

## 5. Literaturverzeichnis

1. Abbott J, Conway S, Etherington C, Fitzjohn J, Gee L, Morton A, Musson H, Webb AK. (2000) Perceived body image and eating behavior in young adults with cystic fibrosis and their healthy peers. *J Behav Med*; 23(6):501-17.
2. Akerkar SM, Bichile LS. (2004) Health information on the internet: patient empowerment or patient deceit? *Indian J Med Sci*; 58(8):321-6.
3. Balkrishnan R, Housman TS, Rummer S, Rapp SR, Clarke J, Feldman SR, Fleischer AB (2003) The family impact of atopic dermatitis in children: the role of the parent caregiver. *Pedatr Dermatol* 20: 5-10
4. Beattie PE, Lewis-Jones MS. (2006) A comparative study of impairment of quality of life in children with skin disease and children with other chronic childhood diseases. *Br J Dermatol*. 155(1):145-51.
5. Ben-Gashir MA, Seed PT, Hay RJ. (2002) Are quality of family life and disease severity related in childhood atopic dermatitis? *J Eur Acad Dermatol Venereol*; 16: 455–462.
6. Bernard-Bonnin, A.-C., Stachenko, S., Bonin, D., Charette, C., Rousseau, E., (1995): Selfmanagement teaching programs and morbidity of pediatric asthma: A meta-analysis. *J. Allergy Clin Immunol*. 95: 34-41.
7. Bibace R, Walsh ME. (1980) Development of children's concepts of illness. *Pediatrics* 66:912-917
8. Bowling A. (2005) Just one question: If one question works, why ask several? *J Epidemiol Community Health* 59(5):342-5.

9. Broberg A, Kalimo K, Lindblad B, Swanbeck G. (1990) Parental education in the treatment of childhood atopic eczema. *Acta Derm Venereol (Stockh)* 70:495-499.
10. Bullinger, M., Kirchberger, I., von Steinbüchel, N. (1993). Der Fragebogen Alltagsleben – ein Verfahren zur Erfassung der gesundheitsbezogenen Lebensqualität. *Zeitschrift für Medizinische Psychologie*, 3, 121-131.
11. Bullinger M, Ravens-Sieberer, U (1995) Grundlagen, Methoden und Anwendungsgebiete der Lebensqualitätsforschung bei Kindern. *Prax Kinderpsychol Kinderpsychiatr* 44:391-398
12. Chinn DJ, Poyner T, Sibley G (2002) Randomized controlled trial of a single dermatology nurse consultation in primary care on the quality of life of children with atopic eczema. *Brit J Dermatol* 146: 432-439
13. Clarke SA, Eiser C. (2004) The measurement of health-related quality of life (QOL) in paediatric clinical trials: a systematic review. *Health Qual Life Outcomes* 22;2: 66.
14. Congleton, J., Hodson, M.E. & Duncan-Skingle, F. (1996). Quality of life in adults with cystic fibrosis. *Thorax*, 51, 936-940.
15. Congleton, J., Hodson, M.E., Duncan-Skingle, F. (1999). Do Nottingham Health Profile scores change over time in cystic fibrosis? *Respiratory Medicine*, 92, 268-272.
16. Czyzewski, D.I., Mariotto, M.J., Bartholomew, L.K., LeCompte, S.H. & Sockrider, M.M. (1994). Measurement of quality of well-being in a child and adolescent cystic fibrosis sample. *Medical Care*, 32(9), 965-972.
17. D'Alessandro DM, Dosa NP (2001) Empowering children and families with information technology. *Arch Pediatr Adolesc Med. Oct;155(10):1131-1136.*

18. De Jong, W., Kaptein, A.A., van der Schans, C.P., Mannes, G., van Aalderen, W., Grevink, R. & Koeter, G. (1997). Quality of life in patients with cystic fibrosis. *Pediatric Pulmonology*, 23, 95-100.
19. Deyo, R.A., Diehr, P. & Patrick, D.L. (1991). Reproducibility and responsiveness of health status measures: Statistics and strategies for evaluation. *Controlled Clinical Trials*, 12, 142S-158S.
20. Diepgen TL (2000) Is the prevalence of atopic dermatitis increasing? In: HC Williams (Ed.) *Epidemiology of Atopic Eczema*. Cambridge University Press, Cambridge 96-109
21. Drotar, D., Doershuk, C.F., Stern, R.C., Boat, T.F., Boyer, W. & Matthews, L. (1981). Psychosocial functioning of children with cystic fibrosis. *Pediatrics*, 67(3), 338-343.
22. Ehlers A, Stangier U, Gieler U. (1995) Treatment of atopic dermatitis: a comparison of psychological and dermatological approaches to relapse prevention. *J Consult Clin Psychol* 63:624-35.
23. Elborn JS, Shale DJ, Britton JR. Cystic fibrosis: current survival and population estimates to the year 2000. *Thorax* 1991; 46:881-885
24. Fegert JM. (1995) Neurodermitis und problematisches Verhalten in den ersten drei Lebensjahren (Atopic Dermatitis and problematic behaviour during the first three years of life). *Habilitation*, Humboldt University, Berlin.
25. Finlay AY. (1992) Quality of life impairment in atopic dermatitis and psoriasis. *Clin Exp Perspect Sandimmun Ther*; 2: 10-11.
26. FitzSimmons SC. The changing epidemiology of cystic fibrosis. *J Pediatr*, 1993;122:1-9
27. Floistrup H, Swartz J, Bergstrom A, Alm JS, Scheynius A, van Hage M, Waser

