact

with family, friends and health professionals, parents did not generally obtain the level of support that was required from these sources. Contact with other parents of limb-deficient children, however, clearly exerted a powerful stress-buffering influence, providing much needed emotional, social and practical support. **CONCLUSIONS:** This study suggests that parents of children with special needs are uniquely qualified to help each other. The challenge is to ensure that health professionals are aware of the potential benefits of parent-to-parent support and provide parents with information about appropriate local organisations/contacts.

Language: English

Keywords: Paralysis / Parents / Social support / Coping

Knafl KA, Deatrick JA. Family matters: the challenge of normalization for families of children with chronic conditions. *Pediatric Nursing*, 2002; 28(1): p.49-53, 56
NIVEL: C 8575

The concept of normalisation continues to be of interest to both clinicians and researchers. Studies of families facing diverse illness challenges have found that over time family members come to view both the child and their life as normal. Less attention has been focused on those families who do not view normalisation as an attainable goal, families who are unable to sustain normalisation over time, or those families whose socio-cultural backgrounds do not support or value normalisation (Deatrick, Knafl, & Murphy-Moore, 1999). The intent of this article is to consider the multiple, sometimes changing, ways that normalisation is manifested in families and discuss the clinical implications of these differences.

Language: English

Keywords: Chronic diseases, general / Family / Psychological stress / Coping

Lin S-L. Coping and adaptation in families of children with cerebral palsy. *Exceptional Children*, 2000; 66(2): p.201-218
NIVEL: C 8363

The aim of this study was to explore the relationship between coping and adaptation in families of children and adolescents with cerebral palsy (CP). Participants were 2,174 families (family member caregivers aged 21-75 years) of persons with CP (aged 21 years or less) recruited through 12

United Cerebral Palsy associations in the north central area of the United States. Factor analysis suggested that 64.7% of the variance in family coping was accounted for by the following factor variables: positive family appraisal, support from concerned others, spiritual support, personal growth and advocacy, and positive social interaction. Stepwise multiple regression of these variables yields that positive family appraisal and spiritual support were predictive of family adaptation. Multivariate analysis of variance with Pillai's criterion reveals that family coping with CP differs in family life cycle stages. Analysis of variance also indicates that family adaptation differs in terms of family life cycle stages.

Language: English

Keywords: Cerebral palsy / Coping / Family relations / Social adjustment / Social support

McGrath P. Treatment for childhood acute lymphoblastic leukaemia: the fathers' perspective. *Australian Health Review*, 2001; 24(2): p.135-142
NIVEL: C 8524

The aim of this study was to examine how fathers experience the diagnosis and treatment of their children with acute lymphoblastic leukaemia (ALL) and how they cope with it. A longitudinal study was conducted at Royal Children's Hospital in Brisbane, Queensland. The findings from this research clearly indicate the emotional pain that fathers face in their struggle to accept the diagnosis of a serious, life-threatening illness such as ALL in their child. The findings challenge the notion of the male stereotype by showing that the shock of diagnosis, the emotional pain of coping with the illness, the expression of pain through tears, the desire to be with the child, the struggle to cope with the medical interventions, and concerns about other family members are not gender specific, but are rather issues common to both parents.

Language: English

Keywords: Leukaemia / Fathers / Parent-child relations / Coping / Grief

Pal DK, Chaudhury G, Das T, Sengupta S. Predictors of parental adjustment to children's epilepsy in rural India. *Child: Care, Health & Development*, 2002; 28(4): p.295-300
NIVEL: C 8343

OBJECTIVE: To test the hypothesis that maternal satisfaction with social support would predict parental adjustment to the child's epilepsy.

METHODS: Forty-six mothers of children aged 6-18 years with epilepsy participated in the study. Social support was measured using the modified Dunst family support scale, and parental adjustment using a locally validated instrument (S-PAM). Correlation was tested using a multiple linear regression model, allowing for confounding variables. **RESULTS:** Parental adjustment at outcome was positively independently correlated with satisfaction with social support at baseline, and negatively with severity of the child's epilepsy. The regression model explained 34% of the total variance. **CONCLUSIONS:** Taken together with evidence from previous studies, this finding supports the idea that helping parents to find more satisfaction within their (new or existing) social networks will promote adjustment to their child's disability.

Language: English

Keywords: Epilepsy / Parents / Social support / Quality of life / Coping

Patistea E, Makrodimitri P, Panteli V. Greek parents' reactions, difficulties and resources in childhood leukaemia at the time of diagnosis. *European Journal of Cancer Care*, 2000; 9(2): p.86-96. (Erratum in: *European Journal of Cancer Care*, 2000; 9(4): p.258-259)
NIVEL: C 8344

The aim of this study was to examine parental psychological reactions, difficulties and resources during the period following the diagnosis of childhood leukaemia. Open-ended interviews were used to obtain data from 71 randomly selected mothers and fathers of children diagnosed with leukaemia at least 3 months prior to the study. The content analysis revealed a wide diversity of parental responses including many of the defensive mechanisms described in the literature such as shock, denial, anxiety and guilt. The most difficult factors for the parents to deal with during the initial period were the psychological upset and the financial burden. Problems associated with relating to others and to the health care system were also identified. Hope, social support and the marital relationship were the most helpful resources in managing the multifaceted problems caused by the diagnosis. Forty-five per cent of the participants felt that the quality of their marital relationship was improved, whereas fewer reported that the diagnosis seriously disturbed their marriage. Spouses were found to adopt symmetrical rather than complementary ways of responding to and coping with the event.

Nurses have a key role in assessing the individual parent, the marital unit and the entire family system and planning appropriate interventions.

Language: English

Keywords: Leukaemia / Parents / Psychological stress / Marital relationship / Quality of life / Coping

Seiffge-Krenke I. "Come on, say something, dad!": communication and coping in fathers of diabetic adolescents. *Journal of Pediatric Psychology*, 2002; 27(5): p.439-450
NIVEL: C 8559

OBJECTIVE: To investigate fathers' coping and communication behaviour in families of adolescents with diabetes, compared to families of healthy adolescents. **METHODS:** Fathers of diabetic adolescents and healthy adolescents (N = 134) were investigated longitudinally with respect to their non-illness-specific coping behaviour, their perceptions of family climate, and communicative behaviour in solving a joint family task. Data were obtained through questionnaires and content analysis of recordings of verbal communication activity. **RESULTS:** Based on questionnaire data, few differences were found between diabetic and healthy adolescents' fathers' styles of coping with non-illness-specific family problems over time. However, several significant differences emerged, both with respect to the fathers' perceptions of family climate and to aspects of family communication, as observed by independent raters. The findings revealed the overall low communicative activity and initiative of diabetic adolescents' fathers, despite the diabetic adolescents' frequent efforts to involve their fathers in solving a joint task. **CONCLUSIONS:** Counselling and related support services for families of chronically ill adolescents should endeavour to reinstate or increase the father's involvement in the family, thereby encouraging him to exercise his distinctive parental functions.

Language: English

Keywords: Diabetes mellitus / Adolescents / Fathers / Coping / Parent-child relations

Wade SL, Borawski EA, Taylor HG, Drotar D, Yeates KO, Stancin T. The relationship of caregiver coping to family outcomes during the initial year following pediatric traumatic injury. *Journal of Consulting and Clinical Psychology*, 2001; 69(3): p.406-415
NIVEL: C 8518

The aim of this study was to identify coping strategies within families of children with traumatic brain injury (TBI). Families of 103 children with TBI and 71 children with orthopaedic injuries were followed prospectively during the initial year postinjury. The groups had comparable preinjury characteristics and hospitalisation experiences but differed on neurological insult. In hierarchical regression analyses, acceptance was associated with lower burden and denial was associated with greater distress in both groups. Active coping resulted in higher distress following TBI but not orthopaedic injuries. Conversely, the use of humour was related to diminishing distress following TBI but unrelated to distress following orthopaedic injuries. Results are discussed in terms of the implications for intervention following TBI.

Language: English

Keywords: Acquired brain injury / Family / Coping / Psychological stress

Wade SL, Holden G, Lynn H, Mitchell H, Ewart C. Cognitive-behavioral predictors of asthma morbidity in inner-city children.

Developmental and Behavioral Pediatrics, 2000; 21(5): p.340-346

NIVEL: C 8485

The aim of this study was to examine the relationship between cognitive-behavioural aspects of asthma management (caretaker asthma knowledge, expectations, and problem-solving) and asthma morbidity in children who live in inner-city areas in the United States, where asthma is a growing problem. A sample of 1,376 inner-city children with physician-diagnosed asthma was studied. In the analyses, baseline symptom severity served as a covariate, and the average of the 3-, 6-, and 9-month follow-up data served as the outcome measure. Children of caregivers with ineffective problem-solving strategies had significantly more days of wheezing over a 14-day period. Ineffective problem-solving capabilities were also associated with poorer functional status; however, positive caregiver expectations were associated with better functional status. Of the cognitive-behavioural factors studied in a high-risk urban population, caregiver problem-solving skills and expectations emerged as meriting further investigation and possible intervention.

Language: English

Keywords: Asthma / Parents / Attitude / Coping / Socioeconomic factors

Williamson GM, Walters AS, Shaffer DR. Caregiver models of self and others, coping, and depression: predictors of depression in children with chronic pain. *Health Psychology*, 2002; 21(4): p.405-410

The aim of this study was to test the plausibility of an unidirectional model in which the personal models of caregivers of children with chronic pain are related to different types of coping strategies. In a sample of 59 chronically ill paediatric patients and their maternal caregivers, both child-reported pain and caregiver-reported depression predicted child-reported depression. Results further suggested that the association between pain and depression in children is ameliorated by caregiver coping strategies and that how caregivers cope is a function of their attachment-related representations of the self and others. Caregivers with a negative model of the self were more depressed, and those with a negative model of others were more prone to use avoidant coping strategies, and, in turn, to be more depressed. However, the extent to which caregivers with negative models of self used more avoidant and less approach coping appeared to depend on whether they perceived that others were likely to respond to their needs.

Language: English

Keywords: Chronic pain / Depression / Parents / Coping / Parent-child relations

3.2 Self care and compliance

3.2.1 Self care from the patient's perspective

Atkin K, Ahmad WIU. Pumping iron: compliance with chelation therapy among young people who have thalassaemia major. *Sociology of Health & Illness*, 2000; 22(4): p.500-524

The aim of this study was to explore how young people who have thalassaemia major respond to their daily chelation therapy. It is suggested that compliance dominates the young person's narratives and represents the most disruptive aspect of their illness. More specifically, compliance evokes both practical and emotional difficulties as the young person tries to make sense of the relationship between body, self and illness. Within this dynamic process the young person has to reconcile the consequences of non-compliance within the broader experience and responsibilities of 'growing-up' and maintaining a positive self-identity.

Language: English

Keywords: Thalassaemia / Patient compliance / Parent-child relations

Bar-Mor G, Bar-Tal Y, Krulik T, Zeevi B. Self-efficacy and physical activity in adolescents with trivial, mild, or moderate congenital cardiac malformations. *Cardiology in the Young*, 2000; 10(6): p.561-566
NIVEL: C 8413

This study was conducted to examine the cognitive processes that influence involvement in physical activity among 100 adolescents, 55 boys and 45 girls, ranging in age from 12 to 18 years, with trivial, mild, or moderate forms of congenital cardiac disease. It was hypothesised, first, that the severity of the congenital cardiac malformation itself has an indirect effect on self-efficacy regarding physical activity, and that the relationship between the two is mediated by the recommendations of the cardiologist and the attitude of the mother. Second, it was argued that self-efficacy serves as a mediating variable between the recommendations of the cardiologist and the attitude of the mother, on the one hand, and involvement in physical activity, on the other. The results confirmed both hypotheses. In a population of adolescents with trivial to moderate congenital cardiac malformations, beliefs in self-efficacy, rather than severity of the disease, were the most influential factors in determining whether or not adolescents will engage in sports or other physical activities. The authors also demonstrated the importance of the role played by the recommendations of the cardiologist in determining both the attitudes of the mother and the belief in self-efficacy of the adolescents.

Language: English

Keywords: Congenital heart defects / Adolescents / Activities of daily living / Self esteem

Barton C, Abramson M, Aroni R, Stewart K, Thien F, Sawyer S. What determines knowledge of asthma among young people and their families? *Journal of Asthma*, 2002; 39(8): p.701-709
NIVEL: C 8455

The aim of this study was to determine factors that predict the level of asthma knowledge in a sample of adolescents with asthma and their parents. Eighty-five young people aged 10-24 years attending tertiary care asthma clinics and 46 of their parents answered validated respiratory and asthma knowledge questionnaires. Older adolescents were more knowledgeable about asthma than were younger adolescents ($r=0.36$, $p=0.001$). Young people with severe asthma ($p=0.015$) scored higher on the asthma knowledge questionnaire than those with mild/moderate asthma. Asthma knowledge

among young people was related to that of their mothers ($r=0.47$, $p=0.014$), however, only age and the asthma knowledge of fathers significantly predicted adolescent asthma knowledge. Adolescents develop increasing autonomy for asthma self-management as they mature, but parents remain an important source of information about asthma for young people.

Language: English

Keywords: Asthma / Adolescents / Parents / Autonomy

Buston KM, Wood SF. Non-compliance amongst adolescents with asthma: listening to what they tell us about self-management. *Family Practice*, 2000; 17(2): p.134-138

OBJECTIVE: To get insight into the reasons for non-compliance in adolescents with asthma. **METHODS:** In-depth interviews were conducted with a sample of 49 adolescents, aged 14-20 years, diagnosed as asthmatic more than a year previously and attending a hospital asthma clinic in Greater Glasgow. The interviews focused on young people's feelings about their illness and on their illness-related behaviour, including self-management. **RESULTS:** Most of the young people interviewed admitted that they had not always adhered to their self-care regimens. Reasons given for non-compliance with prescribed medication in the past or at present were: forgetfulness, belief that the medication is ineffective, denial that one is asthmatic, difficulty using inhalers, inconvenience, fear of side effects, embarrassment and laziness. **CONCLUSIONS:** Most of those interviewed believed that compliance with prescribed medication was extremely important, with many having formed this belief following a negative experience which they attributed to their non-compliance. Nevertheless, barriers exist which mean that optimum self-care is not always achieved. It is suggested that future health care initiatives in this area be designed to provide practical information which aids the surmounting of these barriers and helps children and adolescents to be sufficiently aware of their own vulnerability at an early stage of their career as asthmatics. Peer education initiatives may meet these objectives, and more thought should be given to their development and optimum form.

Language: English

Keywords: Asthma / Adolescents / Patient compliance / Self care

Cook S, Herold K, Edidin DV, Briars R. Increasing problem solving in adolescents with type 1 diabetes: the choices diabetes program. *The Diabetes Educator*, 2002; 28(1): p.115-124
NIVEL: C 8466

The purpose of this pilot study was to develop and evaluate a problem-solving diabetes self-management education program for adolescents with diabetes. It was hypothesised that adolescents with diabetes can learn to become better problem solvers in diabetes self-care and thereby improve their metabolic control. **METHODS:** Fifty-three adolescents aged 13 to 17 with type 1 diabetes were randomly assigned to either a 6-week problem-solving diabetes education program or to a control group (usual care). A1C levels were obtained as well as assessments of problem solving, frequency of behaviour, level of responsibility, and 24-hour behaviour recall at baseline and 6 months. **RESULTS:** The experimental group participants showed significantly improved problem-solving test scores and A1C values from baseline to 6 months, changes not evident in the control group. At 6 months, the experimental group participants were doing blood glucose testing more often than those in the control group. However, there was no significant difference in problem-solving test scores or A1C values. **CONCLUSIONS:** This 6-week intervention for adolescents with diabetes resulted in better problem-solving skills, more frequent blood glucose testing, and improved A1C values. The results suggest that a diabetes problem-solving program for adolescents can be effective in improving metabolic control.

Language: English

Keywords: Diabetes mellitus / Adolescents / Patient compliance / Self care

Es SM van, Kaptein AA, Bezemer PD, Nagelkerke AF, Colland VT, Bouter LM. Predicting adherence to prophylactic medication in adolescents with asthma: an application of the ASE-model. *Patient Education and Counseling*, 2002; 47(2): p.165-171

The objective of this study was to investigate the long-term influence of cognitive variables (attitudes, social influences and self-efficacy expectations) and other psychological and medical determinants on self-reported adherence in adolescents with asthma. An explanatory framework, referred to as the attitude/social influence/self-efficacy-model (ASE-model), was utilised. Data were collected, via a questionnaire, from 86 adolescents with asthma (aged 11 through 18 years) recruited from outpatient clinics. Adherence was assessed by asking the patients to give themselves a report

mark for adherence. The results of the multiple regression analyses showed that the three major ASE-variables were predictors of self-reported adherence to a moderate degree ($R(2)=0.21$). Previous self-reported adherence was found to be the best predictor of self-reported adherence to prophylactic asthma medication 1 year later ($R(2)=0.45$). The results of this study could be useful in the development of interventions to enhance adherence to asthma medication. In future, such interventions should focus on feelings of shame about having asthma and promoting healthy habits, such as adherence to medication.

Language: English

Keywords: Asthma / Adolescents / Patient compliance / Self care

Griva K, Myers LB, Newman S. Illness perceptions and self efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology and Health*, 2000; 15(6): p.733-750

The aims of this study were to examine the relationship between illness perceptions and self-efficacy expectancies and to investigate their respective and combined role in explaining treatment adherence and metabolic control in young outpatients with insulin-dependent diabetes. Sixty-four patients (aged 15-25 years) attended one assessment where blood samples were taken, and then completed a number of questionnaires concerning illness perceptions, generalised and diabetes specific self-efficacy, and a self-report measure of treatment adherence. Metabolic control was also assessed. Results found that control, identity, and consequences components of illness perceptions were significantly correlated with self-efficacy expectancies. Control beliefs were consistently associated with self-reported adherence to treatment. It is concluded that patient self-efficacy and illness perceptions are useful predictors of physiological and behavioural outcomes in diabetes self management.

Language: English

Keywords: Diabetes mellitus / Adolescents / Young adults / Sick role / Self care / Patient compliance

**Hanna KM, Guthrie D. Parents' and adolescents' perceptions of helpful and nonhelpful support for adolescents' assumption of diabetes management responsibility. *Issues in Comprehensive Pediatric Nursing*, 2001; 24(4): p.209-223
NIVEL: C 8527**

This study was aimed at identifying which factors in parental support for adolescents with diabetes are helpful or not, with respect to adolescents' responsibility for diabetes management. Sixteen pairs of parents and adolescents with type 1 diabetes (11-18 years of age) were interviewed. The interviews were audiotaped and transcribed verbatim. Data were analysed for manifest content according to social support dimensions identified by Barrera and Ainlay (1983). Inter-rater agreement between primary investigator and doctorally prepared diabetes nurse and educator was 100%. Both parents and adolescents describe directive guidance and tangible assistance as helpful and nonhelpful, depending on degree of directness and perceived need for help. Nurses can encourage parents to use subtle guidance and adolescents to communicate their needs.

