Title: Disease severity, mental health, and quality of life of children and adolescents with asthma

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Running head: Asthma and mental health in children

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ABBREVIATIONS

CBCL Child Behavior Checklist

GINA Global Initiative against Asthma

QL = Quality of life
Children with asthma are at higher risk for psychological problems, especially internalising problems (Klinnert and others 2000; McQuaid and others 2001; Calam and others 2003; Calam and others 2005). Compared to other chronic conditions asthma also appears to be more often related to psychiatric disorders (Vila and others 1999).

The combination of asthma and psychological symptoms may affect quality of life and the adherence to asthma treatment on the part of the children concerned. Behaviour problems were found to be related to poor adherence, poor asthma management and poor functional health status (Christiaanse and others 1989; Weil C.M. and others 1999). For clinical practice this means that families with an asthmatic child and comorbid psychological problems will be in need of a more comprehensive treatment. Asthma treatment as usual is considered insufficient in these cases (Bussing and others 1995). These findings justify further investigation that focuses on children and adolescents who suffer from asthma and show significant emotional and/or behavioral symptoms.

From a theoretical point of view, there are multiple explanations for the relationship between asthma and behaviour problems. Current research provides a biopsychosocial model of asthma. As a biological pathway for psychological factors triggering the expression of asthma, psychosocial stress is connected with the central nervous system and with immune as well as endocrinal function (Wright R.J. 2003). Disease severity also seems to mediate the connection between asthma and behaviour problems, even if previous findings varied (Bussing and others 1995; Eksi and others 1995; Wamboldt and others 1998; Klinnert and others 2000).

Quality of life for children and adolescents with asthma has been a topic of several investigations, often tackling the question of whether quality of life is influenced by disease severity, and producing inconsistent results (Juniper 1995; Juniper 1997; Sawyer M.G. and others 2000; Annett 2001; Warschburger and others 2004). This research revealed no clear connection between asthma severity and quality of life. In fact, quality of
life of chronically ill persons is not necessarily lower than that of healthy controls (Warschburger and Petermann 2000). The construct of quality of life is, however, considered an important indicator of treatment success for patients who suffer from a chronic disease (Eiser and Morse 2001). A high quality of life in spite of a severe illness can be attributed to a successful process of adaptation to the disease. A theoretical model of adaptation to a chronic disease has been developed by Wallander and Varni (Wallander and Varni 1992; Wallander and Varni 1998). The process of adaptation is supposed to be influenced by various risk and resistance factors, such as disease/disability parameters, intrapersonal factors, psychosocial factors, or stress-processing factors. Psychological problems that may be caused by the chronic disease or which may be independent of it would complicate the process of adaptation.

Research comparing the children and adolescents with mental and physical disorders demonstrated that quality of life with mental disorders is worse than with physical disorders (Sawyer and others 2002). There may be a complex relationship between asthma severity, mental health and quality of life that has not been taken into account sufficiently by previous research. Figure 1 shows the theorized relations between asthma severity, emotional and behavioral symptoms and quality of life. In addition to asthma severity, psychological factors are expected to have consequences for the extent of caregiver’s support due to asthma or due to psychosocial problems. Vila et al. combined measures of quality of life and of behaviour problems for adolescents with asthma and found that quality of life was correlated with psychological symptoms (Vila and others 2003). However, on average, the participants of this study showed no serious emotional or behavioral symptoms.

Therefore we devised a replication of the findings of Vila et al. in a sample with more frequent behavioral and emotional symptoms. Going beyond the results of that study we
wanted to examine the impact of comorbid psychological symptoms on the young patients’ need for support. In this study the following hypotheses were tested:

- Comorbid emotional and behavioral symptoms affect quality of life as well as the need for support given due to asthma and due to psychosocial problems.
- In children and adolescents with asthma, the frequency and intensity of their emotional and behavioral symptoms explains significantly more variance in quality of life than asthma severity.