- M, Braun-Fahrlander C, Schram-Bijkerk D, Huber M, Zutavern A, von Mutius E, Ublagger E, Riedler J, Michaels KB, Pershagen G, (2006) The Parsifal Study Group. Allergic disease and sensitization in Steiner school children. *J Allergy Clin Immunol.* 117(1):59-66.
28. Frewer LJ, Salter B, Lambert N. (2001) Understanding patients' preferences for treatment: the need for innovative methodologies. *Qual Health Care.*;10 Suppl 1:i50-54.
29. Galassi C, De Sario M, Biggeri A, Bisanti L, Chellini E, Ciccone G, Petronio MG, Piffer S, Sestini P, Rusconi F, Viegi G, Forastiere F. (2006) Changes in prevalence of asthma and allergies among children and adolescents in Italy: 1994-2002. *Pediatrics.* Jan;117(1):34-42.
30. Gebert, N., Hümmelink, R., Könning, J., Staab, D., Schmidt, S., Szczepanski, R., Runde, B., Wahn, U., 1998: Efficacy of a self-management program for childhood asthma - A prospective controlled study. *Patient Education and Counseling* 35, 213-220.
31. Gee L, Abbott J, Conway SP, Etherington C, Webb AK. (2003) Quality of life in cystic fibrosis: the impact of gender, general health perceptions and disease severity. *J Cyst Fibros;* 2(4):206-13.
32. Gee L, Abbott J, Hart A, Conway SP, Etherington C, Webb AK. (2005) Associations between clinical variables and quality of life in adults with cystic fibrosis. *J Cyst Fibros;* 4(1):59-66.
33. Gieler U, Koehlein B, Schauer U, Freiling G, Stangier U. (1992) Eltern-Beratung bei Kindern mit atopischer Dermatitis. *Hautarzt* 43(S11):37-42.
34. Gieler, U., J Kupfer, V Niemeier, B Brosig, U Stangier (2000) Atopic eczema prevention programs – a new therapeutical concept for secondary prevention. *Dermatology + Psychosomatics* 1: 138 – 146

35. Gil KM, Keefe FJ, Sampson HA, McCaskill CC, Rodin J, Crisson JE. (1987) The relation of stress and family environment to atopic dermatitis symptoms in children. *J Psychosom Res* 31:673-84.
36. Gruber C, Illi S, Plieth A, Sommerfeld C, Wahn U. (2002) Cultural adaptation is associated with atopy and wheezing among children of Turkish origin living in Germany. *Clin Exp Allergy*; 32(4):526-31.
37. Guillemin, F., Bombardier, C. & Beaton, D. (1993). Cross-cultural adaptation of health-related quality of life measures: Literature review and proposed guidelines. *Journal of Clinical Epidemiology*, 46(12), 1417-1432.
38. Guyatt, G.H., Feeny, D.H. & Patrick, D.L. (1993). Measuring health-related quality of life. *Annals of Internal Medicine*, 118, 622-629.
39. Halkjaer LB, Loland L, Buchvald FF, Agner T, Skov L, Strand M, Bisgaard H. (2006) Development of atopic dermatitis during the first 3 years of life: the Copenhagen prospective study on asthma in childhood cohort study in high-risk children. *Arch Dermatol*. 142(5):561-566.
40. Henry, B., Grosskopf, C., Aussage, P., Goehrs, J.M., Launois, R. & the French CFQoL Study Group (1996b). Construction of a disease specific quality of life questionnaire for cystic fibrosis [abstract]. *Pediatric Pulmonology*, 13(suppl), 337-338.
41. Henry, B., Grosskopf, C., Aussage, P., de Fontbrune, S., Goehrs, J.M. & the French CFQoL Study Group (1997). Measuring quality of life in children with cystic fibrosis: The Cystic Fibrosis Questionnaire [abstract]. *Pediatric Pulmonology*, 14(suppl), 331.
42. Illi S, von Mutius E, Lau S, Nickel R, Gruber C, Niggemann B, Wahn U; Multicenter Allergy Study Group. (2004) The natural course of atopic dermatitis from birth to age 7 years and the association with asthma. *J Allergy Clin Immunol*;113(5):925-31.