Language: English

Keywords: Diabetes mellitus / Adolescents / Self care / Social support / Parent-child relations

Hanna KM, Guthrie D. Adolescents' perceived benefits and barriers related to diabetes self-management: part 1. *Issues in Comprehensive Pediatric Nursing*, 2000; 23(3): p.165-174
NIVEL: C 8402

This study's purpose was to identify adolescents' perceived benefits and barriers about the process of decision making regarding their assumption of diabetes management. Sixteen adolescents with type 1 diabetes were interviewed. Questions were adapted from the Janis and Mann (1977) decisional balance sheet. Interviews were audiotaped and transcribed verbatim. Descriptive expressions were identified and categories inductively generated. Adolescents' perceived benefits for themselves were having knowledge of or confidence in self-management abilities, more freedoms, and approval of others. They perceived benefits for parents as relief from responsibility, stress, and worry. Burden of responsibility was perceived as a barrier to adolescents for self-management. Adolescents perceived barriers for parents as worry/guilt and loss of control. Interrater agreement was initially 74%. Categories with disagreements were recategorised by interraters and then there was 100% agreement. Understanding adolescents' perceptions would be beneficial to their health care professionals.

Language: English

Keywords: Diabetes mellitus / Adolescents / Sick role / Self care

Hoey H, Aanstoot HJ, Chiarelli F, Daneman D, Danne T, Dorchy H, Fitzgerald M, Garandau P, Greene S, Holl R, Hougaard P, Kaprio E, Kocova M, Lynggaard H, Martul P, Matsuura N, McGee HM, Mortensen HB, Robertson K, Schoenle E, Sovik O, Swift P, Tsou RM, Vanelli M, Aman J. Good metabolic control is associated with better quality of life in 2,101 adolescents with type 1 diabetes. *Diabetes Care*, 2001; 24(11): p.1923-1928
NIVEL: C 8470

OBJECTIVE: To get clear whether the demands of good metabolic control or the consequences of poor control have a greater influence on quality of life (QOL) for adolescents with diabetes. **METHODS:** A large international cohort study of adolescents with diabetes and their families was conducted. The study involved 2,101 adolescents, aged 10-18 years, from 21 centres in 17 countries in Europe, Japan, and North America. Clinical and demographic data were collected from March through August 1998. HbA(1c) was analysed centrally (normal range 4.4-6.3%; mean 5.4%). Adolescent QOL was assessed by a previously developed Diabetes Quality of Life (DQOL) questionnaire for adolescents, measuring the impact of diabetes, worries about diabetes, satisfaction with life, and health perception. Parents and health professionals assessed family burden using newly constructed questionnaires. **RESULTS:** Mean HbA(1c) was 8.7% (range 4.8-17.4). Lower HbA(1c) was associated with lower impact ($P < 0.0001$), fewer worries ($P < 0.05$), greater satisfaction ($P < 0.0001$), and better health perception ($P < 0.0001$) for adolescents. Girls showed increased worries ($P < 0.01$), less satisfaction, and poorer health perception ($P < 0.01$) earlier than boys. Parent and health professional perceptions of burden decreased with age of adolescent ($P < 0.0001$). Patients from ethnic minorities had poorer scores for impact ($P < 0.0001$), worries ($P < 0.05$), and health perception ($P < 0.01$). There was no correlation between adolescent and parent or between adolescent and professional scores. **CONCLUSIONS:** In a multiple regression model, lower HbA(1c) was significantly associated with better adolescent-rated QOL on all four subscales and with lower perceived family burden as assessed by parents and health professionals.

Language: English

Keywords: Diabetes mellitus / Adolescents / Self care / Quality of life

Jónasson G, Carlsen KH, Mowinckel P. Asthma drug adherence in a long term clinical trial. *Archives of Disease in Childhood*, 2000; 83(4): p.330-333

NIVEL: C 8474

OBJECTIVE: To measure drug adherence in children with mild asthma receiving long term prophylactic treatment and to examine whether adherence declines over time. **METHODS:** Double blind randomised placebo controlled trial. Patients received inhaled budesonide 100 microg or 200 microg daily, or placebo for 27 months. All participants were asked to inhale medication or placebo from two different Turbuhalers (morning and evening) during the study. A total of 122 children (80 boys, 42 girls) aged 7-16 years with mild asthma (mean FEV(1) 103.7% of predicted) were included in the trial. Drug adherence was assessed by counting the number of remaining doses in the inhaler when study medication was returned at six month intervals. **RESULTS:** A statistically significant and continuing decrease in measured drug adherence was found from three to nine months and then to 27 months, reaching mean values of 40.6% and 46.9% for inhaled morning and evening medication respectively. Drug adherence declined more rapidly in the placebo group (compared to active treatment); this difference became significant after two years of treatment. Children aged 9 years or less had better drug adherence during the entire study period, but the difference was only significant for the first three months of the study. Measured drug adherence was significantly higher for evening medication compared to morning medication for all study intervals after nine months. **CONCLUSION:** Measured drug adherence diminishes significantly when treating children with mild asthma in a long term trial. This emphasises the importance of monitoring compliance in clinical trials.

Language: English

Keywords: Asthma / Patient compliance

Jones A, Pill R, Adams S. Qualitative study of views of health professionals and patients on guided self management plans for asthma. *British Medical Journal*, 2000; 321(7275): p.1507-1510

OBJECTIVE: To get insight into the attitudes of general practitioners, practice nurses, and patients about the role of guided self management plans in asthma care. **METHODS:** A qualitative study was conducted using nine focus groups that each met on two occasions. Participants were 13 asthma nurses, 11 general practitioners (six with an interest in asthma), and 32 patients (13 adults compliant with treatment, 12 non-compliant adults, and seven teenagers). **RESULTS:** Neither health professionals nor patients were enthusiastic about guided self management plans, and, although for different

reasons, almost all participants were ambivalent about their usefulness or relevance. Most professionals opposed their use. Few patients reported sustained use, and most felt that plans were largely irrelevant to them. The attitudes associated with these views reflect the gulf between the professionals' concept of the "responsible asthma patient" and the patients' view. CONCLUSIONS: Attempts to introduce self guided management plans in primary care are unlikely to be successful. A more patient centred, patient negotiated plan is needed for asthma care in the community.

Language: English

Keywords: Asthma / Adolescents / Attitude / Self care

Kyngäs H. Predictors of good compliance in adolescents with epilepsy.

Seizure, 2001; 10(8): p.549-553

NIVEL: C 8375

The aim of this study was to get insight into the factors that predict compliance in adolescents with epilepsy. Three hundred individuals aged 13-17 years were randomly selected from the Finnish Social Insurance Institution's register. Seventy-seven per cent (N= 232) of the selected adolescents with epilepsy returned the questionnaire. The data were analysed with SPSS software. Using the logistic regression model, the compliance of adolescents with epilepsy was predicted on the basis of support from physician and parents, motivation and the disease not being a threat of social well-being. The most powerful predictor was support from the physician. The likelihood of adolescents supported by their physicians complying with their health regimens was 10.56-fold compared with the adolescents who did not receive support from their physicians. Another powerful predictor was support from parents. The adolescents who received support from their parents complied with the health regimens with a 10.47-fold likelihood compared with adolescents who did not receive support from their parents. Adolescents with good motivation were 9.77 times more likely to comply than adolescents who did not have good motivation. Adolescents who did not feel the disease to be a threat to their social well-being complied with health regimens with an 8.38-fold likelihood compared to those who felt the disease to be a threat to social well-being. The value of the -2Log likelihood was 64.68 and the goodness of fit index was 214.735. The value of Nagelkerke was 0.893, which indicates that the logistic regression model explains 89% of the variance. The model predicts correctly 97% of compliance in adolescents showing good compliance. These values show the logistic regression model to be good and to match well with the data.

Language: English

Keywords: Epilepsy / Adolescents / Patient compliance / Parent-child relations / Doctor-patient relations / Social support

Kyngäs H, Rissanen M. Support as a crucial predictor of good compliance of adolescents with a chronic disease. *Journal of Clinical Nursing*, 2001; 10(6): p.767-774
NIVEL: C 8451

The purpose of this study was to get insight into the factors that predict compliance among adolescents with a chronic illness. The data were collected by questionnaires from adolescents with asthma, epilepsy, juvenile rheumatoid arthritis (JRA) and insulin-dependent diabetes mellitus (IDDM). Groups of 300 adolescents with these illnesses were selected from the Finnish Social Insurance Institution's register, giving a total study series of 1200 individuals. The final response percentage was 88% (n = 1061). The data were analysed with the SPSS software. Logistic regression was used to indicate the predictors of good compliance. The compliance of adolescents with a chronic disease was predicted on the basis of support from parents, nurses, physicians and friends, as well as motivation, energy and willpower. The most powerful predictor was support from nurses. The likelihood of adolescents supported by nurses complying with health regimens was 7.28-fold compared to the adolescents who did not receive support from nurses. Support from parents, physicians and friends similarly predicted good compliance with health regimens. Another powerful predictor was energy and willpower. Adolescents who had the energy and willpower to take care of themselves complied with health regimens with a 6.69-fold likelihood compared to the adolescents who did not have energy and willpower. Adolescents who had good motivation were 5.28 times more likely to comply than the adolescents who did not have motivation.

Language: English

Keywords: Asthma / Rheumatoid arthritis / Epilepsy / Diabetes mellitus / Adolescents / Patient compliance / Social support

Kyngäs H. Compliance of adolescents with chronic disease. *Journal of Clinical Nursing*, 2000; 9(4): p.549-556
NIVEL: C 8450

The purpose of this study was to get insight into the factors that affect compliance in adolescents with a chronic illness and to compare these

between adolescents with asthma, epilepsy, rheumatoid arthritis (JRA) and insulin dependent diabetes mellitus (IDDM). The data were collected by questionnaire. Altogether 1200 individuals were selected from the Finnish Social Insurance Institution's register. The response percentage was 88 (n = 1061). One-fifth (23%) of adolescents with chronic disease felt that they had complied fully with health regimens, while 60% placed themselves in the category of satisfactory compliance and the remaining 17% reported poor compliance. In each patient group compliance was promoted by good motivation, a strong sense of normality, a positive attitude towards the disease and treatment, energy and will-power, experience of results, support from the parents, nurses and physicians, and a feeling that the disease was not a threat to social well-being.

Language: English

Keywords: Asthma / Rheumatoid arthritis / Epilepsy / Diabetes mellitus / Adolescents / Patient compliance

Kyngäs H. Compliance of adolescents with diabetes. *Journal of Pediatric Nursing*, 2000; 15(4): p.260-267
NIVEL: C 8467

The purpose of this study was to get insight into the compliance of adolescents with diabetes and which factors are connected to it. Altogether, 300 individuals aged 13 to 17 years were randomly selected from the Finnish Social Insurance Institution's register. Every fifth person on the list was included in the sample. Ninety-seven percent (N = 289) of the adolescents with diabetes returned the questionnaire. The data were analysed by using the Statistical Package for the Social Sciences (SPSS) software. Only about one fifth (19%) of the respondents with diabetes felt that they complied fully with the health regimens, whereas 75% placed themselves in the category of satisfactory compliance and the remaining 6% reported poor compliance. Compliance with home monitoring was poorest: Only 25% said they fully complied with the home monitoring instructions, and 51% showed poor home monitoring compliance. The highest degree of compliance was reported for insulin treatment, with 81% of the patients ranking in the top category. Some statistically significant ($p < .001$) relationships between the degree of compliance and the background variables, such as the duration of disease; exercise; smoking; alcohol intake; and serum glycosylated haemoglobin (GHbA1c) value, were found. Good motivation, a strong sense of normality, energy and willpower, support from parents, physicians and nurses, a positive attitude toward the disease and its treatment, no threat to

one's social well-being, and fears of complications explained good compliance ($p < .001$).

Language: English

Keywords: Diabetes mellitus / Adolescents / Patient compliance

Kyngäs H. Compliance with health regimens of adolescents with epilepsy. *Seizure*, 2000; 9(8): p.598-604
NIVEL: C 8468

The purpose of this study was to get insight into the compliance of adolescents with epilepsy and which factors are connected to it. Altogether 300 individuals with epilepsy aged 13-17 years were randomly selected from the Finnish Social Insurance Institution's register. Every fifth person on the list was included in the sample. Seventy-seven per cent ($n= 232$) of the selected adolescents with epilepsy returned a questionnaire sent to them relating to compliance. The data were analysed using the SPSS software. Twenty-two per cent of the adolescents with epilepsy felt that they complied fully with their suggested health regimens, while 44% placed themselves in the category of "satisfactory compliance", and the remaining 34% reported poor compliance. Compliance with their recommended life-style was poorest, while the highest degree of compliance was recorded for medication. Background variables, such as the duration of the disease, exercise, smoking, alcohol-intake and the number of seizures, were statistically significantly related to compliance ($P < 0.001$). Good motivation, a strong sense of normality, experience of results, subjective outcome, energy and will-power, support from parents, physicians and nurses, and a positive attitude towards to the disease and its treatment, no threat to social and emotional well-being and no fears of complications and no fear of seizures explained good compliance ($P < 0.001$).

Language: English

Keywords: Epilepsy / Adolescents / Patient compliance

Law GU, Kelly TP, Huey D, Summerbell C. Self-management and well-being in adolescents with diabetes mellitus: do illness representations play a regulatory role? *Journal of Adolescent Health*, 2002; 31(4): p.381-385
NIVEL: C 8339

The purpose of this study was to explore the relations between illness beliefs, self-management behaviour, psychological well-being, and blood glucose control in adolescents with diabetes mellitus. The applicability of the self-regulatory model to this population was investigated. Thirty adolescents attending outpatient clinics in the United Kingdom participated. Correlation and regression analyses indicated that illness beliefs were not related to self-management behaviour, but both were important contributors to psychological well-being.

Language: English

Keywords: Diabetes mellitus / Adolescents / Quality of life / Self care / Sick role

Palisano RJ, Tieman BL, Walter SD, Bartlett DJ, Rosenbaum PL, Russell D, Hanna SE. Effect of environmental setting on mobility methods of children with cerebral palsy. *Developmental Medicine & Child Neurology*, 2003; 45(2): p.113-120
NIVEL: C 8454

The aim of this study was to investigate how mobility methods of children with cerebral palsy (CP) and their need for adult assistance vary across environmental settings like home, school, outdoors and in the community. The participants were a stratified random sample of 636 children with CP (355 males and 281 females; 2 to 12 years of age, mean 6.8 years SD 2.7), receiving rehabilitation services. Children were grouped by age and Gross Motor Function Classification System (GMFCS) level. Among the five levels of the GMFCS, there were 185 children classified at level I, 81 children at level II, 113 children at level III, 132 children at level IV, and 125 children at level V. Information on children's usual mobility was obtained by parent report. The results of logistic regression indicated that compared with the school setting, children were more dependent on adult assistance for mobility when outdoors/in the community and less dependent at home. The majority of children aged from 4 to 12 years at levels III to V used wheelchair mobility at school and outdoors or in the community, however, only a small percentage self-propelled their wheelchair or used powered mobility. Of the children aged 4 to 12 years at level V, 39% were carried at home. The findings suggest that environmental setting is an important consideration for assessment and intervention to improve mobility of children with CP. For children who do not walk, attention should be given to the needs of caregivers and factors that are important for successful powered mobility.

Language: English

Keywords: Cerebral palsy / Motor skills / Activities of daily living / Needs assessment

Rich M, Patashnick J, Chalfen R. Visual illness narratives of asthma: explanatory models and health-related behaviour. *American Journal of Health Behavior*, 2002; 26(6): p.442-453
NIVEL: C 8525

OBJECTIVE: To examine explanatory models of asthma to determine how these belief systems contribute to medical self-management, compliance and asthma-related behaviour. **METHODS:** Children and adolescents with poorly controlled asthma used Video Intervention/Prevention Assessment (VIA) to generate visual illness narratives. Visual narratives were logged, structured using ATLAS.ti software, and coded for asthma-related beliefs and behaviours. **RESULTS:** Participants' knowledge of asthma reflected biomedical models they had been taught, but explanatory models of its origin, natural history, and prognosis were more responsive to personal experience, anecdote, and cultural beliefs. Self-management and behaviour were more powerfully affected by these models than by knowledge. **CONCLUSION:** Understanding and responding to explanatory models of asthma management may be more important than education to improve asthma-related behaviours and adherence to medical plans.

Language: English

Keywords: Asthma / Sick role / Explanatory models / Patient compliance / Self care / Health behaviour

Skinner TC, Hampson SE, Fife-Schaw C. Personality, personal model beliefs, and self-care in adolescents and young adults with Type 1 diabetes. *Health Psychology*, 2002; 21(1): p.61-70

The purpose of this study was to compare 3 models of association between personality, personal model beliefs, and self-care in adolescents with asthma. These models were as follows: (a) Emotional stability determines self-care indirectly through personal model beliefs, and conscientiousness is a direct predictor of self-care; (b) emotional stability determines self-care indirectly through personal model beliefs, and conscientiousness moderates the association between beliefs and self-care; (c) both emotional stability and conscientiousness determine self-care indirectly through personal model beliefs. A cross-sectional design was used. Participants (N = 358, aged 12-30 years) with Type 1 diabetes completed measures of personality, personal

model beliefs, and self-care. Structural equation modelling indicated that Model C was the best fit to the data.

Language: English

Keywords: Asthma / Adolescents / Young adults / Personality / Self care / Sick role / Explanatory models

Skinner TC, John M, Hampson SE. Social support and personal models of diabetes as predictors of self-care and well-being: a longitudinal study of adolescents with diabetes. *Journal of Pediatric Psychology*, 2000; 25(4): p.257-267

NIVEL: C 8558

OBJECTIVE: To examine the influence of support and personal models of illness representations on self care and quality of life in adolescents with diabetes. **METHODS:** Fifty-two adolescents (12-18 years old) with Type I diabetes were recruited and followed over 6 months, completing assessments of self-management, well-being, and social support. **RESULTS:** Perceived impact of diabetes and supportive family and friends were prospectively predictive of participants' well-being measures. Although support from family and friends was predictive of better dietary self-care, this relationship was mediated by personal model beliefs. In particular, beliefs about the effectiveness of the diabetes treatment regimen to control diabetes was predictive of better dietary self-care. **CONCLUSIONS:** Both friends and family are important to support adolescents as they live with and manage their diabetes. Personal models of diabetes are important determinants of both dietary self-care and well-being. In addition, personal models may serve to mediate the relationship between social support and dietary behaviour.

