TITLE: AT RISK MARRIAGES: CONFRONTING BREATHLESSNESS AND LOSS

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RATIONALE: In order to develop psychoeducational approaches for couples affected by alpha-1 antitrypsin deficiency emphysema, it is important to describe individual and marital characteristics, functioning and coping in marriages which may be at most risk for problems managing dyspnea and multiple losses. *METHODS:* An expansion of earlier studies of marital stress and coping in A1AD, this study used a mailed survey based on the Marital Coping in Chronic Illness Model and several well-established measures of individual and marital functioning and coping. Descriptive analysis of data from each spouse in 234 marriages included cluster analysis and t-testing to distinguish couples in less satisfying marriages from those in more mutually satisfying marriages. *RESULTS:* Couples in 77 of the 234 marriages perceived their marriages as less satisfying – sources of stress rather than support. These "at risk" marriages were distinguished from the satisfying marriages by characteristics such as younger age at diagnosis and onset of dyspnea, lower income and employment levels and higher symptom stress - without significant differences in mean FEV_1. Dramatic differences were found in variables reflecting marital functioning. Avoidance coping strategies were more common in less satisfied couples. Depressive symptoms were more frequent and levels of optimism and self-esteem were lower. *CONCLUSIONS:* Description of marriages "at risk" will facilitate their identification and the development of early interventions targeted to altered functioning/coping.

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INNER-CITY CAREGIVERS' REPORTS OF THEIR PHYSICIANS' ASTHMA MANAGEMENT PRACTICES.

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RATIONALE: The physician-patient encounter is an essential component of asthma management. The purpose of this study was to evaluate inner-city caregivers' reports of their physicians' asthma management practices. METHODS: Two hundred sixty-seven caregivers of school age children with asthma completed a survey about the child's asthma that included 13 questions about physician behaviors critical to asthma management standards of care. RESULTS: ninety-three percent of caregivers reported a regular source of asthma care, however, 46% had 1 visit or less in the past year. Twenty-nine percent of children were treated in the ER in the previous 6 months and 5% were hospitalized during the same time period. Sixty-four percent had asthma symptoms less that 7 days/month, 21% had symptoms 8-19 days/month, and 14% had symptoms 20+ days/month. Of those children with more than 1 visit/year, 80% of caregivers reported that physicians asked about medication use at all or most regular visits. In contrast, patient education activities were reported less frequently. For example 60% of caregivers reported being provided educational materials and 62% reported discussion of allergen control at all or most visits. The frequency of many patient education activities increased with increased frequency of symptoms ($p < .01$), but was not related to ER use, hospitalization, or number of asthma visits in the past year. CONCLUSIONS: According to inner-city caregivers, their physicians fairly consistently ask about medication use, but are less likely to regularly provide essential patient education. Only increased symptom frequency was associated with the increased occurrence of many patient education activities.

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DETERMINANTS OF CARE GIVER REPORT OF QUALITY OF LIFE

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RATIONALE: Quality of life (QOL) has increased in popularity as an outcome in health research. Yet, QOL is a subjective measure that often shows little association with objective measures. Further, QOL is heavily influenced by respondent characteristics. We had the opportunity to study the determinants of caregiver report of QOL within 2 very different cohorts of children with asthma or wheezy illness.

METHOD: Two separate asthma studies with similar measures were part of this analysis, each study using a standardized objective method of coding medical records. The first is the Pediatric Outcome Study (POS) where 98 children who were consecutively admitted to a Pediatric Day Program for an asthma evaluation and treatment were enrolled. The second, the Childhood Asthma Prevention Study (CAPS), enrolled 180 low-income children under 2 years of age with 3 or more physician documented episodes of wheezing. Each study had baseline assessments where an interviewer obtained questionnaires (i.e. quality of life, mental health status). A complete set of medical records for the year prior to baseline was collected for the POS cohort, while lifetime medical records (range 9-24 months) were collected for the CAPS children. The medical records were systematically coded for medical encounter utilization. Medical encounter categories included number of corticosteroid bursts, episodes, clinic sick visits, emergency department visits, and hospitalizations. Results are reported as Spearman correlation coefficients. For CAPS, age at baseline was controlled in the analysis.

RESULTS: QOL was related to corticosteroid bursts in both cohorts (POS $r=-0.23$, $p<0.05$; CAPS $r=-0.16$, $p<0.05$) and to clinic sick visits in the CAPS cohort ($r=-0.17$, $p<0.05$). Caregiver report of QOL was significantly related to caregiver self-report of anxiety and depression in both CAPS ($r=-0.37$, $p<0.0001$; $r=-0.27$, $p<0.001$, respectively) and in POS ($r=-0.30$, $p<0.001$; $r=-0.34$, $p<0.0001$, respectively).

CONCLUSIONS: Caregiver report of QOL is highly influenced by respondent affect state. Understanding this relationship is important for appreciating the role of QOL in outcomes and for providing an opportunity for intervention.