43. Jones, P.W., Baveystock, C.M. & Littlejohns, P. (1989). Relationships between general health measured with the Sickness Impact Profile and respiratory symptoms, physiological measures and mood in patients with chronic airflow limitation. *American Review of Respiratory Diseases*, 35, 99-110.
44. Juniper EF, Wisniewski ME, Cox FM, Emmett AH, Nielsen KE, O'Byrne PM. (2004) Relationship between quality of life and clinical status in asthma: a factor analysis. *Eur Respir J*; 23(2):287-91
45. Kay J, Gawkrodger DJ, Mortimer MJ, Jaron AG. (1994) The prevalence of childhood eczema in the general population. *J Am Acad Dermatol* 30:35-39.
46. Klijn PH, van Stel HF, Quittner AL, van der Net J, Doeleman W, van derSchans CP, van der Ent CK. (2004) Validation of the Dutch cystic fibrosis questionnaire (CFQ) in adolescents and adults. *J Cyst Fibros*. Mar;3(1):29-36.
47. Koblenzer CS, Koblenzer PJ. (1988) Chronic intractable atopic eczema. *Arch Dermatol* 124:1673-1677.
48. Koopman HM, Baars RM, Chaplin J, Zwinderman KH. (2004) Illness through the eyes of the child: the development of children's understanding of the causes of illness. *Patient Educ Couns*; 55(3):363-370.
49. Kuhr J, Fischer T, Karmans W, Meinert R, Barth R, Urbanek R (1992) Clinical atopy and associated factors in primary school pupils. *Allergy* 42: 650-655
50. Kummeling I, Thijs C, Penders J, Snijders BE, Stelma F, Reimerink J, Koopmans M, Dagnelie PC, Huber M, Jansen MC, de Bie R, van den Brandt PA. (2005) Etiology of atopy in infancy: the KOALA Birth Cohort Study. *Pediatr Allergy Immunol*;16(8):679-84.

51. Kupfer J, Keins P, Brosig B, Darsow U, Diepgen T, Fartasch M, Korsch E, Lob-Corzilius T, Niemeier V, Scheidt R, Schmid-Ott G, Staab D, Szczepanski R, Werfel T, Wittenmeier M, Gieler U (2003) Development of Questionaires on Coping with Disease and Itching Cognitions for Children and Adolescents with Atopic Eczema. *Dermatol Psychosom* 4: 79-85
52. Lewis-Jones MS, Finlay AY. The Children's Dermatology Life Quality Index (CDLQI): initial validation and practical use. *Br J Dermatol* 1995; 132: 942–949.
53. Lohaus A. (1990) Gesundheit und Krankheit aus der Sicht von Kindern, Hogrefe, Göttingen
54. Mador, J.A. & Smith, D.H. (1989). The psychosocial adaptation of adolescents with cystic fibrosis. *Journal of Adolescent Health Care*, 10, 136-142.
55. Mathias, S.D., Fifer, S.K. & Patrick, D.L. (1994). Rapid translation of quality of life measures for international clinical trials: Avoiding errors in the minimalist approach. *Quality of Life Research*, 3, 403-412.
56. Mazzuca S, Moormann N, Wheeler (1986) The diabetes education study. A controlled trial of the effects of diabetes patient education. *Diabetes Care* 9:1-16.
57. McKenna SP, Doward LC, Niero M, Erdman R.(2004) Development of needs-based quality of life instruments. *Value Health*; 7 Suppl 1: S17–21
58. McSkimming J, Gleeson L, Sinclair M. (1984) A pilot study of a support group for parents of children with eczema. *Aust J Derm*;25:8-11.
59. Melin L, Fredericksen T, Noren P, Swebilius BG. (1986) Behavioral treatment of scratching in patients with atopic dermatitis. *Br J Dermatol* 115:467-74.