Language: English

Keywords: Diabetes mellitus / Adolescents / Sick role / Social support / Self care / Quality of life

Stewart SM, Lee PW, Low LC, Cheng A, Yeung W, Huen KF, O'Donnell D. Pathways from emotional adjustment to glycemic control in youths with diabetes in Hong Kong. *Journal of Pediatric Psychology*, 2000; 25(6): p.393-402

NIVEL: C 8493

OBJECTIVE: To get insight into the factors that influence emotional adjustment, adherence to diabetic care, and glycemic control in children and adolescents with insulin-dependent diabetes mellitus (IDDM). **METHODS:** Seventy children and adolescents living in Hong Kong, their mothers, and matched controls provided information on health beliefs, authoritarian parenting style, parent-child conflict, emotional adjustment, and adherence to medical regimen. Glycosylated haemoglobin levels were obtained to measure glycemic control. **RESULTS:** Predictors explained 34% of the variance in emotional adjustment and 39% of the variance in glycemic control. The data supported a pathway from emotional adjustment to self-efficacy to adherence behaviours to glycemic control. In contrast to Western culture and consistent with prediction, parenting style did not associate with negative outcomes, and even relatively low levels of parent-child conflict correlated negatively with emotional adjustment in this culture. **CONCLUSIONS:** Management of conflict and self-efficacy enhancing interactions are suggested interventions to enhance adherence to diabetic care in Hong Kong youths with IDDM.

Language: English

Keywords: Diabetes mellitus / Patient compliance / Coping / Sick role / Autonomy / Parent-child relations

Streisand R, Respass D, Overstreet S, Gonzalez de Pijem L, Chen RS, Holmes C. Brief report: Self-care behaviors of children with type 1 diabetes living in Puerto Rico. *Journal of Pediatric Psychology*, 2002; 27(8): p.759-764
NIVEL: C 8338

OBJECTIVE: 1) To investigate self-care behaviour of children and adolescents with type 1 diabetes living in Puerto Rico, 2) to identify potential demographic predictors of self-care behaviour, and 3) to examine the utility of the 24-hour recall interview within a Hispanic population. **METHODS:** Forty-one children (M age = 12.6 years) with type 1 diabetes, and their mothers, were administered the 24-hour recall interview on three separate occasions to assess diabetes-related self-care behaviours. **RESULTS:** Children reported self-care behaviours that included daily administration of an average of two insulin injections and two blood glucose tests, and consumption of 5.5 meals a day comprised of 52% carbohydrates and 29% fat. Younger age, female gender, longer illness duration, and better metabolic control were associated with higher rates of several self-care behaviours. **CONCLUSIONS:** Data provide a first look at self-care

behaviours of children with type 1 diabetes living in Puerto Rico and suggest the utility of the 24-hour recall interview within this population.

Language: English

Keywords: Diabetes mellitus / Self care / Socioeconomic factors

Williams C. Doing health, doing gender: teenagers, diabetes and asthma. *Social Science & Medicine*, 2000; 50(3): p.387-396

The aim of this study was to explore the interaction of gender with the management of chronic illness during adolescence, focusing on the ways in which the social constructions of femininities and masculinities affect how teenagers live with asthma or diabetes. The majority of girls incorporated these conditions and the associated treatment regimens into their social and personal identities, showing a greater adaptability to living with asthma or diabetes. However, this could have detrimental effects in terms of control, as girls sometimes lowered expectations for themselves. In addition, two aspects of the treatment regimens, diet and exercise, were found to disadvantage girls and advantage boys, because of contemporary meanings of femininities and masculinities. The social construction of femininities meant that these conditions were not seen as the threat that they were by the majority of boys interviewed, who made every effort to keep both conditions outside their personal and social identities by passing. The majority of boys maintained a 'valued' identity by feeling in control of their body and their condition. However, for the small minority of boys who were no longer able to pass the impact of chronic illness led to a 'disparaged' identity. The interaction of gender and health is seen as a complex two-way process, with aspects of contemporary femininities and masculinities impacting on the management of these conditions, and aspects of these conditions impacting in gendered ways upon the constructions of gender.

Language: English

Keywords: Asthma / Diabetes mellitus / Adolescents / Sex differences / Self care

3.2.2 *Self care from the family's perspective*

Brouwer CN, Lok CL, Wolffers I, Sebagalls S. Psychosocial and economic aspects of HIV/AIDS and counselling of caretakers of HIV-infected children in Uganda. *AIDS Care*, 2000; 12(5): p.535-540
NIVEL: C 8357

The objective of this study was to investigate the problems and needs of the caretakers of HIV-infected children in Uganda and to explore ways to improve the support given to them. A qualitative study was performed, consisting of focus group discussions with 37 participants and in-depth interviews with 11 caregivers and 10 counsellors. The knowledge that a child is infected puts a heavy emotional burden on a caregiver. Despair or depression lead to difficulties in reacting to the options and advice given by health workers. The compliance of the mother also is largely dependent on her acceptance of the HIV status of the child. Additionally, the belief that the child might die any moment may cause her not to take proper care of the child anymore. Worries of the caretakers are frequently related to poverty. Counselling of caretakers at the health centre could and should be an important element in care for HIV-infected children. Psychological and material support and advice concerning HIV infection, proper childcare and material problems may empower the caretakers. This may lead to a better follow-up of the child by health care workers and to increased compliance of and better care by the caretaker, which will improve life and survival of an infected child.

Language: English

Keywords: Hiv / Aids / Parents / Psychological stress / Socioeconomic factors / Developing countries

Butz AM, Eggleston P, Huss K, Kolodner K, Vargas P, Rand C.
Children with asthma and nebulizer use: parental asthma self-care practices and beliefs. *Journal of Asthma*, 2001; 38(7): p.565-573
NIVEL: C 8356

The aims of this study were: 1) to examine demographic characteristics, patterns of medication use, asthma morbidity, and asthma self-management practices and beliefs among inner-city children currently using a nebulizer, and 2) to describe the relationship between asthma self-management practices and beliefs and anti-inflammatory (AI) therapy. A high rate of morbidity, including frequent emergency room visits, hospitalisations, symptom days and nights, and school absences were observed in this group of school-aged children with asthma. More than three-quarters (81%) reported asthma symptoms consistent with mild persistent or greater severity of asthma, and therefore these subjects should be taking AI medications. Another 16% (36 of 231) of these children reported symptoms consistent with mild intermittent asthma. Only 1 out of 7 children in this study reported taking AI medications. It was concluded that parents of children taking daily

AI medications were more likely to agree with the belief that children should use asthma medications daily even when the child is not reporting any symptoms.

Language: English

Keywords: Asthma / Parents / Attitude / Patient compliance / Self care

Callery P, Milnes L, Verduyn C, Couriel J. Qualitative study of young people's and parents' beliefs about childhood asthma. *British Journal of General Practice*, 2003; 53 (488): p.185-190

OBJECTIVE: To explore the beliefs of a group of young people with asthma and their carers about the illness and its management. **METHODS:** A qualitative study was conducted using conversational-style interviews. Interviews were conducted with 25 young people with asthma and separately with their carers. The interviews were analysed using the principles and procedures of grounded theory. **RESULTS:** Carers reported assessing asthma symptoms through observed effects on the child and other family members, including emotions and behaviours that disrupted family life. Young people emphasised the effect of asthma on their everyday lives and in particular the extent to which they appeared different to their peers. Some young people reported continuing symptoms and restrictions of activity that differed widely from the reports of their carers.

CONCLUSIONS: Differences between young people's and carers' criteria for assessment suggest explanations for some 'non-compliant' behaviour. Carers' assessment of asthma severity through the absence of acute attacks is consistent with managing asthma as intermittent acute episodes. Professionals should take account of differences between young people's, carers' and professionals' perceptions of asthma.

Language: English

Keywords: Asthma / Sick role / Parents / Self care / Patient compliance

Foster C, Eiser C, Oades P, Sheldon C, Tripp J, Goldman P, Rice S, Trott J. Treatment demands and differential treatment of patients with cystic fibrosis and their siblings: patient, parent and sibling accounts. *Child: Care, Health and Development* 2001; 27(4): p.349-364
NIVEL: C 8417

The aim of this study was to get insight into the impact of cystic fibrosis (CF) on patients, their mothers and siblings. Mothers are often reported to experience greater stress and poorer adjustment than mothers of well children or population norms. Patients and siblings are also reported to display adjustment difficulties. Siblings have rarely been included in research designs. This qualitative study investigates the impact of CF and treatment on 8 patients, 8 mothers, 1 father and 8 siblings. A family systems perspective was adopted. Each individual was interviewed independently using semi-structured interviews. Patients and siblings were aged between 9 and 21 years. Qualitative analyses revealed high levels of non-adherence (intentional and unintentional) and parental involvement in treatment, minimal involvement of siblings, and preferential treatment towards patients. Demanding treatment, coupled with the progressive nature of CF, promote high levels of parental involvement for younger children as well as older teenagers, often due to attempted or actual non-adherence. Siblings may receive less attention while patients' needs take priority. Future development of a measure of adherence suitable for children and adolescents should take into account different motivations for non-adherence, particularly regarding the level of personal control over adherence to treatment. In addition, the potential impact of having a brother or sister with CF should not be underestimated and the needs of siblings should not go unnoticed.

Language: English

Keywords: Cystic fibrosis / Mothers / Siblings / Family relations / Patient compliance

Hanna KM, Guthrie D. Parents' perceived benefits and barriers of adolescents' diabetes self-management: part 2. *Issues in Comprehensive Pediatric Nursing*, 2000; 23(4): p.193-202
NIVEL: C 8403

This study's purpose was to identify perceived benefits and barriers of the parents of diabetic adolescents about the process of decision making regarding the adolescents' assumption of diabetes management. The researchers interviewed 17 parents of adolescents with type I diabetes. Questions were adapted from Janis and Mann's (1977) decisional balance sheet. Interviews were audiotaped and transcribed verbatim. Descriptive expressions were identified and categories inductively generated. Inter-rater agreement was initially 85% and was 100% after discussion of disagreements. Parents' perceived benefits for themselves were relief from burden and knowledge and confidence and/or pride in adolescents' abilities.

Their perceived benefits for their sons and daughters were also twofold: knowledge and/or confidence in abilities and freedom, independence, and/or control. Parents perceived barriers for themselves were loss of control, authority, and supervision, dealing with consequences. and expression of lack of barriers. Their perceived barriers for their sons and daughters were burden of responsibility and also lack of barriers. Understanding parents' perceived benefits and barriers would be beneficial to health care professionals when working with parents, because decision making related to the transfer of diabetes management to their adolescent sons and daughters is crucial to the success of its management.

Language: English

Keywords: Diabetes mellitus / Adolescents / Sick role / Self care / Parents

Otero S, Hodes M. Maternal expressed emotion and treatment compliance of children with epilepsy. *Developmental Medicine & Child Neurology*, 2000; 42(9): p.604-608
NIVEL: C 8453

The aim of this study was to investigate the association between family relations, in particular expressed emotion, and treatment compliance in children with epilepsy. It was hypothesised that maternal expressed emotion would be associated with poor compliance and that epilepsy frequency and psychiatric symptoms would be greater in children with poor compliance. It was a prospective study of 21 families with a child who had epilepsy attending Central Middlesex Hospital, London. There were 13 boys and eight girls, with a mean age of 12.0 years (SD 2.9) at initial assessment. Mothers were interviewed for assessment of expressed emotion as a measure of parent-child relationships. Assessment of the mothers' adjustment using the General Health Questionnaire (Goldberg 1978), and psychological adjustment of the children using the Rutter Scales (Rutter et al. 1970a), were completed by mothers and teachers. Reassessment was 3 to 4 years after initial contact, including a paediatric case-note review to assess clinic attendance and overall treatment compliance. Significantly more of the group who had a good level of compliance had recovered from epilepsy at follow-up. Good treatment compliance was found to be associated with less maternal hostility and criticism. Children and mothers in the good compliance group had fewer psychiatric symptoms. Poor treatment compliance and the associated psychological disturbances suggest that assertive paediatric and psychosocial intervention may be needed for some children with epilepsy.

Language: English

Keywords: Epilepsy / Patient compliance / Parent-child relations / Psychological stress / Mental disorders

Pendley JS, Kasmien LJ, Miller DL, Donze J, Swenson C, Reeves G. Peer and family support in children and adolescents with type 1 diabetes. *Journal of Pediatric Psychology*, 2002; 27(5): p.429-438
NIVEL: C 8550

OBJECTIVE: To examine the influences of peer and family social support on the management and health outcome of children and adolescents with diabetes. **METHODS:** Sixty-eight youths ages 8 to 17 diagnosed with type 1 diabetes participated. This study represents the phase 1 data from a multisystemic, home-based intervention. Data included parent and youth report of disease management and conflict, youth-reported perceptions of support, peer participation in the intervention, and HbA1c. **RESULTS:** Adolescents perceived greater diabetes-related peer support than did school-age children. Perceived peer and family support were not correlated with metabolic control. Peer participation in the intervention was correlated with metabolic control. **CONCLUSIONS:** There is a developmental shift in perceptions of peer support. Increased perceptions of peer and family support overall may not result in improved metabolic control. Social support interventions should focus on the types of support that are most highly associated with positive health outcomes.

Language: English

Keywords: Diabetes mellitus / Social support / Family relations / Peer relations / Self care / Health status

Powers SW, Patton SR, Byars KC, Mitchell MJ, Jelalian E, Mulvihill MM, Hovell MF, Stark LJ. Caloric intake and eating behavior in infants and toddlers with cystic fibrosis. *Pediatrics*, 2002; 109(5): E75: 1-10
NIVEL: C 8462

OBJECTIVE: To compare the caloric intake, including percentage of Recommended Daily Allowance (RDA), between infants and toddlers with Cystic Fibrosis (CF) and healthy peers. Also, (problematic) eating behaviours were compared. **METHODS:** A 2-group comparison study was carried out with a clinical sample of 35 infants and toddlers with CF (M = 18.6; standard deviation = 8.1 months; range = 7-35 months) and a community sample of 34 healthy peers matched for age, gender,

socioeconomic status, and number of parents and siblings present during mealtimes. Children's caloric intake was measured using 3-day diet diaries. RESULTS: The 2 groups did not differ on the total number of calories consumed per day, the percentage of calories derived from fat, or the percentage of RDA consumed per day. Infants and toddlers with CF were not meeting the CF dietary recommendations of 120% to 150% RDA for energy with 40% of calories coming from fat. Videotaped recordings of children's dinner meals were scored for meal duration, number of bites and sips per minute, number of calories per bite or sip, and the percentage of 10-second intervals with bites and sips. The CF sample had significantly longer mealtimes (20.2 minutes) than the control group (16.4 minutes), but did not differ on calories consumed at the meal, bites and sips per minute, calories per bite and sip, or time spent eating during the meal. On the Behavioral Pediatrics Feeding Assessment Scale, a measure of parental perceptions of mealtime behaviour that was completed by a subset of families (39 families), parents of infants and toddlers with CF endorsed a greater number of mealtime behaviours as problems and a higher occurrence of problems than did parents of controls. Parents of children with CF chose a greater number of mealtime strategies and feelings as problems and reported more frequently using problematic strategies at mealtimes than did parents of controls. For the entire sample, a positive correlation of 0.29 was found between the number of mealtime behaviour problems reported by parents and meal duration, suggesting the co-occurrence of problematic mealtime behaviour with longer meal duration. No relationship was found between the number of child mealtime behaviour problems reported by parents and the number of calories consumed during the filmed meal. For the CF sample, a correlation of -0.26 between children's weight percentile for age and the filmed meal duration was found, suggesting a tendency for meal duration to increase as children's weight for age decreases. Post-hoc analyses were conducted comparing infants and toddlers with previously reported samples of preschool and school-aged children on meal duration. Results demonstrated that in each group, children with CF had longer meals than age-matched controls. CONCLUSIONS: These findings reveal significant deficits in achieving dietary recommendations for many families of infants and toddlers with CF. Only 11% of infants and toddlers with CF met the CF dietary recommendation of at least 120% of the RDA/day for energy. In addition, infants and toddlers were found to derive only 34% of their daily calories from fat, compared with the recommended 40% needed for a moderate to high fat diet. These results underscore the need for intervention in families of infants and toddlers with CF.

Language: English

Keywords: Cystic fibrosis / Infants / Pre-school children / Feeding

Sayre JM, Pianta RC, Marvin RS, Saft EW. Mothers' representations of relationships with their children: relations with mother characteristics and feeding sensitivity. *Journal of Pediatric Psychology*, 2001; 26(6): p.375-384
NIVEL: C 8497

OBJECTIVE: To get insight into the relationship between representations of the caregiving relationship and feeding interactions of mothers of children with a serious disability, cerebral palsy (CP), and the extent to which mothers' representations predict their feeding behaviour beyond other mother and child characteristics. **METHODS:** Fifty-eight mothers of children with mild to severe CP ages 16 to 52 months were interviewed with an adapted form of the Parent Development Interview (PDI). Correlation and regression analyses examined relations between representations (compliance with parental requests, achievement, secure base, enmeshment, worry about the child's future, and emotional pain), demographic characteristics, diagnostic severity, and developmental status. **RESULTS:** Mothers with more compliance-related concerns showed less sensitivity, acceptance, and delight during feeding. Mothers experiencing more emotional pain displayed more hostility. Mothers reporting worries about the child displayed sensitivity and delight. Representations of compliance-related experiences and worry about the child's future accounted for significant increments in explained variance in mothers' feeding behaviour, after children's skills and abilities were controlled for. **CONCLUSIONS:** Findings suggest maternal representations of relationships are associated with caregiving behaviour for mothers of children with CP apart from other child and maternal characteristics and may be a useful focus for research and practice related to parenting children with special needs.

Language: English

Keywords: Cerebral palsy / Infants / Pre-school children / Parent-child relations / Feeding

Spieth LE, Stark LJ, Mitchell MJ, Schiller M, Cohen LL, Mulvihill M, Hovell MF. Observational assessment of family functioning at mealtime in preschool children with cystic fibrosis. *Journal of Pediatric Psychology*, 2001; 26(4): p.215-224
NIVEL: C 8491

OBJECTIVE: To examine how family systems are affected by dietary regimes for children with a chronic illness. **METHODS:** Twenty-nine families of children with Cystic Fibrosis (CF) and 29 families of children with no chronic illness, aged 2 to 6 years, were involved. Ratings of 7 dimensions of family functioning on the McMaster Mealtime Family Interaction Coding System (MICS) were obtained during a videotaped dinner meal at home. **RESULTS:** Ratings of families with a child with CF were significantly lower than those for families of children without a chronic illness on Overall Family Functioning and five of the six MICS dimensions: Communication, Interpersonal Involvement, Affect Management, Behaviour Control, and Role Allocation and approached significance on the Task Accomplishment dimension. The ratings of families of a child with CF were in the "clinically significant" range on all subscales, including Task Accomplishment. **CONCLUSIONS:** This study suggests that family functioning at mealtimes may be different in families of children with CF in which explicit dietary guidelines exist than in families of children with no illness or dietary guidelines. These results are discussed in terms of global family functioning and treatment approaches to dietary treatment recommendations.