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THE ROYAL COLLEGE OF PHYSICIANS' 'THREE KEY QUESTIONS FOR ASTHMA': A QUALITATIVE STUDY

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Introduction: The Royal College of Physicians, UK, (RCP) has developed a clinical, patient-centred outcome measure by consensus, the 'Three Key Questions'. It inquires about asthma symptoms over the last month occurring at night, during the day and disrupting usual activities. Several issues related to the outcome measure have emerged in a qualitative study. **Method:** *Setting*: Seven family practices in Tayside, UK. *Sample*: 24 adults aged 16-42 years with asthma diagnosed for at least 2 years, on steps 1-4 of the British Thoracic Society guidelines, with no significant co-morbidity. *Data collection*: a semi-structured interview survey. *Analysis*: the interviews are tape-recorded, transcribed verbatim and the transcripts analysed using "Framework"[1]. **Results**: The outcome measure is subject to recall bias. The same symptoms may be counted twice if daytime symptoms also occur on activity. 'Interference with activity' is a subjective term the interpretation of which varies considerably. Some patients feel that asthma has not interfered with an activity if the activity is completed using medication. Changes in the level of activity undertaken may be measured rather than changes in symptom severity. The 'Three Key Questions' are not fully patient-centred because they assess the presence of symptoms rather than their importance to the individual. **Conclusion:** Several issues related to the 'Three Key Questions' have emerged which may confound the resulting score and which require further investigation. **References:** 1. Ritchie J and Spencer L. Qualitative data analysis for applied policy research, *in* Bryman A and Burgess RG (eds), 1994, Analysing qualitative data, Routledge.

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PERCEIVED CONTROL OF ASTHMA AND QUALITY OF LIFE AMONG ADULTS WITH ASTHMA.

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Background: Perceived control of certain chronic conditions influences both quality of life (QOL) and psychological adjustment. We wished to establish this relationship among adults with asthma. **Methods:** Data were drawn from multiple waves of a longitudinal cohort study of adults with asthma surveyed by telephone at 18-month intervals (n=128). A scale measuring perceived control of asthma (PCoA) was administered at baseline and follow-up. This 12-item scale was derived from a validated arthritis perceived control measure. The PCoA showed high internal consistency (Cronbach's $\alpha = .76$) and was significantly correlated with asthma severity both at baseline ($r=-.27$, $p=.002$) and at follow-up ($r=-.23$, $p=.008$). The Marks Asthma Quality of Life Questionnaire (AQLQ) and CES-D depressive symptom scale were also administered longitudinally. We estimated the association between changes in PCoA over time and AQLQ and CES-D scores at follow-up, controlling for baseline AQLQ, CES-D, and changes in asthma severity. **Results:** Even controlling for changes in severity and prior AQLQ, decreases in PCoA were associated with worse QOL at follow-up ($p<.0001$). Similarly, controlling for changes in severity and prior CES-D scores, decreases in PCoA were associated with higher levels of depressive symptoms at follow-up ($p=.004$). In these models, PCoA explained 11% of the variance in AQLQ (model $R^2=.25$) and 6% of the variance in CES-D (model $R^2=.12$). **Conclusions:** Although changes in asthma severity are associated with changes in individuals' perceived control of asthma, PCoA has an independent effect on asthma-specific QOL and psychological adjustment.

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PERFORMANCE OF THE SELF-ADMINISTERED PEDIATRIC ASTHMA QUALITY OF LIFE QUESTIONNAIRE (PAQLQ) AMONG CHILDREN ATTENDING AN URBAN PUBLIC CLINIC

EN Grant, A Segalene, AM Malone, LA Asmussen , KB Weiss.

Background: The Pediatric Asthma Quality of Life Questionnaire (PAQLQ) is a 23 item-child report measure in use for pediatric asthma research. Little is known about how children of diverse backgrounds are able to understand and complete the PAQLQ. **Methods:** Children with asthma, ages 7 – 17 were recruited from an asthma clinic at an urban public hospital. Subjects completed the self-administered PAQLQ as well as a structured interview aimed at exploring their ability to define key terms. Each subject answered a random sample of survey items administered by an interviewer. Several aspects of performance were examined: 1) Internal consistency 2) Ability to understand key terms, 3) Differences between responses to items read to children by an interviewer versus self-administered. **Results:** Ninety-eight children completed the study. The mean age of the children was 11.6 (+/-2.9) years; 50.0 % were male, 87.8% were African-American, and 72.8% were from households with an annual income <$15,000. Internal consistency of the items in the PAQLQ was generally high, with alpha coefficients ranging from 0.81 (activities) to 0.92 (symptoms). However, only 50% of the children were able to define the key term "worried", and 66.3% were able to define "bothered". Ability to define essential terms varied by item as well as the age and reading level of the child. There were differences in children's responses to interviewer- versus self- administered items, with intra-class correlation coefficients for each item ranging from 0.33 to 0.82. Older children (≥12 years) and those with higher reading levels (≥6th grade) appeared to perform better in key term definition. Internal consistency, particularly for the activities domain, appeared to be higher in older children and those with higher reading levels. **Conclusions**: These findings suggest that in this minority low-income population, the PAQLQ (interviewer or self-administered) may have better performance characteristics for children aged 12 and older, and those with at least 6th grade reading levels. The generalizability of these findings to other clinical settings and patient populations remains uncertain.

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ABSTRACTS

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