60. Modi AC, Quittner AL. (2006) Barriers to Treatment Adherence for Children with Cystic Fibrosis and Asthma: What Gets in the Way? *J Pediatr Psychol.* Jan 9; [Epub ahead of print]
61. Modi AC, Lim CS, Yu N, Geller D, Wagner MH, Quittner AL. (2006) A multi-method assessment of treatment adherence for children with cystic fibrosis. *J Cyst Fibros.* May 4; [Epub ahead of print]
62. Mohammedamin RS, van der Wouden JC, Koning S, van der Linden MW, Schellevis FG, van Suijlekom-Smit LW, Koes BW. (2006) Increasing incidence of skin disorders in children? A comparison between 1987 and 2001. *BMC Dermatol* 21;6:4.
63. Muthny FA. *Freiburger Fragebogen zur Krankheitsverarbeitung.* Weinheim: Beltz Test GmbH, 1989.
64. Naleway AL. (2004) Asthma and atopy in rural children: is farming protective? *Clin Med Res.* Feb;2(1):5-12
65. Orenstein, D., Nixon, P., Ross, E. & Kaplan, R. (1989). The quality of well-being in cystic fibrosis. *Chest*, 95, 344-347.
66. Pauli-Pott U, Darui A, Beckmann D. Infants with atopic dermatitis: maternal hopelessness, child-rearing attitudes and perceived infant temperament. *Psychother Psychosom* 1999; 68: 39–45.
67. Petermann F, J Lecheler (1992) Patientenschulung. Dustri, München
68. Quittner, A.L. (1998) Measurement of quality of life in cystic fibrosis.. Measurement of quality of life in cystic fibrosis. *Curr Opin Pulm Med*;4(6):326-331.

69. Quittner AL, Buu A, Messer MA, Modi AC, Watrous M. (2005) Development and validation of The Cystic Fibrosis Questionnaire in the United States: a health-related quality-of-life measure for cystic fibrosis. *Chest*;128(4):2347-54.
70. Rozov T, Cunha MT, Nascimento O, Quittner AL, Jardim JR. (2006) Linguistic validation of cystic fibrosis quality of life questionnaires *J Pediatr*;82(2):151-6.
71. Scheewe S, Warschburger P, Clausen K, Skusa-Freeman B, Petermann F. (1997) Neurodermitis-Verhaltenstraining für Kinder, Jugendliche und ihre Eltern. München MMV.
72. Schmidt-Grüber C, Deicke B, Nickel G, Niggemann B, Lehmann C, Paul K, Pohl C, Wahn U. (1996) Elternschulung bei Kindern mit atopischer Dermatitis. *Sozialpädiatrie u Kinderärztliche Praxis* 18:46-50.
73. Schultz Larsen F. (1996) Atopic dermatitis: an increasing problem. *Pediatr Allergy Immunol* 7(suppl 9):51-53.
74. Squires B, Learmonth I. (2003) Empowerment of patients---fact or fiction? *BMJ*. 29;326(7391):710.
75. Su JC, Kemp AS, Varigos GA, Nolan TM (1997) Atopic eczema: its impact on the family and financial cost. *Arch Dis Childh* 76:159-62
76. Szczepanski R, Schon M, Lob-Corzilius T. (1994) Das juckt uns nicht. Ein Lern- und Lesebuch für Kinder mit Neurodermitis und ihre Eltern. Stuttgart, G. Thieme Verlag,
77. Testa, M.A. & Simonson, D.C. (1996). Assessment of quality-of-life outcomes. *The New England Journal of Medicine*, 334(13), 835-840
78. Tullis, D.E. & Guyatt, G.H. (1995). Quality of life in cystic fibrosis. *PharmacoEconomics*, 8(1), 23-33.

79. The International Study of Asthma and Allergies in Childhood (ISAAC) (1998) Steering Committee. Worldwide variation in prevalence of symptoms of asthma, allergic rhinoconjunctivitis, and atopic eczema: ISAAC. *Lancet* 351: 1225-1235
80. von Rüden U, Staab D, Kehrt R, Wahn U. (1999) Entwicklung und Validierung eines krankheitsspezifischen Fragebogens zur Erfassung der Lebensqualität von Eltern neurodermitiskranker Kinder. *Zeitschrift für Gesundheitswissenschaften (Journal of public health)* 4: 335-50
81. Wahn U. (2000) What drives the allergic march? *Allergy*; 55(7):591-9.
82. Warschburger P, Buchholz HT, Petermann F. Psychological adjustment in parents of young children with atopic dermatitis: which factors predict parental quality of life? *Br J Dermatol* 2004; 150: 304–311.
83. Wensing M. (2000) Evidence-based patient empowerment *Qual Health Care.*;9(4):200-1.
84. Werfel T, Kapp A. (1998) Environmental and other major provocation factors in atopic dermatitis. *Allergy*; 53(8):731-9.
85. Werner S, Buser K, Kapp A, Werfel T. (2002) The incidence of atopic dermatitis in school entrants is associated with individual life-style factors but not with local environmental factors in Hannover, Germany. *Br J Dermatol*; 147(1):95-104.
86. Williams H, Flohr C. (2006) How epidemiology has challenged 3 prevailing concepts about atopic dermatitis. *J Allergy Clin Immunol*;118(1):209-13
87. Zutavern A, Hirsch T, Leupold W, Weiland S, Keil U, von Mutius E. (2005) Atopic dermatitis, extrinsic atopic dermatitis and the hygiene hypothesis: results from a cross-sectional study. *Clin Exp Allergy*. Oct;35(10):1301-8.