Language: English

Keywords: Cystic fibrosis / Infants / Pre-school children / Family relations / Feeding

Steele RG, Anderson B, Rindel B, Dreyer ML, Perrin K, Christensen R, Tyc V, Flynn PM. Adherence to antiretroviral therapy among HIV-positive children: examination of the role of caregiver health beliefs. *AIDS Care*, 2001; 13(5): p.617-629
NIVEL: C 8348

The aim of this study was to examine the association between two components of the Health Belief Model (perceived vulnerability and barriers) and adherence to antiretroviral therapy (ART) among HIV-infected children. The parents/caregivers of 30 children (mean age = 5.21, SD = 3.18) who were HIV-infected and who were on active ART were surveyed to assess current methods of adherence assessment and educational efforts within the institution. All participants (except one) were African American and reported low monthly family incomes. Assessment instruments included measures of perceived vulnerability, caregiver-reported adherence and perceived barriers, and objective measures of adherence (clinical pill count; electronic measurement). The results failed to demonstrate a significant relationship between parental perceived vulnerability, perceived barriers and

adherence to antiretroviral medications. Methods of assessing adherence provided significantly discrepant estimates of adherence. Results are discussed in terms of implications for patient care and for future research in this area. The addition of behavioural and motivational components to traditional educational approaches may positively impact treatment results.

Language: English

Keywords: Hiv / Attitude / Parents / Patient compliance

Sullivan-Bolyai S, Deatrck J, Gruppuso P, Tamborlane W, Grey M. Constant vigilance: mothers' work parenting young children with type 1 diabetes. *Journal of Pediatric Nursing*, 2003; 18(1): p.21-29
NIVEL: C 8511

The aim of this study was to describe the day-to-day experiences of mothers raising young children under 4 years of age with type 1 diabetes. Twenty-eight mothers were involved in this study. Descriptive, naturalistic inquiry principles were used to interview subjects, as well as to manage and analyse the data. The mothers reported using the management behaviour of constant vigilance. Their concerns about hypoglycemia and providing competent care reflected the interplay between their fears and profound sense of responsibility for managing the disease. Mothers reported having to learn the management behaviours and to occasionally adjust the day-to-day management when either severe hypoglycemia or developmental milestones occurred. Although mothers initially had feelings of incompetence with the care they provided, with time, they became very skilled. There were also reports of limited access to babysitting, child care, or respite services. The intensity of their constant vigilance associated with their concerns, responsibility, and lack of supports resulted in some mothers having physical and/or emotional problems. The findings of the study highlight the importance of identifying family and/or community resources that may provide mothers with support that could reduce some of the tremendous stress and burden of responsibility experienced after diagnosis of diabetes.

Language: English

Keywords: Diabetes mellitus / Pre-school children / Mothers / Psychological stress

Thompson SJ, Auslander WF, White NH. Influence of family structure on health among youths with diabetes. *Health & Social Work*, 2001; 26(1): p.7-14

NIVEL: C 8526

The aim of this study was to examine the extent to which family structure is significantly associated with health in youths with Type 1 diabetes. A convenience sample of 155 children with diabetes and their mothers completed face-to-face interviews; multiple regression analyses were conducted. Findings demonstrated that family structure remains a significant predictor of youths' health when statistically controlling for race, child's age, family socioeconomic status, and adherence. Social workers in outpatient medical settings are in a unique position to develop family-oriented strategies targeting this neglected area of primary care.

Language: English

Keywords: Diabetes mellitus / Family relations / Family environment / Health status / Socioeconomic factors

Williams C. Alert assistants in managing chronic illness: the case of mothers and teenage sons. *Sociology of Health & Illness*, 2000; 22(2): p.254-272

The purpose of this study was to develop the organising concept of the 'alert assistant' to identify and explore the skilled and often invisible work which mothers of teenage boys with a chronic illness carried out on behalf of their sons. The term 'alert assistant' implies that the needs of the person being assisted are identified, or preferably anticipated and subsequently met, by the assistant. Two inter-relating factors influenced how mothers constructed the need of their sons for an alert assistant: mothers' perceptions of the self-care abilities of their sons, and the gendered ways in which boys lived with chronic illness. Dilemmas for the alert assistant, including being blamed for mollycoddling, are discussed. It is suggested that the incisive concept of the alert assistant not only has the potential to increase understandings of the gendered management and experience of illness, but that it also could be useful in other diverse settings.

Language: English

Keywords: Asthma / Diabetes mellitus / Adolescents / Mothers / Parent-child relations / Social support / Self care

Worrall-Davies A, Owens D, Holland P, Haigh D. The effect of parental expressed emotion on glycaemic control in children with Type 1

diabetes: parental expressed emotion and glycaemic control in children.

Journal of Psychosomatic Research, 2002; 52(2): p.107-113

OBJECTIVE: To measure expressed emotion (EE) in parents of young children with diabetes and to examine the relation between EE and glycaemic control in children with Type 1 diabetes in a longitudinal study over 24 months. It was hypothesised that good glycaemic control, as measured by low glycated haemoglobin levels, would be predicted by high parental emotional over-involvement, low frequency of critical comments and absence of hostility. It was predicted that these effects would be stronger in maternal than paternal scores. **METHODS:** Forty-seven children attending a Paediatric Diabetes Clinic and their parents were studied over 24 months. Glycated haemoglobin was measured on three occasions, at the start of the study period, 12 and 24 months later. At 12 months, parental EE was measured using an adapted version of the Camberwell Family Interview, and child emotional and behavioural problems were measured using the parent version of the Child Behavior Checklist. Multiple regression models were used to test the hypotheses. **RESULTS:** Forty-three maternal and 33 paternal interviews of adequate quality for analysis were obtained. Paternal hostility was found to be associated with elevated glycated haemoglobin measured 12 months before interview and 12 months after interview, accounting for 22% and 29% of the variation in glycated haemoglobin respectively. **CONCLUSIONS:** Parental emotional over-involvement or criticism did not predict glycaemic control. Presence of hostility was important, but in contrast to the study's hypothesis, this was paternal rather than maternal hostility. The authors suggest that (i) relatively absent, rejecting fathers play little role in diabetes management and children perceive this negatively, or (ii) mothers who are unsupported by fathers cannot in turn support their children in diabetes care.

Language: English

Keywords: Diabetes mellitus / Parent-child relations / Health status / Self care

4 Health care service

4.1 Health care service from the patient's perspective

Amre DK, Infante-Rivard C, Gautrin D, Malo JL. Socioeconomic status and utilization of health care services among asthmatic children. *Journal of Asthma*, 2002; 39(7): p.625-631

NIVEL: C 8337

The purpose of this study was to evaluate the relationship between socioeconomic factors and hospitalisation and/or emergency department (ED) visits among asthmatic children who have universal access to health care. Newly diagnosed asthmatic children, aged 3-4 years, were followed for a period of 6 years. Information on hospitalisation and ED visits was obtained by interviewing parents. Socioeconomic status (SES) was measured by paternal occupation, race, type of dwelling, and an index of crowding. After adjusting for asthma severity, logistic regression analysis showed that children with fathers in the economically least advantaged occupations were more likely to be hospitalised due to their asthma [father's occupation group 3 (FOG3), odds ratio (OR)=2.1, 95% confidence interval (95% CI)=0.2-19.8; father's occupation group 4 (FOG4), OR=13.9, 95% CI=1.1-181.4]. The probability of emergency department visits was not significantly different according to the studied variables. Emergency department visits were not influenced by SES variables, probably due to the absence of financial barriers to access health care. However, SES differences in hospitalisation may suggest differential management and/or treatment practices according to socioeconomic status at the emergency departments.

Language: English

Keywords: Asthma / Hospitalisation / Health care utilisation / Socioeconomic factors

Canobbio MM. Health care issues facing adolescents with congenital heart disease. *Journal of Pediatric Nursing*, 2001; 16(5): p.363-370
NIVEL: C 8444

The aim of this article is to review a number of issues beyond the medical and clinical aspects that are important in providing health care to adolescents with congenital heart disease. Transitional health-related issues facing these adolescents include medical follow-up, insurability, employability, sexuality, and reproduction. Besides, advising and counselling of both patients and parents is discussed.

Language: English

Keywords: Congenital heart defects / Adolescents / Employment / Sexual behaviour / School / Needs assessment

Carter B. Chronic pain in childhood and the medical encounter: professional ventriloquism and hidden voices. *Qualitative Health Research*, 2002; 12(1): p.28-41

NIVEL: C 8458

The aim of this study was to explore the impact of chronic pain on affected children and their families. Three families participated in an elaborate interview study. In the interviews, not only the effect of chronic pain on family life was an important issue, but also the difficulties families experienced with the medical professionals. The children and families experienced numerous encounters with health professionals during their "quest for a diagnosis" for chronic pain. In a high proportion of these encounters, the children/families felt they were judged, disbelieved, and labelled as difficult or dysfunctional, and this compounded the stresses they were already dealing with. The families described situations in which their accounts of pain were reinterpreted through a variety of professional lenses, and the children felt that their voices were muted or ignored. Professional ventriloquism is presented as a means of exploring the way in which the child's words are reinterpreted and mistranslated through professionals' own paradigms of understanding. Professionals need to stand back from what they believe to determine what the children themselves know about their pain.

Language: English

Keywords: Chronic pain / Doctor-patient relations / Professional-family relations

DiNapoli PP, Murphy D. The marginalization of chronically ill adolescents. *The Nursing Clinics of North America*, 2002; 37(3): p.565-572
NIVEL: C 8580

In this article, the ways adolescents with chronic illnesses experience marginalisation are discussed. The authors also address how nurses can better help adolescents meeting developmental needs for autonomy, self esteem and social acceptance. In the author's proposed model, it is essential that nurses promote strategies that empower chronically ill adolescents. Care should be community-based and have an integrated multidisciplinary approach involving nursing, medicine, allied health care providers, and, (very importantly) the social networks of the adolescent. For optimal health outcomes, we must begin to empower the chronically ill to meet their developmental need both within their social and medical contexts.

Language: English

Keywords: Chronic diseases, general / Adolescents / Social participation / Autonomy / Nursing

Eekelen FC van, Perquin CW, Hunfeld JA, Hazebroek-Kampschreur AA, Suijlekom-Smit LW van, Koes BW, Passchier J, Wouden JC van der. Comparison between children and adolescents with and without chronic benign pain: consultation rate and pain characteristics. *British Journal of General Practice*, 2002; 52(476): p.211-213

The purpose of this study was to examine whether children with chronic benign pain consult their general practitioner (GP) more frequently than those without chronic benign pain. A random sample of children and adolescents aged between 0 and 18 years of age was drawn from the records of ten general practices. According to their responses to a pain questionnaire, subjects were assigned to the chronic benign pain group (n = 95) if they had pain of more than three months' duration, or to the control group (n = 105) if they had pain of less than three months' duration or no pain at all. All the subjects had an average GP consultation rate of 2.6 contacts per year. No significant age and sex differences were found. Chronic benign pain in childhood and adolescence is not related to increased use of healthcare services, suggesting that somatisation does not play a major role in children with chronic benign pain.

Language: English

Keywords: Chronic pain / Health care utilisation

Fleming E, Carter B, Gillibrand W. The transition of adolescents with diabetes from the children's health care service into the adult health care service: a review of the literature. *Journal of Clinical Nursing*, 2002; 11(5): p.560-567
NIVEL: C 8438

Adolescents with diabetes have unique health needs, which impact upon their transition from children's health care services into adult health care services. These health needs result from the precarious period in their lives. The impact of emotional and physical demands upon the adolescent means that they are more susceptible to non-adherence, which may result in reduced diabetic control. This literature review identifies some of the many barriers erected to the transition from the children's health care services into the adult health care system; these barriers may be constructed by any one of the parties involved: the children's health care team, adult health care team, the adolescent or their family. Principles of a successful transition are explored, along with the prerequisite qualities required of health care providers and the health care service.

Language: English

Keywords: Diabetes mellitus / Adolescents / Quality of care / Needs assessment / Reviews

Houston EC, Cunningham CC, Metcalfe E, Newton R. The information needs and understanding of 5-10-year old children with epilepsy, asthma or diabetes. *Seizure*, 2000; 9(5): p.340-343
NIVEL: C 8530

The aim of this exploratory study was to investigate what children between 5 and 10 years of age with epilepsy, asthma or diabetes know about their condition, where they have obtained this information and how they feel the condition affect their lives. Twenty-two 5-10-year olds with epilepsy were compared with 10 children with asthma and 10 with diabetes of the same age range. The children were interviewed whilst attending specialist clinics by the first author and were unaware of her professional status. All the children had access to specialist nurses and their families had received literature about their condition. The interview covered five main areas: knowledge of their condition, psychological effects, medication, restrictions on lifestyle, where they obtained their information and if they had unanswered questions. The children with epilepsy had far more unanswered questions and felt excluded from discussions with doctors. They also appeared reluctant to tell their friends their diagnosis and, at such a young age, felt stigmatised by their condition. The results highlight a contrast in the understanding of children with epilepsy when compared with those with asthma or diabetes. It is proposed that if a simple biological model were used to explain epilepsy this could aid children's understanding and reduce their reluctance to disclose their diagnosis.

Language: English

Keywords: Epilepsy / Asthma / Diabetes mellitus / Needs assessment / Quality of life

Köhlen C, Beier J, Danzer G. "They don't leave you on your own:" a qualitative study of the home care of chronically ill children. *Pediatric Nursing*, 2000; 26(4): p.364-371
NIVEL: C 8400

This study was aimed at describing how families with a chronically ill child experience the home care they receive. A qualitative study was carried out in which interviews were taken with 5 families and 2 head nurses at External

Care Services (EPD) in Berlin, Germany, an institution focused exclusively on home care for children. The positive experiences expressed by parents reflect the patient-oriented understanding of caring developed by the EPD, which strives for the qualified instruction of families and the building of caring relationships. As a result of the care offered by the EPD, many children are spared the repeated hospitalisations that so hinder the normalisation of family life and impede family health.

Language: English

Keywords: Chronic diseases, general / Home care / Nursing / Professional-family relations

McGrath P, Pitcher L. 'Enough is enough': qualitative findings on the impact of dexamethasone during reinduction/consolidation for paediatric acute lymphoblastic leukaemia. *Supportive Care in Cancer*, 2002; 10(2): p.146-155
NIVEL: C 8396

The aim of this longitudinal study was to explore the experience of treatment for acute lymphoblastic leukaemia (ALL) and related haematological disorders with the drug dexamethasone, from the perspective of the sick children, their parents and their well siblings. Interviews were conducted with the parents and children of the first 11 ALL families who have completed the re-consolidation stage of treatment. The results indicate that the negative impact of this drug is particularly severe during the reconsolidation stage, when families are exhausted with coping with the intensity of treatment. Thus, the administration of dexamethasone is a critical point in the pathway of care for children with ALL. The emotional consequences of the drug are profoundly disturbing, not only for the child, but for the whole family. The findings indicate that the period when dexamethasone is being administered is an important time for providing families with emotional support and information about likely sequelae of treatment. Because of guilt and self-doubt parents will not necessarily seek help, even if it is greatly needed. Recommendations are provided as to possible ways of reducing the distressing impact of the administration of this pharmaceutical intervention.

Language: English

Keywords: Leukaemia / Psychological stress

Nordli DR Jr. Special needs of the adolescent with epilepsy. *Epilepsia*, 2001; 42 (Suppl 8): p.10-17
NIVEL: C 8408

The aim of this review is to address factors which affect seizure control in adolescents with epilepsy. Matching the medicine to the patient is particularly important in teenagers, a group of patients with special needs. Common seizure syndromes presenting in adolescence are briefly reviewed and used to illustrate key issues that may arise in the selection of antiepileptic medication (AED). Compliance, interaction with other medications including oral contraceptive medications, cosmetic effects, teratogenicity, and impact on behaviour are all factors to be considered. Newer medications may have some advantages over older compounds in this regard, and evidence of their utility is reviewed in the specific context of the epilepsy syndromes. In addition to prescribing medication, other important parts of the therapeutic management involve education, counselling, support, and advocacy. To identify issues and to provide appropriate counselling, it is beneficial to devote some of the office visit to an independent interaction with the patient, apart from the parents. One study questionnaire indicated that nurse specialists may be particularly valuable in supporting and meeting the needs of patients in this age group. Some centres have developed elegant methods of helping the patient make the transition from child neurology to adult neurology.

Language: English

Keywords: Epilepsy / Adolescents / Social support / Needs assessment / Reviews

Perquin CW, Hunfeld JA, Hazebroek-Kampschreur AA, Suijlekom-Smit LW van, Passchier J, Koes BW, Wouden JC van der. Insights in the use of health care services in chronic benign pain in childhood and adolescence. *Pain*, 2001; 94(2): p.205-213
NIVEL: C 8354

The aim of this study was to investigate the utilisation of health care services in children and adolescents with chronic benign pain. A Dutch population sample of 254 chronic pain sufferers aged 0-18 years, who had reported chronic pain (continuous or recurrent pain >3 months) in a previous prevalence study, were asked to keep a 3-week diary on their pain and to fill out questionnaires on background factors, health care use and the impact of pain. Parent ratings were used for children aged 0-11 years, self-report was used in adolescents (12-18 years). In a 3-month period, in 53.4% of the cases

medication was used for pain, and general practitioners and specialists were consulted for pain in 31.1% and 13.9% of subjects, respectively. Physiotherapists, psychologists and alternative health providers were visited by 11.5, 2.8, and 4.0%, respectively. In the preceding year, 6.4% had been hospitalised due to pain. The most important factors linked to utilising medical services were gender, various pain characteristics, school absenteeism and disability. Although consulters reported to be less physically fit and less satisfied with health, their parents were better adapted to the pain, by talking and sharing, mutual support, normalisation of the child and heightened self esteem, than non-consulters. Prospective studies are needed to test causality of coping on care-seeking behaviour.

Language: English

Keywords: Chronic pain / Health care utilisation / School absenteeism

Perquin CW, Hazebroek-Kampschreur AA, Hunfeld JA, Suijlekom-Smit LW van, Passchier J, Wouden JC van der. Chronic pain among children and adolescents: physician consultation and medication use.

Clinical Journal of Pain, 2000; 16(3): p.229-235

NIVEL: C 8614

OBJECTIVE: To assess physician consultation and use of medication in Dutch children and adolescents (0-18 years old) having chronic pain in relation to sociodemographic factors and pain characteristics. **METHODS:** A population-based cross-sectional survey was used. A questionnaire was either mailed to the participants' parents or distributed at school, and it was filled out by the parents (for children aged 0-7 years) or by the participant (for children and adolescents aged 8-18 years). Participants included a random sample of 1,300 children aged 0 to 3 years taken from the register of population. In addition, 41 schools were selected to obtain a representative sample of 5,336 children and adolescents aged 4 to 18 years. Outcome measures were reported physician consultation and medication use. **RESULTS:** Of the 6,636 children and adolescents surveyed, 5,424 (82%) responded. A total of 1,358 respondents (25%) reported chronic pain. Of these, 57% had consulted a physician and 39% had used medication for the pain. Respondents with earache, more intense pain, and more frequent pain and those attending lower vocational training programs were more likely to consult a physician for the pain than the average respondent. Respondents with earache, sore throat, headache, more intense pain, and multiple pain, children aged 0 to 3 years, and girls were more likely to use medication for the pain. Logistic regression analyses showed that for physician consultation,

the most significant predictive factors were the intensity of pain, age, and earache as well as the level of education for respondents aged 12 to 16 years. The use of medication was predicted by earache, headache, limb pain, intensity of pain, and age. **CONCLUSIONS:** Chronic pain is a common complaint in children and adolescents, frequently resulting in consultation of a physician and medication use. Regarding physician consultation, children and adolescents with a lower educational level seem to be a group at risk.

Language: English

Keywords: Chronic pain / Health care utilisation

Sartain SA, Clarke CL, Heyman R. Hearing the voices of children with chronic illness. *Journal of Advanced Nursing*, 2000; 32(4): p.913-921

The aim of this study was to explore children's, parents' and health professionals' experience of childhood chronic illness. A qualitative study was carried out; seven families and their professional carers participated in semistructured interviews. The children's interviews were augmented with a 'drawing' technique. A grounded theory approach facilitated data collection and analysis. This article debates the perceived passivity of the voice of children in health care and research and illustrates data collection methods that seek to give children and other disadvantaged groups a voice. The children who participated in this study are described as competent interpreters of their world.

Language: English

Keywords: Chronic diseases, general / Sick role / Hospitalisation / Autonomy

Sawin KJ, Lannon SL, Austin JK. Camp experiences and attitudes toward epilepsy: a pilot study. *Journal of Neuroscience Nursing*, 2001; 33(1): p.57-64

NIVEL: C 8394

The aim of this study was to examine the effect of a camp experience on the attitudes of children and adolescents with epilepsy. It was hypothesised that the camping experience would help them to develop more positive attitudes toward their condition. Twenty campers with epilepsy who were 8-16 years of age participated in this pilot study. Attitudes, measured by the 13-item Child Attitude Toward Illness Scale (CATIS), were assessed before and after the camp experience. No pretest or posttest difference in attitude toward

epilepsy was found in the total group. However, when attitudes were examined by seizure frequency, there was a trend for those with more frequent seizures to report a more positive attitude after the camp experience. Issues in evaluating camp experiences for youth with chronic conditions are reviewed, and recommendations are made for a comprehensive camp evaluation. Nurses are encouraged to assist families whose child is challenged by more frequent seizures to consider a camp experience.

Language: English

Keywords: Epilepsy / Sick role / Leisure / Self care

Ullrich G, Mattussek S, Dressler F, Thon A. How do adolescents with juvenile chronic arthritis consider their disease related knowledge, their unmet service needs, and the attractiveness of various services?

European Journal of Medical Research, 2002; 7(1): p.8-18

NIVEL: C 8520

AIMS: To explore the information needs of adolescents with juvenile chronic arthritis (JCA) with respect to patient education and other measures to promote self-management. METHODS: A standardised cross-sectional inquiry was conducted, concerning disease-related knowledge, perceived importance of information giving, unmet needs as well as perceived attractiveness of a range of services (lecture, structured patient education, support group, self-help group) to promote self-management. The study sample consisted of 48 adolescents with JCA (mean age $x = 14.9 (+/- 2.1)$ years; 56% female; 17% had the oligoarthritis form of JCA, 40% juvenile spondylarthritis, 25% polyarthritis and systemic form, 19% other rheumatic diseases). RESULTS: The majority of adolescents considered themselves as sufficiently well-informed and voted in favour of detailed information giving. However, 30% were unsatisfied with their current information and knowledge. Information needs predominantly related to the prognosis, course, and treatment of JCA, whereas the psychosocial impact (except sports and job matters) were judged as less important. Adolescents with a lower level of education were generally more interested than those with a high level of education. As for the attractiveness of services nearly half of the adolescents judged all of them as not very attractive. CONCLUSIONS: The majority of adolescents is interested in detailed information giving and some of them point to unmet needs, but nearly half of them is hesitant towards services which are delivered in a group format (such as structured patient education or support groups).

Language: English

Keywords: Rheumatoid arthritis / Adolescents / Needs assessment

Verhoeven-Wind L. Oud en wijs genoeg. (Old and wise enough.) *TVZ: Tijdschrift voor Verpleegkundigen*, 2002; 112(8): p.62-65

The purpose of this study was to examine the experiences with transition from paediatric to adult care, with respect to adolescents suffering cystic fibrosis. The main question was how adolescents and their parents subjectively experience this transition. Adolescents aged 18-21 years and their parents were interviewed. The majority of the respondents did not experience many problems. Transition of care turned out to be problematic for a relatively small group of adolescents who had intensive contact in paediatric care. Although in this study only a small group of adolescents with cystic fibrosis was involved, and only one academic centre, these results are possibly relevant for adults and their parents who live in a comparable situation.

Language: Dutch

Keywords: Cystic fibrosis / Adolescents / Parents / Quality of care / Patient satisfaction

4.2 Health care service from the family's perspective

Aytch LS, Hammond R, White C. Seizures in infants and young children: an exploratory study of family experiences and needs for information and support. *Journal of Neuroscience Nursing*, 2001; 33(5): p.278-285
NIVEL: C 8412

This exploratory study was conducted to get insight into the experiences of parents caring for young children with seizure disorders and their perceived needs for information and support. A questionnaire and interview protocol was designed to elicit information about the child's seizure history, child and parent health history, medical and support services, child and family demographic information, parent experiences in caring for a young child with seizures, and perceptions about needs for information and support. Interviews were conducted with 31 parents who were recruited from a paediatric neurology clinic at a university hospital. Interviews were audiotaped, transcribed, and analysed for major themes. The study revealed a broad range of experiences in caring for young children with seizures, and

the early onset and severity of seizures often influenced these experiences. Obtaining information that was easily accessible and helped them to better understand their child's diagnosis and treatment was a challenge reported by many parents. In addition, interviews revealed that parents felt a need for support and information from individuals who were knowledgeable about the medical, developmental, emotional, and family issues related to coping with seizures in infants and young children. Recommendations for a comprehensive approach to the management of seizures for infants and young children are proposed, with particular focus on the role of nurses and early intervention professionals in providing information and support to families.

Language: English

Keywords: Epilepsy / Family relations / Needs assessment

Balling K, McCubbin M. Hospitalized children with chronic illness: parental caregiving needs and valuing parental expertise. *Journal of Pediatric Nursing*, 2001; 16(2): p.110-119
NIVEL: C 8421

Parents who care for a child with a chronic illness are forced to relinquish much of the control of the child's care when the child is hospitalised. This study focused on the relationship between parents of hospitalised children with chronic illness and health care professionals. By using the family systems theory as the underlying framework, the amount of control that parents of children with chronic illness wanted over their hospitalised child's care, and the degree to which parents felt health care professionals valued their expertise, was examined in a national sample of 50 parent caregivers. Participation in information sharing and technical care were areas over which parents wanted the most control. Nurses and attending physicians were rated highest in valuing parental expertise. Content analysis of an open-ended question on parental control revealed that parents felt a higher quality of care was given at home than in the hospital; nurses were too busy or understaffed to provide optimal care in the hospital; and the child's control of care and decision making should increase as the child grew older.

Language: English

Keywords: Chronic diseases, general / Parents / Professional-family relations / Hospitalisation / Needs assessment

Bothwell JE, Dooley JM, Gordon KE, MacAuley A, Camfield PR, MacSween J. Duchenne muscular dystrophy: parental perceptions.

Clinical Pediatrics, 2002; 41(2): p.105-109

NIVEL: C 8540

The purpose of this study was to evaluate the perceptions of the importance of services and of quality of life in parents of boys with Duchenne muscular dystrophy. Besides, changes in importance as the disease progresses were explored in order to help to identify the evaluation of required services. 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. Paediatricians 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.

Language: English

Keywords: Duchenne muscular dystrophy / Family / Needs assessment / Quality of life

Bruns DA. Leaving home at an early age: parents' decisions about out-of-home placement for young children with complex medical needs.

Mental Retardation, 2000; 38(1): p.50-60

NIVEL: C 8361

The aim of this study was to examine the process leading to a decision by parents of out-of-home placement of a young child (aged 5-13 years) with complex medical needs. A series of in-depth, semi-structured interviews were conducted with 5 parents (aged 30-49 years) who had made the decision for out-of-home placement. Results indicated that these parents went through a similar process: initial feelings of excitement turn to weariness, first thoughts about the need for additional assistance in caring for their child, realisation of the need for out-of-home placement based on minimal social supports, difficulties with services, overwhelming medical care, and mounting financial concerns ("triggering event"); need for approval for the decision; and reflections on the decision. Conclusions and implications for practice, policy, and future research are provided.

Language: English

Keywords: Chronic diseases, general / Mental retardation / Parents / Residential care

Buran CF, McDaniel AM, Brei TJ. Needs assessment in a spina bifida program: a comparison of the perceptions by adolescents with spina bifida and their parents. *Clinical Nurse Specialist*, 2002; 16(5): p.256-262
NIVEL: C 8428

This study was aimed at assessing medical, psychosocial, and economic needs of adolescents and young adults with a neural tube defect and their parents. Besides, the establishment of the psychometric properties of a previously published needs assessment tool was intended. 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.

Language: English

Keywords: Spina bifida / Adolescents / Parents / Needs assessment / Questionnaires

Chen E, Bloomberg GR, Fisher EB Jr, Strunk RC. Predictors of repeat hospitalizations in children with asthma: the role of psychosocial and socioenvironmental factors. *Health Psychology*, 2003; 22(1): p.12-18

The aim of this study was to examine the relationships between psychosocial factors and rehospitalisation patterns in children with asthma. Subjects were 115 children (ages 4-15) who had $>$ or $=$ 1 hospitalisation during the study period. Lifetime history of hospitalisations and new hospitalisations during a 1-year follow-up period were measured, controlling for baseline asthma symptoms and medications. Prospectively, caretaker characteristics (lower sense of mastery, being less emotionally bothered by asthma) predicted greater likelihood of future asthma hospitalisations. Lifetime history of hospitalisations was associated with family impacts (greater family strain, family conflict and greater financial strain) as well as caretaker characteristics (greater personal strain, beliefs about not being able to manage one's child's asthma). These findings could help guide future interventions targeted at the subgroup of children who represent a high proportion of asthma hospitalisations.

Language: English

Keywords: Asthma / Hospitalisation / Family relations / Family environment / Quality of life

Fisher HR. The needs of parents with chronically sick children: a literature review. *Journal of Advanced Nursing*, 2001; 36(4): p.600-607

OBJECTIVE: To get insight into the needs of parents with chronically sick children. **METHODS:** A critical literature review was conducted. Eight research studies were examined that were carried out from 1987 to 1997, written in the English language and analysing solely the needs or experiences of both parents with at least one chronically sick child. **RESULTS:** Appropriately all eight studies were carried out from the naturalistic paradigm and yielded rich data. The synthesis of the results of the papers found three main themes emerging: the need for normality and certainty, the need for information, and the need for partnership. **CONCLUSION:** The results of the review serve to emphasise and reiterate the burden of the demands made on these parents, and act as a reminder of the need for empathetic care delivery.

Language: English

Keywords: Chronic diseases, general / Parents / Needs assessment / Professional-family relations / Reviews

Forsander GA, Sundelin J, Persson B. Influence of the initial management regimen and family social situation on glycemic control

and medical care in children with type I diabetes mellitus. *Acta Paediatrica*, 2000; 89(12): p.1462-1468
NIVEL: C 8482

It is well known that social family factors are of importance in diabetes care, but it is not clear whether the initial management regimen can buffer these factors. This study aimed at investigating whether a family psychosocial intervention at diagnosis could improve glycemic control and minimise hospital admissions. A prospective, randomised intervention study was carried out, in which 36 children with diabetes mellitus (type I) were followed. The control group was treated initially in a hospital ward, while the study group received problem-based learning and family-therapeutic and social support in an out-hospital training apartment. A number of family social variables were evaluated at the time of diagnosis and 6, 12 and 24 months later. Family function was assessed using the self-estimated Family Climate Test at these same time-points. HbA1c values and information concerning in- and out-hospital visits to the paediatric clinic were collected for the 5-year period following diagnosis. No association was found between the offered management regimen and glycemic control or rate of readmission. In the study group only, both parents reported a significant improvement of the family climate. An increased risk for poor glycemic control was recorded in children living in one-parent families ($p = 0.03$) or in families where the father had a low level of education ($p = 0.04$). Younger age ($p = 0.05$), a single-parent family ($p = 0.05$) and poor glycemic control ($p = 0.02$) were associated with more days of rehospitalisation. The rate of divorce in the whole group was at least as high as in the normal population but, surprisingly, maternal dysfunction was associated with lower HbA1c value. The conclusion is that even with an initial management regimen designed to offer a family-individual care regimen based on accurate estimation of the psychological and pedagogical needs, the social family background is a most important factor for the glycemic control and need for readmission.

Language: English

Keywords: Diabetes mellitus / Family relations / Social support / Hospitalisation

Hawley CA, Ward AB, Magnay AR, Long J. Children's brain injury: a postal follow-up of 525 children from one health region in the UK. *Brain Injury*, 2002; 16(11): p.969-985
NIVEL: C 8480

OBJECTIVE: To get insight into the outcomes following mild, moderate and severe brain injury in children, 1-6 years post-injury. Issues of interest were: the information and follow-up needs of the family, the effects on the family, behavioural problems and return to school. **METHODS:** A postal questionnaire survey was carried out in a population of children admitted to one Hospital Trust with traumatic brain injury. Questionnaires were mailed to parents of all 974 surviving children on a register of paediatric TBI admissions, 525 completed questionnaires were returned (56.2%). Most children (419) had suffered mild TBI, 57 moderate, and 49 severe. **RESULTS:** Thirty per cent of parents received no information on post-injury symptoms, and clinical follow-up was limited. Statistically significant differences were observed between mild and moderate/severe groups for cognitive, social, emotional, and mobility problems. Nevertheless, approximately 20% of the mild group suffered from poor concentration, personality change and educational problems post-injury. Few schools (20%) made special provision for children returning after injury. **CONCLUSIONS:** Children can have long-lasting and wide-ranging sequelae following TBI. Information should be routinely given to parents and schools after brain injury.

Language: English

Keywords: Acquired brain injury / Needs assessment / Family / Behaviour problems / Psychological stress

Heidari F, Dumbrell A, Galvin K, Holloway I. Brain injury: the uncertainties of using complementary therapies. *Complementary Therapies in Nursing & Midwifery*, 2001; 7(2): p.66-71
NIVEL: C 8459

The aim of this study was to explore the views of families using a specific complementary therapy in the care of their brain-injured children, and of professionals involved in the care of the children. A qualitative approach was used, in which 20 families were interviewed. It was found that most families experience difficulties and unmet needs, like lack of communication and information, in the regular services, which led them to use complementary therapies. The main concerns of professionals were the lack of scientific research, the training of therapists and the communication between professionals in conventional and complementary therapies. Some major implications for quality improvement are discussed.

Language: English

Keywords: Acquired brain injury / Professional-family relations

Lima RA de, Rocha SM, Scochi CG, Callery P. Involvement and fragmentation: a study of parental care of hospitalized children in Brazil. *Pediatric Nursing*, 2001; 27(6): p.559-564, 580
NIVEL: C 8484

Parental involvement in the care of children who are hospitalised has been encouraged by the government in Brazil, as it has in the United Kingdom (UK). In this article, key aspects of the literature are discussed, and implications for hospital care of children in Brazil are considered. A study was carried out to examine parental participation and involvement during the hospitalisation of a child; the work between nurses and the mothers (or other relatives) of 10 children hospitalised with chronic illnesses was considered. Data were collected by participant observation of child care in a Brazilian hospital. The results highlight some of the difficulties that arise in the integration of the work of mothers and nurses in hospital care of children and the fragmentation of care into "manual" and "intellectual" work. The results are considered within the theoretical framework of the model of technologic organisation of work (Goncalves, 1979, 1994). Implications for the organisation of child care in the hospital are discussed.

Language: English

Keywords: Chronic diseases, general / Hospitalisation / Mothers / Professional-family relations

McGrath P. Identifying support issues of parents of children with leukaemia. *Cancer Practice*, 2001; 9(4): p.198-205
NIVEL: C 8386

OBJECTIVE: To get insight into health services and social support needs of parents of children with acute lymphoblastic leukaemia (ALL). **METHODS:** A longitudinal, qualitative study informed by a phenomenological methodology was conducted. The results were taken from parent interviews undertaken during the time period from the end of induction-remission to the end of the 5-week period (time period T1), collected over the first year of operation of the study. **RESULTS:** The need for support was reported as intense, and offers of support tend to lessen over time. Among the sources of support noted were partners, family, friends, employers, hospital staff, and other parents in the same situation. However, community resources appeared to be lacking, underused, or both. **CONCLUSIONS:** Suggestions for support include the provision of practical assistance through appropriately trained volunteers, the involvement of a liaison person to mentor families through

the initial stages of treatment, development of parent support groups, and the opportunity for families to meet children who are successfully off treatment. Such support strategies involve sensitivity to particularly vulnerable families who have limited support available and respect for the variation in individual styles of accessing support.

Language: English

Keywords: Leukaemia / Parents / Needs assessment / Social support

McGrath P. Trained volunteers for families coping with a child with a life-limiting condition. *Child and Family Social Work*, 2001; 6(1): p.23-29
NIVEL: C 8539

The aim of this study was to examine the need for, and appropriate use of, trained volunteers for families caring for a child with a life-limiting condition. Hundred and seven families with a child diagnosed with a life-limiting condition were surveyed on their need for a trained volunteer. In summary, Ss' responses indicate that many families have only minimal or no support, and are coping with extraordinary physical, emotional and social demands from the child's condition and treatment. The majority of the Ss are very positive about the need for a trained volunteer and are clear about the activities that trained volunteers could provide assistance with. These activities range from practical assistance such as baby-sitting and help with household chores and errands to emotional support. Not all families would be comfortable using a volunteer, and some respondents did outline perceived obstacles to including a volunteer in family activities. For others there were comments about why volunteers would be perceived as unproblematic. Ss specified important criteria that would need to be addressed in volunteer training. The largest number of Ss were coping with cystic fibrosis and muscular dystrophy.

Language: English

Keywords: Cystic fibrosis / Duchenne muscular dystrophy / Terminal illness / Needs assessment / Family / Volunteers

Melnyk BM, Feinstein NF, Moldenhouer Z, Small L. Coping in parents of children who are chronically ill: strategies for assessment and intervention. *Pediatric Nursing*, 2001; 27(6): p.548-558
NIVEL: C 8387

The purposes of this review are: (a) to provide an overview of the stressors of childhood chronic illness for parents over time; (b) to provide a summary of tools that can be used to assess parental coping, (c) to delineate important nursing assessments, (d) to review interventions that have resulted in improved parental coping outcomes, and (e) to describe a theoretical framework that can be used to assess and intervene with parents of chronically ill children.

Language: English

Keywords: Chronic diseases, general / Parents / Psychological stress / Coping / Assessment / Reviews

Mérelle ME, Huisman J, Alderden-van der Vecht A, Taat F, Bezemer D, Griffioen RW, Brinkhorst G, Dankert-Roelse JE. Early versus late diagnosis: psychological impact on parents of children with cystic fibrosis. *Pediatrics*, 2003; 111(2): p.346-350
NIVEL: C 8395

OBJECTIVE: To explore the relationship between the period preceding diagnosis and the way parents of children with cystic fibrosis (CF) experience and handle their child's disease. **METHODS:** A retrospective study was carried out in the CF Center "Noordwest Nederland," the Netherlands. Participants were the parents of children <13 years old with CF who were treated at the CF Center "Noordwest Nederland." The participants were divided into 2 groups according to the duration of prediagnostic period: <3 months (defined as early diagnosis) and ≥3 months (defined as late diagnosis). The main outcome measures were: experience of the prediagnostic period, contact with the medical profession, coping, future perspective, and attitudes toward neonatal screening for CF. **RESULTS:** Parents of 55 children were eligible for study participation; 45 were enrolled. Retrospectively, the period preceding an early diagnosis was less negatively experienced by parents than the period preceding a late diagnosis. Parents of children with an early diagnosis had retrospectively more confidence in the medical profession before confirmation of diagnosis. In general, parents in this study used adaptive coping styles. Duration of prediagnostic period was not significantly related to future perspective. Hopelessness seemed to be mainly determined by a severe course of disease as experienced by the parents. Ninety-eight percent of all parents were in favour of neonatal screening for CF. **CONCLUSIONS:** A short prediagnostic period is associated with less negative feelings and increased confidence in the medical profession among parents of children with CF. Neonatal screening

for CF may be of benefit to parents by removing the stress of a delayed diagnosis.

Language: English

Keywords: Cystic fibrosis / Parents / Family relations / Coping / Psychological stress / Assessment

Moor J de, Savelberg M, Oud J. Parents' reasons for enrolment of their motor-disabled child in a Dutch therapeutic toddler class. *International Journal of Rehabilitation Research*, 2002; 25(1): p.1-7
NIVEL: C 8427

The aim of this study was to get insight into the motives of parents of motor-disabled children for enrolling them into a therapeutic toddler class, a special centre-based service in early intervention. The results among a representative Dutch sample of 84 mothers showed that child-related reasons were considered more important than family- and parent-related reasons. Family- and parent-related reasons were influenced by the presence and severity of the child's behaviour problems. The results of this study are discussed within the context of parental expectations in early intervention, and the concept of family centredness.

Language: English

Keywords: Cerebral palsy / Spina bifida / Motor disorders / Needs assessment / Parents

Neufeld SM, Query B, Drummond JE. Respite care users who have children with chronic conditions: are they getting a break? *Journal of Pediatric Nursing*, 2001; 16(4): p.234-244
NIVEL: C 8367

To promote and maintain quality of life of the child, primary caregiver, and entire family, respite care has been established as an important resource for caregivers of children with chronic illness and disabilities. The purpose of this study was to describe primary caregivers' respite service use, perceptions of actual respite, and barriers to respite and respite care. A descriptive design with written survey methods and convenience sampling techniques was used. The authors found that, despite accessing a variety of respite services, the participants perceived limited actual respite from caregiving. Increased preparation of respite care providers and revision of

available services could be some means for achieving respite for primary caregivers and their families.

Language: English

Keywords: Chronic diseases, general / Parents / Needs assessment / Health care utilisation

Peterson JW, Sterling YM, Stout JW. Explanatory models of asthma from African-American caregivers of children with asthma. *Journal of Asthma*, 2002; 39(7): p.577-590
NIVEL: C 8475

This study was aimed at understanding how African-American families with children suffering asthma perceive the illness and its management. Explanatory models (EMs) were collected from 20 African-American adult primary caregivers, in Seattle and New Orleans, who have children with asthma, to understand asthma from their perspective. Family EMs of asthma shed light on the meaning family members give to the illness, and how they make internally logical decisions related to their healthcare behaviour. Study findings show that families have their own EMs of asthma. Families draw on their cultural context to understand asthma. They compare their lived experience with healthcare-provider explanations of asthma. Specifically, the African-American families in this study drew much of their information about asthma from other family members and from personal experience. Collecting EMs of asthma may help healthcare providers know the meaning of asthma as understood by specific families and may reduce unscheduled use of health services. Further research should include encounters which increase the healthcare provider's context for understanding patient and family EMs.

Language: English

Keywords: Asthma / Ethnic minorities / Family / Attitude to health

Piggot J, Paterson J, Hocking C. Participation in home therapy programs for children with cerebral palsy: a compelling challenge. *Qualitative Health Research*, 2002; 12(8): p.1112-1129
NIVEL: C 8475

The purpose of this study was to generate and describe a conceptual model of the experience of parents and therapists involved in home therapy programs for children with cerebral palsy. There were 12 participants: 4

therapists and 8 parents. Through constant comparative method of analysis, a process emerged interpreted as the compelling challenge comprising two time-distinct phases that described the parents' journey of adjustment and their capacity to participate in activities to improve their child's abilities. Initially, parents were coming to grips with the diagnosis, and this precluded their full involvement in home activities. However, at a point of breakthrough, they entered a phase of high participation interpreted as striving to maximise. The authors discuss the implications of this process for service providers and therapists.

Language: English

Keywords: Cerebral palsy / Home care / Parents / Explanatory models

Starke M, Wikland KA, Möller A. Parents' experiences of receiving the diagnosis of Turner syndrome: an explorative and retrospective study. *Patient Education and Counseling*, 2002; 47(4): p.347-354

OBJECTIVE: To explore the experiences of parents whose children are diagnosed of having Turner syndrome (TS), a sex-chromosome disorder occurring in approximately 1:2500 female births.

METHODS: In this explorative and retrospective study, parents (33 mothers and 11 fathers) from different families, each containing a girl with TS, were interviewed to explore their perceptions and experiences of the diagnostic process, including the period of investigation and the time when the diagnosis was given. There was wide variation in degree of retrospection in this study; one parent who was interviewed had a daughter of 17 years of age who was diagnosed before 1 month of age. On the other hand, two girls had been diagnosed only 6 months before their parents were interviewed.

RESULTS: Most parents (N=27) reported that it was professionals who observed that their daughter should be referred for investigation, and the remainder (n=17) reported that they themselves perceived the need for investigation. Their experiences were found to affect the parents' descriptions of the diagnostic process. The parents who initiated the investigation themselves described the diagnosis in terms of confirmation of their own suspicions. When professionals initiated the investigation the parents reported that they felt unprepared when they received the diagnosis.

CONCLUSIONS: The results of this study indicate that the parents' experiences of receiving the diagnosis of TS appear to depend on the ability of the doctor to provide relevant information and to manage the psychosocial aspects correctly. A better understanding of parents' experiences should

enable health professionals to counsel parents more effectively concerning the diagnosis of TS.

Language: English

Keywords: Turner syndrome / Parents / Professional-family relations

Tomlin P, Clarke M, Robinson G, Roach J. Rehabilitation in severe head injury in children: outcome and provision of care. *Developmental Medicine & Child Neurology*, 2002; 44(12): p.828-837
NIVEL: C 8489

This study was aimed at examining the provision of care to and functional outcome of children with severe head injury. Eighty-two children (males:females 2.7:1; age range 0 to 16 years) with severe head injury were admitted to the intensive care units of the Regional Neuroscience Units of the Greater Manchester and Lancashire districts of the North West Region of the UK between 1994 and 1996. A questionnaire was devised based on 12 areas of recovery and data were collected at discharge and 6 weeks, 6 months and 12 months from discharge. Data were collected during home visits and at joint assessment at 12 months with the district consultant community paediatrician (CCP). Early involvement of the CCP enhanced the provision of needs at discharge and 6 weeks after discharge, as did a period of stay in district-level care before discharge home. CCPs received formal notification of the injured child in only 32% of cases by discharge, and 54% of cases by 6 months. Sixty-five per cent of children required early educational support but structured help reached only 55% of these children by the end of the study. Integrated planning between health and education was achieved in about half of the study population. Good physical recovery was achieved by the majority of children but parents said they did not feel prepared for the degree of help which their child still required 12 months after discharge. Children who required anticonvulsants at 12 months' follow-up scored significantly lower on cognitive potential. Psychosocial family functioning deteriorated in a substantial number of families according to parental perception. Prevalence of this perception did not diminish over the study period. Aspects of caregivers' understanding and the child's language deficits, self-care skills, fine and gross motor performance, as well as family, social, and financial consequences were assessed. A dedicated and integrated approach to assessment and provision of care across the domains of hospital, education, and community is discussed.

Language: English

Keywords: Acquired brain injury / Quality of care / Self care / Social adjustment / Cognition disorders / Academic achievement / Health status

Yantzi N, Rosenberg MW, Burke SO, Harrison MB. The impacts of distance to hospital on families with a child with a chronic condition. *Social Science & Medicine*, 2001; 52(12): p.1777-1791

Many families of children with chronic conditions have to travel substantial distances to access some of the necessary aspects of their child's health care. In this study, the Burke et al. (1994-1996) data of repeatedly hospitalised children and their families are used to explore a geographical dimension of family impact, distance. Outcome measures from the Feetham Family Functioning Survey and the Questionnaire on Resources and Stress are analysed using exploratory and multivariate analysis. Results show that distance to hospital plays a role in the two areas of family life regarding relationships within the immediate family, and issues surrounding the ability to maintain the child in the family home. The implications of the results for family, health care intervention, and government policies and guidelines are discussed.

Language: English

Keywords: Chronic diseases, general / Hospitalisation / Family relations / Family / Psychological stress

4.3 Health care - questionnaires

Häussler M, Streit A, Strassburg HM. Validität der Pflegebegutachtung bei körperbehinderten und bei geistig behinderten Kindern. (Validity of care assessment in disabled and mentally retarded children.) *Gesundheitswesen*, 2002; 64(10): p.527-533

The aim of this study was to assess the validity of the "Self-Care" and "Mobility" scales of the Pediatric Evaluation of Disability Inventory (PEDI) in a group of children with cerebral palsy and a group of mentally retarded children. Age-adjusted PEDI scores were compared with the classification according to the three levels of the German statutory nursing insurance. Good correlations and highly significant dependence were found in children with spastic cerebral palsy but no dependence was seen in mentally retarded children. Apparently, assessment guidelines of the German statutory nursing insurance do not guarantee a valid assessment in all disabled children. In

conclusion, future assessments of nursing needs in children should employ standardised assessment methods.

Language: German

Keywords: Cerebral palsy / Mental retardation / Self care / Activities of daily living / Needs assessment / Assessment

Author index

- Aanstoot HJ, 174
Abbott J, 3; 102
Abdalian SE, 159
Abramson M, 169
Achilles J, 127
Adamoli L, 27
Adams CD, 145
Adams S, 175
Adkins R, 73
Adolescent Medicine HIV/AIDS
 Research Network, 159
Ahmad WIU, 147; 168
Ahrens M, 56
Akcakaya N, 137
Al-Dawood KM, 118
Alderden-van der Vecht A, 214
Alderfer MA, 119
Algatt-Bergstrom P, 123
Alonso J, 114
Alwash RH, 3
Aman J, 174
Amodei N, 32; 133
Amre DK, 195
Andelman F, 4
Anderson B, 192
Anderson BJ, 51
Anderson CJ, 119
Anderson J, 77
Andersson F, 143
Anlar Y, 137
Annett RD, 5; 53
Anthony KK, 142
Anyanwu E, 51
Anyanwu I, 51
Aro H, 129
Aro HM, 19
Aromaa M, 52
Aroni R, 169
Arunkumar G, 95
Ashley DM, 45
Asmussen L, 96
Atherton HD, 8
Atkin K, 147; 168
Auslander WF, 193
Aussage P, 106; 117
Austin JK, 5; 6; 105; 127; 203
Austin SB, 41
Auweele Y van den, 128
Axia G, 148
Aytch LS, 205
Azar R, 157
Backes M, 160
Baghurst P, 84
Bakeman R, 132
Balen R, 143
Balling K, 206
Bar-Mor G, 169
Barnard M, 92
Barr RD, 6
Bar-Tal Y, 169
Bartlett DJ, 180
Barton C, 169
Battistella PA, 148
Baumann DA, 7
Baumann U, 3
Baving A, 149
Baxter-Jones AD, 109
Bearss K, 110
Beckung E, 120
Behnke W, 135
Beier J, 199
Bekkers MJ, 122
Bellinger DC, 90
Belzer M, 159
Bender BG, 5; 53
Bengtsson BA, 48
Benzaquen H, 59
Berge Henegouwen GP van, 122

- Bernstein BH, 46
Berry C, 97
Bertina W, 69
Best M, 54
Bezemer D, 214
Bezemer PD, 171
Bijstra JO, 134; 135; 151
Bijttebier P, 97
Bilenberg N, 8
Bleasel AF, 33
Bleil ME, 55
Blindness, 129
Bloomberg GR, 208
Boer J de, 121
Boisen LS, 32
Boland EA, 150
Bolotin A, 82
Bond L., 112
Borawski EA, 166
Bordeaux JD, 32; 133
Bothwell JE, 207
Bousquet J, 25
Bouter LM, 171
Bowes G, 112
Bowman CM, 13
Brace MJ, 55
Braumann KM, 135
Breau L, 99
Brei TJ, 208
Briars R, 171
Brinkhorst G, 214
Britto MT, 8; 49
Brock P, 97
Brodin J, 121
Broome ME, 144
Brouwer CN, 184
Brouwer HJ, 124
Brown LK, 9
Brown RT, 21
Bruns DA, 207
Bryden KS, 10
Bullinger M, 98; 155
Buran CF, 208
Burant C, 88
Burchinal M, 66
Burke SO, 56; 219
Burwinkle TM, 36
Bury M, 126
Buskila D, 82
Buston KM, 170
Butz AM, 185
Byars KC, 81; 189
Bye AM, 33
Caffrey HM, 5
Cairns DR, 33
Calaminus G, 11
Caldwell LL, 122
Callery P, 186; 212
Calsbeek H, 122
Calvert R, 26
Cameron F, 44
Camfield C, 99; 114
Camfield P, 99
Camfield PR, 207
Canobbio MM, 196
Carlsen KH, 174
Carter B, 196; 198
Casari EF, 107
Casey S, 93
Castillo L, 6
Catania L, 54
Cathers T, 21
Cavusoglu H, 12
Cederbaum JA, 56
Cederbaum SD, 56
Chacham A, 128
Chalfen R, 111; 181
Chaney JM, 15
Chang YY, 158
Chapieski L, 12
Charman T, 88
Charmet GP, 27
Charron-Prochownik D, 158
Chaudhury G, 164

- Chen E, 208
Chen JY, 158
Chen RS, 183
Chen SS, 158
Cheng A, 182
Chiarelli F, 174
Choquet M, 43
Christensen R, 192
Christian BJ, 147
Chumlea WC, 26
Claessens M, 121
Clark ST, 127
Clarke CL, 203
Clarke M, 218
Coakley RM, 67
Coffey C, 112
Cohen LL, 191
Colland V, 35
Colland VT, 171
Comito M, 62
Conaway M, 26
Connolly MB, 114
Conway S, 3
Conway SP, 102
Cook S, 171
Corbetta A, 27
Cottrell D, 58
Couriel J, 186
Cramer JA, 105
Crawford S, 63
Crovitz HF, 28
Cunningham CC, 199
Curry H, 92
Daneman D, 174
D'Angelo LJ, 159
Dankert-Roelse JE, 214
Danne T, 174
Danzer G, 199
Darrah J, 73
Das T, 164
D'Auria JP, 147
Davidson M, 150
De Paola P, 62
De Vincenzo A, 62
Deatrick J, 193
Deatrick JA, 163
Dekker J, 122
Dellatolas G, 43
DeMaso DR, 89
Demers B, 122
DeMuro-Mercon C, 104
Denecke J, 139
Destree-Vonk A, 108
Devinsky O, 105
Di Lorenzo C, 35
Di Sarno AM, 62
Diette GB, 123
DiMario FJ, 76
DiNapoli PP, 197
Dinner DS, 40
DISABKIDS Group, 98
Dixon-Woods M, 94
Docherty S, 66
Dolan LM, 81
Donders J, 92
Donenberg GR, 24
Donfield S, 133
Donze J, 189
Dooley JM, 207
Dorchy H, 174
Dorr HG, 39
Dressler F, 204
Dreyer ML, 192
Drotar D, 22; 38; 88; 91; 166
Drummond JE, 215
Dubuis JM, 7
Duhamel TR, 5
DuHamel TR, 53
Duijn NP van, 124
Duivenvoorden HJ, 70
Dumbrell A, 211
Dunger DB, 10
Dunn DW, 5; 6; 127
Dunn S, 107

- Durst CL, 13
Dutch Study Group of Epilepsy in
 Childhood, 138
Dykman R, 93
Eckman MH, 49
Edgar T, 93; 140
Edidin DV, 171
Eekelen FC van, 198
Eggleston P, 185
Eiser C, 57; 100; 101; 186
Eiser JR, 57
Ellis N, 58
Endo H, 41
Erenberg G, 40
Erickson JD, 89
Erklin S, 68
Es SM van, 171
Etherington C, 3; 102
Evans M, 58
Ewart C, 167
Eyrl KL, 114
Fagan J, 96
Fantino AG, 107
Farrell K, 114
Fasth A, 34; 121
Fearnow-Kenney M, 148
Fehlings DL, 71
Feinstein NF, 213
Fekkes M, 125
Feldmann R, 139
Fernandes PT, 59
Ferrer M, 114
Feuillan P, 134
Fiese BH, 75
Fife-Schaw C, 181
Figueras G, 114
Findlay M, 94
Findley D, 86
Finkelstein JW, 122
Fisher EB Jr, 208
Fisher HR, 209
Fisher LA, 110
Fitzgerald M, 174
Fleming E, 198
Fliess O, 128
Flynn PM, 192
Forsander GA, 209
Foster C, 186
Fottland H, 125
Franken WM, 65
Frare M, 148
Fraschini D, 27
Friedman A, 12
Frindik P, 93
Fritz GK, 14
Fu L, 6
Fuggle P, 88
Fuiko R, 49
Fung E, 26
Furlong W, 6
Gabe J, 126
Gaebler-Spira DJ, 113
Galatzer A, 59
Galvin K, 211
Ganesan V, 14
Garandeanu P, 174
Garralda E, 126
Gasquet I, 43
Gautrin D, 195
Gee L, 3; 102
Gelijns AC, 116
Gerhardt CA, 60; 136
German Cystic Fibrosis
 Questionnaire study group, 117
Gibson Nitza A, 110
Gil KM, 142
Gillaspy SR, 15
Gilliam F, 95
Gillibrand W, 198
Giuffre RM, 63
Glasscock R, 61
Gledhill J, 126
Gnehm HE, 72
Gobel U, 11

- Goehrs JM, 106
Goldbeck L, 103; 104; 149
Goldman P, 186
Goldschneider KR, 20; 151
Gontard A von, 160
Gonzalez A, 6; 114
Gonzalez de Pijem L, 183
Gonzalez-Heydrich J, 89
Gool CH van, 16
Gool SW van, 97
Gooskens RHJM, 124
Gordon A, 14
Gordon CM, 41
Gordon J, 111
Gordon KE, 207
Graetz BW, 62
Graff JC, 92
Graham TB, 20
Grant EN, 96
Grassi R, 27
Grau G, 114
Gray D, 127
Green E, 59
Greene S, 174
Grenzebach M, 139
Grey M, 16; 150; 193
Griebel M, 93
Griebel ML, 140
Griffioen RW, 214
Gritti A, 62
Griva K, 172
Grootenhuis MA, 17; 108
Grosskopf C, 106
Gruppuso P, 193
Guneser S, 137
Gupta S, 63
Gurucharri LM, 113
Gustafsson D, 143
Guthrie D, 172; 173; 187
Gutierrez AL, 113
Hafeman C, 92
Hagberg G, 120
Haigh D, 194
Hajszan M, 49
Haley T, 93
Hall K, 154
Hallberg LR, 34
Hammond R, 205
Hampson SE, 181; 182
Hanewald GJ, 107
Hanna KM, 172; 173; 187
Hanna SE, 180
Hanrahan D, 77
Hanson S, 92
Hardman GE, 130
Harezlak J, 5
Harrison MB, 56; 219
Hartmaier SL, 104
Hartmann DP, 119
Häussler M, 219
Havens L, 21
Hawley CA, 17; 64; 210
Haynes B, 147
Hazebroek-Kampschreur AA, 69;
70; 109; 198; 201; 202
Heck GL van, 16
Heidari F, 211
Heimlich TE, 105
Helenius H, 52
Helms PJ, 109
Hemophilia Growth and
Development Study, 133
Henderson RC, 26
Henderson ZG, 147
Hendriks AHC, 65
Hendriks HJE, 16
Heney D, 94
Henry B, 106; 110
Henry J, 28
Herle M, 49
Herlin T, 156
Herold K, 171
Herpertz-Dahlmann B, 18
Hershey AD, 151

- Hesketh K, 44
Hesketh KD, 45
Heyman R, 203
Heymans HSA, 108
Hicks EM, 77
Hidalgo HA, 108
Hijikigawa F, 131
Hill SD, 133
Hoare P, 107
Hocking C, 216
Hodes M, 188
Hodgkinson R, 161
Hoekstra-Weebers JEHM, 162
Hoey H, 174
Hoff AL, 15
Hoffman N, 159
Hogan A, 14
Holden G, 167
Holditch-Davis D, 66
Holl R, 174
Holland P, 194
Hollidge C, 66
Holloway I, 211
Holmbeck GN, 67; 68
Holmes C, 183
Hommeyer JS, 67
Horn MV, 13
Hornung RW, 8
Horsman J, 6
Horton TV, 68
Hougaard P, 174
Houston EC, 199
Hovell MF, 189; 191
Hövels-Gürich HH, 18
Huberty TJ, 127
Huen KF, 182
Huey D, 179
Huff N, 30
Huisman J, 214
Hunfeld JA, 69; 70; 109; 198;
201; 202
Huntington GS, 138
Huss K, 185
Hussein MJ, 3
Huster GA, 127
Hutzler Y, 128
Huurre T, 129
Huurre TM, 19
Hyman PE, 35
IJzerman MJ, 131
Ikle D, 53
Imamura M, 41
Infante-Rivard C, 195
Isaacs E, 14
Ito M, 131
Jankovic M, 27
Janusz J, 22
Javornisky G, 76
Jelalian E, 189
Jennekens-Schinkel A, 79; 138
Johannsson G, 48
John M, 182
Johnson JC, 78
Johnson SZ, 68
Jónasson G, 174
Jones A, 175
Jong YJ, 158
Joseph KE, 145
Kaiser L, 156
Kamphuis M, 125
Kamphuis RP, 125
Kane JH, 87
Kaneko U, 41
Kannenberg R, 39
Kaprio E, 174
Kaptein AA, 171
Karp M, 59
Kashikar-Zuck S, 20; 151
Kasmen LJ, 189
Katkhouda C, 49
Katsovich L, 86
Kauffmann E, 56
Kazak AE, 54
Kelly TP, 179

- Kemper T, 68
Kendall L, 130
Kennedy C, 80
Kennedy D, 83; 84
Kennedy PJ, 77
Kerr SM, 162
Kerssens JJ, 122
Key JD, 21
Khan NZ, 78
Kieboom A, 49
Kieran MW, 31
King D, 71
King GA, 21
King RA, 86
Kirkham FJ, 14
Kirkwood M, 22
Kirpalani HM, 71
Klebba KB, 94
Kliebenstein MA, 144
Kliwer W, 148
Knafl KA, 163
Knight TS, 115
Koch HG, 139
Kociela VL, 49
Kocova M, 174
Koes BW, 69; 198; 201
Köhlen C, 199
Kohne E, 149
Kokkonen ER, 23
Kokkonen J, 23
Kolk AM, 107
Kolodner K, 185
Konrad K, 18
Kool E, 86
Kopel SJ, 30
Kort AC de, 131
Kotagal P, 40; 95
Kotagal UR, 8; 49
Kovacs M, 158
Kratochvil M, 73
Kreyenbroek ME, 17
Kromer ME, 108
Kruitwagen CL, 79
Krulik T, 169
Kumagai T, 131
Kumar L, 28
Kupferberg S, 132
Kushner H, 134
Kyngäs H, 176; 177; 178; 179
Lachar D, 12
Laimbacher J, 72
Lande MB, 86
Landgraf JM, 96
Landolt MA, 7; 24; 72
Lange B, 93; 140
Lannon SL, 203
Lapidus J, 5
LaSalle J, 56
Last BF, 17; 108
Lastra Martínez I, 29
Laufersweiler-Plass C, 160
Lavigne JV, 24
Law GU, 179
Law M, 112
Lawson JA, 33
LeBovidge JS, 24
Leckman JF, 86
Lee PW, 182
Lehmkuhl G, 160
Leigh L, 154
LeMons C, 56
LERNER, Y., 250
Lester H, 161
Leuenberg K, 92
Levy DE, 116
Lewin RJ, 130
Leynaert B, 25
Lia R, 27
Liard R, 25
Lie HR, 8
Liebergen A, 92
Lima RA de, 212
Lin S-L, 163
Lincoln A, 5

- Lincoln NB, 154
Lindberg B, 143
Linder S, 104
Lindsley CB, 46
Linnenbank R, 139
Liptak GS, 26
Lok CL, 184
Lombroso PJ, 86
Long J, 64; 210
Longchong M, 6
Lourie KJ, 9
Loveland KA, 32; 133
Low LC, 182
Lowe L, 72
Luis CA, 26
Luzuriaga Tomás C, 29
Lyne P, 72
Lynggaard H, 174
Lynn H, 167
Maathuis CG, 131
MacAuley A, 207
Machnick MA, 135
MacKinnon E, 21
MacLaughlin EF, 13
MacSween, 207
Madson KL, 46
Maggiolini A, 27
Magill-Evans J, 73
Magnay AR, 64; 210
Mahoney EM, 32; 133
Makrodimitri P, 165
Malhi P, 28; 73
Malhotra S, 74
Malin Z, 39
Malo JL, 195
Mann H, 107
Manuel JC, 75
Markson L, 123
Markson S, 75
Marschark M, 28
Marsh LD, 21
Martin AJ, 84
Martin C, 43
Martin J, 83
Martínez Chamorro MJ, 29
Martul P, 174
Marvin RS, 191
Masera G, 27
Massey C, 114
Matloub FF, 3
Matsutomo Y, 131
Matsuura N, 174
Mattie-Luksic M, 76
Mattussek S, 204
Mayou RA, 10
McCauley E, 55; 134
McConachie H, 78
McCubbin M, 206
McCubbin MA, 87
McCusker CG, 77
McDaniel AM, 208
McGee HM, 174
McGrath P, 30; 164; 200; 212;
213
McIntosh JB, 162
McKellop JM, 60
McKernon W, 68
McMahon MA, 78
McMahon WM, 127
McMillen JS, 138
McQuaid EL, 14; 30
Meijer SA, 134; 135; 151
Mellenbergh GJ, 134; 135; 151
Melnyk BM, 213
Mérelle ME, 214
Merlijn VP, 109
Messmer BJ, 18
Metcalf E, 199
Meyer A, 135
Meyer EA, 31
Michaud LJ, 78
Miles MS, 66
Miller BD, 55; 94
Miller DL, 189

- Miller JC, 20
Miller ML, 24
Miller R, 47
Milnes L, 186
Minich NM, 38; 91
Minkenberg R, 18
Mitchell H, 167
Mitchell I, 63
Mitchell MJ, 81; 189; 191
Mittenberg W, 26
Mobarak R., 78
Moilanen I, 23
Moldenhauer Z, 213
Möller A, 217
Moor J de, 215
Moor JMH de, 65
Morris MK, 132
Morse R, 100; 101
Mortensen HB, 174
Moscicki AB, 152
Moskowitz AJ, 116
Mousa H, 35
Mowinckel P, 174
Muenz LR, 152
Mullins LL, 15
Mulvihill M, 191
Mulvihill MM, 189
Munir S, 78
Munzenberger P, 110
Murphy D, 197
Murphy DA, 152
Myers LB, 172
Nagelkerke AF, 171
Nassau JH, 30
Neil A, 10
Neufeld SM, 215
Neukirch C, 25
Neukirch F, 25
Neumann L, 82
Newburger JW, 90
Newman S, 172
Newton R, 199
Nguyen TT, 123
Nichols S, 32; 133
Nie AJ van, 71
Nielson DW, 49
Noll RB, 60; 78; 136
Nordli DR Jr, 201
Numata O, 41
Nuoffer JM, 24
Oades P, 186
O'Brien ME, 79
O'Donnell D, 182
O'Donnell KA, 91
O'Donnell M, 26
Ofan R, 59
Ogawa Y, 41
Olofsson N, 143
Olson LM, 96
Olson NY, 46
Ones U, 137
Ong HT, 95
Oonk J, 17
Oostrom KJ, 79; 138
Osman LM, 109
O'Sullivan P, 42
Otero S, 188
Ottenkamp J, 125
Oud J, 215
Oud JHL, 65
Ouden AL den, 116
Overstreet S, 183
Owens D, 194
Pain K, 73
Pal DK, 164
Palermo TM, 145
Palisano RJ, 180
Palmer ML, 32
Paneth N, 116
Panteli V, 165
Pao M, 9
Parker-Cohen NY, 127
Parkin PC, 71
Parsons JM, 130

- Passchier J, 69; 70; 109; 198; 201; 202
Passo M, 60
Passo MH, 136
Patashnick J, 181
Paterson J, 216
Patistea E, 165
Patton SR, 81; 189
Pelt JC van, 15
Pendley JS, 189
Perkins SM, 5
Perquin CW, 69; 70; 198; 201; 202
Perrin K, 192
Persson B, 209
Pestman WR, 138
Peters AC, 79; 138
Petersen C, 98; 155
Peterson BS, 86
Peterson JW, 216
Peveler RC, 10
Phillips T, 140
Phipps S, 153; 154
Pianta RC, 191
Pietsch M, 139
Piggot J, 216
Pill R, 175
Pit- ten Cate IM, 80
Pitcher L, 200
Polgar JM, 21
Powers SW, 81; 151; 189
Press J, 82
Prihoda TJ, 108
Provantini K, 27
Query B, 215
Quinn K, 97
Quirk J, 130
Quittner AL, 110
Ramesh S, 55
Ramsay R, 126
Rand C, 53; 185
Rangel L, 126
Rapoff MA, 46
Rappaport LA, 90
Rautava P, 52
Recknor JC, 21
Reeve DK, 154
Reeves G, 189
Reid DT, 82
Reiter-Purtill J, 136
Renwick RM, 82
Respass D, 183
Ribi K, 72
Rice S, 186
Rich M, 41; 111; 181
Richardson JT, 28
Richtsmeier LM, 28
Ridder L, 92
Rijken M, 122
Rindel B, 192
Rissanen M, 177
Ritholz MD, 91
Roach J, 218
Robertson K, 174
Robinson G, 218
Rocha SM, 212
Röder I, 155
Ronen GM, 112
Rose B, 68
Rose DF, 5
Rosen M, 56
Rosenbaum P, 26; 112
Rosenbaum PL, 71; 180
Rosenberg MW, 219
Ross JL, 134
Rossiter L, 84
Rothner AD, 40
Rowhani A, 35
Roye DP Jr, 116
Rudnik-Schoneborn S, 160
Rulkens MP, 131
Russell D, 180
Rutishauser C, 112
Sabaz M, 33

- Saft EW, 191
Sakakibara K, 131
Sällfors C, 34
Samson-Fang L, 26
Sanchez E, 114
Sanders S, 92
Santanello NC, 104
Saraclar Y, 137
Sarimski K, 35
Sarr M, 159
Sartain SA, 203
Saudino KJ, 90
Savaser S, 50
Savelberg M, 215
Savelberg MMHW, 65
Sawin KJ, 203
Sawyer MG, 62; 83; 84
Sawyer S, 169
Sawyer SM, 112
Sayre JM, 191
Scahill L, 86
Schanberg LE, 142
Scherpbier HJ, 17
Schiller M, 191
Schipper JL, 107
Schlösser M, 35
Schmidt S, 98; 155
Schmitz TG, 104
Schneider JW, 113
Schoenle E, 174
Schollin J, 143
Schouten A, 79; 138
Schubert MT, 49
Schwankovsky L, 35
Schwimmer JB, 36
Scochi CG, 212
Scott Smith M, 55
Seamark D, 101
Sebagalls S, 184
Seid M, 115
Seiffge-Krenke I, 37; 166
Seiner SH, 127
Sekerel BE, 137
Sekijima K, 131
Sengupta S, 164
Sennhauser FH, 72
Sensky T, 140
Setter RK, 92
Shack N, 14
Shaffer DR, 168
Shalowitz M, 97
Shapera WE, 67
Sharp G, 93
Sharp GB, 140
Sharpe D, 84
Sheldon C, 186
Sherman EM, 114
Sherry DD, 55
Shiach C, 58
Shute RH, 62
Shy CM, 141
Sillanpaa M, 52
Silver CH, 146
Simeonsson RJ, 138
Simpson P, 140
Singh G, 74
Singh M, 28
Singh S, 73
Sinnema G, 134; 135; 151
Sirois PA, 32; 133
Sizonenko PC, 7
Skinner EA, 123
Skinner TC, 181; 182
Slick DJ, 114
Sloper P, 85
Small L, 213
Smibert E, 45
Soliday E, 86
Solomon CR, 157
Souza EA, 59
Sovik O, 174
Spellmann M, 116
Spence LJ, 156
Spieth LE, 191

- Spinetta J, 27
Spratt EG, 21
Spurrier N, 83; 84
Staab D, 117
Stallings VA, 26
Stancin T, 22; 38; 88; 91; 166
Standiford DA, 81
Stanton A, 92
Stark LJ, 189; 191
Starke M, 217
Starnes VA, 13
Steele R, 153
Steele RG, 154; 192
Stehbens JA, 32; 133
Stein A, 10
Steinbok P, 114
Steinhausen HC, 39
Steinmann B, 24
Sterling YM, 216
Stevenson J, 80
Stevenson RD, 26
Stewart K, 169
Stewart SM, 182
Storck M, 103
Stout JW, 216
Strassburg HM, 219
Streiner DL, 112
Streisand R, 54; 183
Streisand RM, 145
Streit A, 219
Strunk RC, 208
Strunk RC for the CAMP
 Research Group, 53
Suijlekom-Smit LW van, 69; 70;
 198; 201; 202
Sukhodolsky DG, 86
Sullivan JE, 39
Sullivan-Bolyai S, 193
Summerbell C, 179
Sundelin J, 209
Superti-Furga A, 24
Suzuki H, 41
Svavarsdottir EK, 87
Sweeny S, 110
Swenson C, 189
Swift P, 174
Szabo CA, 40
Szer IS, 115
Taat F, 214
Takeuchi K, 41
Tamborlane W, 16; 193
Tamborlane WV, 150
Tanac R, 137
Tatlioglu GS, 50
Tauler E, 114
Taylor, 88
Taylor HG, 22; 38; 88; 91; 166
Taylor J, 60
Teske C, 11
Thastum M, 156
The Adolescent Medicine
 HIV/AIDS Research Network,
 152
Thien F, 169
Thompson P, 58
Thompson SJ, 193
Thon A, 204
Tieman BL, 180
Tomlin P, 218
Torigoe K, 41
Trent ME, 41
Tripp J, 186
Trott J, 186
Tsevat J, 8; 49
Tsou RM, 174
Tyc V, 192
Ullrich G, 204
Upton D, 58
Usuda T, 41
Uyttbroeck A, 97
Uzark K, 115
Uziel Y, 82
Vajro P, 62
Vall O, 114

- Van Horn M, 89
Vance YH, 101
Vanelli M, 174
Vannatta K, 60; 136
Vardi P, 59
Vargas P, 185
Varni JW, 36; 46; 115
Vaught MH, 20; 151
Veldtman GR, 130
Vercruysse T, 97
Verdisco L, 116
Verduyn C, 186
Verhoeven-Wind L, 205
Verloove-Vanhorick SP, 116; 125
Vermund SH, 152
Verrips E, 125
Verrips GH, 116
Vertommen H, 97
Vessey JA, 42
Viguier D, 43
Vilagut G, 114
Vinson JA, 43
Visconti KJ, 90
Vitale MG, 116
Vizcaino MP, 6
Vogel LC, 119
Vogels AG, 116
Vogels T, 125
Voll R, 44
Vollrath M, 72
Von Bernuth G, 18
Von Der Schulenburg JM, 3
Vonachen S, 56
Vries J de, 16
Wade SL, 22; 38; 88; 91; 166;
167
Wahn U, 117
Wake M, 44
Wake MA, 45
Wallander JL, 68
Walter SD, 180
Walters AS, 168
Ward AB, 64; 210
Waters EB, 45
Watkins JM, 133
Watrous M, 110
Webb AK, 102
Webb K, 3
Weglage J, 139
Weinger K, 91
Weinspach S, 11
Weintrob N, 59
Weiss KB, 96
Weiss RT von, 46
Wendland C, 160
Wenninger K, 117
Werder EA, 7
Westbrook LE, 105
Westhoven VC, 67
Wetterwald R, 7
Whaites L, 84
White C, 205
White NH, 193
White T, 127
Whittemore R, 16
Wiebe DJ, 119
Wiegner S, 92
Wiesner M, 18
Wikland KA, 217
Willan AR, 71
Williams AR, 92
Williams C, 184; 194
Williams J, 93; 140
Williams PD, 92
Williamson GM, 168
Willis E, 47
Wills KE, 68
Wilmott RW, 8; 49
Winner P, 104
Wirén L, 48
Wolf R, 97
Wolffers I, 184
Wolrey G, 26
Wolters WH, 135; 151

Wolters WHG, 134
Wong C, 56
Woo MS, 13
Wood BL, 55; 94
Wood PR, 108
Wood SF, 170
Worrall-Davies A, 194
Wouden JC van der, 69; 70; 109;
198; 201; 202
Wray J, 140
Wu AW, 123
Wurst E, 49
Wyllie E, 40; 95
Wyn J, 47
Yamada H, 131
Yamazaki Y, 131
Yang YH, 158
Yantzi N, 219
Yeates KO, 22; 38; 88; 91; 166
Yeatts KB, 141
Yeung W, 182
Yi MS, 49
Yildiz S, 50
Yosefsberg Z, 59
Young B, 94
Zachariae R, 156
Zaman SS, 78
Zawacki T, 145
Zeevi B, 169
Zeller M, 60
Zerres K, 160
Zhang H, 86

Subject index

- Academic achievement, 13; 40;
121; 124; 126; 127; 128; 138;
140; 141; 146; 219
- Acquired brain injury, 219
- Acquired brain injury, 18; 22; 27;
29; 39; 43; 65; 78; 88; 91; 131;
133; 146; 167; 211
- Activities of daily living, 15; 20;
26; 39; 53; 71; 81; 92; 96; 97;
103; 105; 106; 113; 114; 117;
120; 121; 122; 124; 129; 131;
132; 137; 139; 142; 145; 151;
169; 181; 220
- Adolescents, 3; 4; 8; 11; 12; 13;
14; 16; 20; 21; 22; 28; 38; 40;
42; 43; 47; 48; 50; 51; 52; 56;
62; 70; 71; 73; 83; 92; 103;
104; 105; 106; 109; 111; 113;
116; 120; 122; 126; 127; 129;
130; 134; 135; 140; 148; 151;
152; 153; 155; 160; 166; 169;
170; 171; 172; 173; 174; 176;
177; 178; 179; 180; 182; 184;
188; 194; 196; 197; 199; 201;
205; 208
- Aids, 10; 17; 185
- Allergic rhinitis, 26
- Anxiety, 4; 5; 6; 16; 18; 25; 30;
31; 32; 47; 51; 55; 60; 63; 64;
76; 82; 90; 93; 94; 153
- Anxiety disorders, 27
- Apert syndrome, 35
- Assessment, 99; 111; 112; 146;
214; 215; 220
- Asthma, 5; 16; 26; 28; 31; 35; 44;
54; 55; 64; 76; 84; 88; 94; 97;
102; 108; 110; 111; 113; 115;
119; 124; 126; 128; 136; 137;
142; 144; 155; 167; 170; 172;
175; 176; 177; 178; 181; 182;
184; 186; 194; 196; 199; 209;
216
- Attention, 41
- Attention Deficit Hyperactivity
Disorder, 8; 87; 134
- Attitude, 50; 59; 72; 80; 106; 143;
167; 176; 186; 193
- Attitude to health, 216
- Autonomy, 68; 129; 170; 183;
197; 203
- Behaviour problems, 6; 8; 11; 14;
18; 19; 25; 28; 31; 32; 35; 39;
40; 43; 47; 49; 59; 62; 64; 66;
77; 78; 80; 82; 84; 86; 87; 88;
90; 119; 140; 146; 211
- Body image, 43; 47
- Brain tumour, 32
- Bronchopulmonary dysplasia, 66
- Cancer, 7; 12; 32; 37; 57; 86; 95;
98; 126; 143; 148; 154; 162
- Cerebral palsy, 22; 26; 61; 66; 69;
73; 79; 92; 114; 121; 122; 164;
181; 191; 215; 217; 220
- Cerebrovascular accident, 15
- Child development, 38; 51; 66;
109; 156
- Chronic diseases, general, 14; 20;
21; 23; 38; 49; 56; 74; 79; 85;
89; 93; 99; 100; 101; 102; 104;
107; 109; 111; 116; 119; 121;
127; 130; 135; 143; 145; 146;
152; 156; 163; 197; 200; 203;
206; 208; 209; 212; 214; 216;
219
- Chronic fatigue syndrome, 56;
127
- Chronic pain, 34; 70; 71; 109;
145; 151; 157; 168; 197; 198;
202; 203

- Coeliac disease, 123
- Cognition disorders, 13; 15; 18;
22; 35; 43; 133; 138; 140; 141;
146; 219
- Cognitive development, 10; 29;
30
- Comorbidity, 17; 87; 121
- Congenital digestive disorders,
123
- Congenital heart defects, 19; 43;
51; 64; 90; 125; 130; 141; 169;
196
- Coping, 10; 20; 28; 30; 38; 44;
51; 52; 54; 55; 67; 69; 70; 74;
76; 86; 126; 147; 148; 149;
150; 151; 152; 153; 154; 155;
156; 157; 158; 159; 161; 162;
163; 164; 165; 166; 167; 168;
183; 214; 215
- Cultural differences, 3
- Cystic fibrosis, 3; 9; 14; 33; 47;
50; 62; 103; 104; 106; 110;
118; 148; 154; 162; 187; 191;
192; 205; 213; 215
- Depression, 4; 6; 16; 17; 20; 21;
22; 25; 30; 31; 32; 43; 47; 51;
55; 56; 63; 78; 82; 90; 151;
153; 168
- Developing countries, 79; 185
- Diabetes mellitus, 11; 12; 17; 30;
45; 51; 60; 67; 69; 72; 73; 82;
92; 93; 107; 122; 140; 151;
154; 158; 166; 171; 172; 173;
174; 177; 178; 179; 180; 182;
183; 184; 188; 189; 193; 194;
195; 199; 210
- Doctor-patient relations, 177; 197
- Drug utilisation, 48; 86
- Duchenne muscular dystrophy,
83; 159; 207; 213
- Dwarfism, 39; 122
- Educational achievement, 133;
134
- Employment, 40; 120; 123; 124;
125; 127; 131; 132; 196
- Epilepsy, 4; 6; 34; 40; 58; 59; 77;
80; 93; 96; 100; 106; 107; 112;
114; 128; 138; 140; 155; 165;
177; 178; 179; 189; 199; 201;
204; 206
- Ethnic minorities, 16; 147; 216
- Explanatory models, 44; 68; 93;
94; 181; 182; 217
- Family, 52; 57; 62; 70; 71; 76; 79;
81; 83; 91; 97; 107; 108; 143;
144; 145; 161; 163; 167; 207;
211; 213; 216; 219
- Family environment, 10; 51; 194;
209
- Family relations, 44; 51; 53; 54;
56; 58; 59; 61; 68; 73; 74; 75;
77; 84; 86; 87; 88; 89; 91; 92;
93; 94; 100; 149; 164; 187;
189; 192; 194; 206; 209; 210;
215; 219
- Feeding, 191; 192
- Fibromyalgia, 20
- Food allergy, 123
- Friendship, 62; 130; 137; 148
- Growth hormone deficiency, 48
- Haemophilia, 32; 59; 133
- Headache, 124
- Health behaviour, 20; 181
- Health care utilisation, 26; 142;
196; 198; 202; 203; 216
- Health status, 5; 7; 9; 11; 26; 32;
34; 39; 45; 46; 50; 65; 108;
117; 189; 194; 195; 219
- Hiv, 10; 17; 32; 133; 153; 160;
185; 193
- Hospitalisation, 56; 86; 158; 196;
203; 206; 209; 210; 212; 219
- Hydrocephalus, 8; 81

- Hypodynamia, 41
Infants, 51; 66; 88; 191; 192
Inflammatory bowel disease, 123
Intelligence, 133; 141
Intestinal pseudo-obstruction, 36
Kidney disease, 86
Latin America, 7
Leisure, 121; 122; 123; 126; 143; 204
Leukaemia, 12; 28; 30; 46; 55; 98; 164; 166; 200; 213
Liver disease, 63; 123
Liver transplantation, 63
Lung transplantation, 14
Marital relationship, 145; 166
Marital status, 40; 127
213
Mental disorders, 10; 13; 23; 40; 74; 127; 158; 161; 162; 189
Mental retardation, 34; 161; 208; 220
Meta-analysis, 25; 31; 85
Metabolic diseases, 57
Migraine, 53; 105; 124; 149
Mood disorders, 27; 127
Mothers, 49; 57; 61; 64; 69; 75; 79; 90; 95; 162; 187; 193; 194; 212
Motivation, 41
Motor disorders, 66; 122; 215
Motor skills, 121; 133; 181
Musculoskeletal diseases, 117
Myelomeningocele, 8
Needs assessment, 6; 57; 66; 122; 181; 196; 199; 201; 205; 206; 207; 208; 209; 211; 213; 215; 216; 220
Nursing, 162; 197; 200
Obesity, 37
Orthostatic dysregulation, 41
Pain, 20; 53
Paralysis, 44; 92; 120; 129; 163
Parent-child relations, 17; 55; 56; 66; 68; 72; 77; 92; 95; 160; 164; 166; 168; 173; 177; 183; 189; 191; 194; 195
Parents, 36; 45; 55; 56; 59; 60; 61; 65; 66; 72; 73; 74; 80; 82; 86; 88; 90; 92; 93; 104; 110; 114; 124; 143; 145; 157; 158; 159; 162; 163; 165; 166; 167; 168; 170; 185; 186; 188; 193; 205; 206; 208; 209; 213; 214; 215; 216; 217; 218
Patient compliance, 47; 111; 150; 168; 170; 171; 172; 175; 177; 178; 179; 181; 183; 186; 187; 189; 193
Patient satisfaction, 6; 121; 205
Peer relations, 100; 119; 121; 123; 129; 130; 134; 135; 146; 148; 160; 189
Personality, 154; 182
Personality development, 134
Phenylketonuria, 24; 40; 140
Physically disabled, 44
Play and playthings, 30
Polycystic ovary syndrome, 42
Postoperative complications, 19; 141
Posttraumatic stress symptoms, 55; 72
Precocious puberty, 8
Pre-school children, 30; 51; 53; 66; 82; 88; 110; 191; 192; 193
Prevention, 76
Professional-family relations, 162; 197; 200; 206; 209; 211; 212; 218
Professional-patient relations, 137
Psychological stress, 16; 27; 29; 47; 49; 52; 56; 57; 59; 61; 65; 67; 69; 70; 71; 74; 75; 76; 77; 79; 82; 83; 86; 88; 90; 91; 92;

- 95; 97; 100; 107; 114; 145;
148; 153; 155; 156; 159; 161;
162; 163; 166; 167; 185; 189;
193; 200; 211; 214; 215; 219
- Psychosocial problems, 8; 9; 11;
13; 14; 28; 34; 35; 37; 39; 40;
43; 45; 46; 52; 53; 57; 58; 59;
62; 63; 83; 84; 85; 89; 93; 106;
121; 127; 130; 131; 137; 140;
144; 150; 162
- Quality of care, 121; 199; 205;
219
- Quality of life, 3; 4; 5; 6; 7; 9; 10;
12; 14; 16; 17; 19; 20; 22; 24;
26; 32; 33; 34; 35; 36; 37; 39;
41; 42; 44; 45; 46; 48; 49; 50;
52; 54; 57; 58; 61; 63; 70; 71;
72; 73; 74; 75; 79; 80; 81; 82;
84; 88; 94; 95; 96; 97; 98; 99;
100; 101; 102; 103; 104; 105;
106; 107; 108; 109; 110; 111;
112; 113; 114; 115; 116; 117;
118; 125; 126; 129; 132; 148;
149; 151; 165; 166; 174; 180;
182; 199; 207; 209
- Questionnaires, 12; 35; 45; 96;
97; 98; 100; 101; 102; 103;
104; 105; 106; 107; 108; 109;
110; 113; 114; 115; 116; 117;
118; 146; 208
- Rehabilitation, 44; 131
- Residential care, 208
- Reviews, 4; 6; 10; 14; 17; 25; 31;
35; 51; 59; 73; 85; 100; 101;
145; 146; 156; 199; 201; 209;
214
- Rheumatoid arthritis, 25; 34; 47;
56; 61; 74; 75; 82; 127; 137;
154; 157; 177; 178; 205
- Risk factors, 16; 22; 23; 25; 27;
55; 86
- Risk taking, 50
- School, 18; 105; 121; 126; 127;
128; 136; 145; 155; 196
- School absenteeism, 20; 56; 119;
123; 124; 142; 143; 144; 146;
202
- School-age children, 13; 35; 51;
68; 80; 84; 112; 135
- Screening, 60
- Self care, 151; 170; 171; 172;
173; 174; 176; 180; 181; 182;
184; 186; 188; 189; 194; 195;
204; 219; 220
- Self esteem, 12; 22; 30; 40; 44;
100; 126; 128; 140; 155; 169
- Self image, 16; 25; 28; 78
- Sex differences, 47; 158; 184
- Sexual behaviour, 196
- Siblings, 6; 67; 78; 85; 89; 93;
187
- Sick role, 30; 42; 56; 57; 111;
126; 130; 157; 159; 172; 173;
180; 181; 182; 183; 186; 188;
203; 204
- Sickle cell disease, 52; 147
- Social adjustment, 17; 19; 24; 30;
32; 37; 39; 40; 46; 56; 74; 77;
83; 87; 114; 119; 128; 131;
134; 135; 137; 140; 143; 145;
146; 148; 152; 164; 219
- Social development, 23
- Social participation, 100; 125;
139; 146; 197
- Social skills, 133; 135
- Social support, 22; 47; 51; 61; 62;
69; 73; 75; 86; 90; 121; 122;
137; 153; 155; 162; 163; 164;
165; 173; 177; 182; 189; 194;
201; 210; 213
- Socioeconomic factors, 10; 16;
22; 68; 75; 93; 97; 119; 140;
167; 184; 185; 194; 196
- Special education, 132

- Spina bifida, 66; 68; 69; 72; 81;
92; 122; 139; 208; 215
- Spinal muscular atrophy, 161
- Sturge-Weber syndrome, 13
- Survivors, 28; 127
- Tension headache, 53; 149
- Terminal illness, 213
- Thalassemia, 147; 150; 168
- Tourette syndrome, 87
- Turner syndrome, 134; 218
- Vocational education, 125
- Volunteers, 213
- West syndrome, 132
- Young adults, 11; 20; 22; 23; 26;
29; 33; 40; 43; 47; 73; 109;
125; 127; 130; 131; 172; 182

Appendix 1 Search profile

The search profile can globally be described as follows.

(Infants OR Preschool children OR Children OR Adolescents OR Young adults)

AND

((Leukemia OR Haemophilia OR Acquired immunodeficiency syndrome OR Congenital heart defects OR Vascular diseases OR Rheumatoid arthritis OR Muscular diseases OR Central nervous system diseases OR Spinal dysraphism OR Epilepsy OR Migraine OR Asthma OR Eczema OR Endocrine diseases OR Metabolic disease OR Celiac disease OR Cystic fibrosis OR Diabetes mellitus)

OR

(Chronic diseases OR chronic illness OR Chronic pain))

Depending on the databases, search profiles were refined, like in the update search in Pubmed and Psychinfo, or simplified, like, for instance, in the catalogues of the Dutch ministries. It also depended on the databases which keywords exactly could be used, and whether free texts terms were necessary. Free text terms are words in title or abstract, and can be used when there is not an adequate keyword available for the given concept.

Appendix 2 Overview of relevant documents in reviews

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**Eksi A, Molzan J, Savasir I, Gueler N. Psychological adjustment of children with mild and moderate severe asthma. *European Child and Adolescent Psychiatry*, 1995; 4(2): p.77-84
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Gravelle AM. Caring for a child with a progressive illness during the complex chronic phase: parents' experience of facing adversity. *Journal of Advanced Nursing*, 1997; 25(4): p.738-745

**Hagglund KJ, Vieth AZ, Sadler CS, Johnson JC, Hewett JE. Caregiver personality characteristics and adaptation to juvenile rheumatic disease. *Rehabilitation Psychology*, 2000; 45(3): p.242-259
NIVEL: C 8617**

**Hentinen M, Kyngäs H. Factors associated with the adaptation of parents with a chronically ill child. *Journal of Clinical Nursing*, 1998; 7(4): p.316- 324
NIVEL: C 6440**

**Holden EW, Chmielewski D, Nelson CC, Kager VA, Foltz L. Controlling for general and disease-specific effects in child and family adjustment to chronic childhood illness. *Journal of Pediatric Psychology*, 1997; 22(1): p.15-27
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**Ireys HT, Sills EM, Kolodner KB, Walsh BB. A social support intervention for parents of children with juvenile rheumatoid arthritis: results of a randomized trial. *Journal of Pediatric Psychology*, 1996; 21(5): p.633-641
NIVEL: C 8623**

Jacobson AM, Hauser ST, Willett JB, Wolfsdorf JI, Dvorak R, Herman L, Groot M de. Psychological adjustment to IDDM: 10-year follow-up of an onset cohort of child and adolescent patients. *Diabetes Care*, 1997; 20(5): p.811-818
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