METHODS

Participants

105 of 110 eligible participants took part in this study. 24 of the participants had to be excluded due to missing data. Finally, complete data were available for 81 children and adolescents with asthma (62 boys, 19 girls). Besides an asthma diagnosis, reading ability was another inclusion criterion because participants in this study had to be able to answer a questionnaire. The participants had an average age of 14.1 years, with a range from 7 to 18 years. 10 patients visited elementary school, 52 secondary school (9 years of school) and 19 upper secondary school (10-13 years of school). The patients’ socio-economic status as indicated by parental profession according to (Kleining and Moore 1968) was rather low. 43 (53%) families belonged to the working class, 37 (46%) to middle class and one family was of high socio-economic status. 48% of the children and adolescents came from families with separated parents.

64 of the participants took part in a long-term inpatient rehabilitation program at a German asthma centre to which patients with asthma are typically referred if their disease is difficult to manage at home e.g. due to disease severity, high trigger exposure,
psychosocial and/or behaviour problems. Hence, most of these children and adolescents showed a persistent and complicated course of disease. At the time of assessment, the average duration of rehabilitation in this sample was about two years. During this time the children and adolescents lived together in several boarding-school-like groups and visited the affiliated regular school.

19 of the participants received outpatient treatment because of asthma. The recruitment took place with the help of a regional centre of outpatient asthma education and three office-based paediatricians. Five participants took part in an asthma summer camp.

**Measures**

**Child Behavior Checklist**

The Child Behavior Checklist (CBCL 4/18) is a standardised questionnaire for assessing emotional and behavioral problems of children and adolescents by parent or caregiver ratings (Achenbach 1991). In our study, either caregivers in the asthma centre or parents of outpatients filled in the CBCL. Results of this questionnaire can be summarised in a global score and expressed in scores for internalisation and externalisation. Internalising behaviour problems include anxiety or depression, withdrawal, and somatic complaints. Externalising problems include aggressive and delinquent behaviour. We used the 120-item German version of the CBCL that showed good reliability and validity with an internal consistency of the global score of $\alpha = .94$ for a clinical sample and $\alpha = .92$ for a non-clinical reference sample (Döpfner and others 1994).

**Ulm Inventory for Children**

The Ulm Inventory for Children is a multi-dimensional instrument for assessing health-related quality of life of children and adolescents with chronic conditions (Goldbeck and Braun 2003). It contains 27 items which can be summarised in 5 dimensions: physical well-being, psychological well-being, disease- and therapy-related distress, family relations, and perception of general quality of life. The self-report version of the
questionnaire was used in this study. All items were rated on a five-point scale with a range from 0 to 4 (0: never, 1: seldom, 2: sometimes, 3: often, 4: always). A sum score can be calculated across these dimensions. Scores were transformed to 0 - 100 scales. The authors reported a good internal consistency of the subscales and the global scale (Cronbach’s $\alpha = 0.70 – 0.88$). An additional disease-specific scale with three items measured perceived asthma symptoms (cough, shortness of breath) and asthma-related impairment.

Asthma and social support

The extent of support due to asthma or due to psychosocial problems were each rated by caregivers/parents on a five-point scale with 1 meaning the child/adolescent needs support only seldom, 2 the child/adolescent needs support only sometimes (at most about once a week), 3 the child/adolescent needs support regularly (but not daily), 4 the child/adolescent needs support daily and 5 the child/adolescent needs persistent intensive support. Anchor examples for each scale were given. Analysis of raw score distributions showed that all scale points from 1 to 5 were used.

Asthma severity

Asthma severity of the participants was judged by physicians with expertise in pulmonology according to the GINA classification (Global initiative against asthma (GINA). 2004). This classification scheme is based on the examination of present pulmonary state and on medical charts and divides asthma severity into four classes with 4 being the most severe degree.

**Procedure**

Informed consent was acquired according to the principles of the local ethical committee at the research centre. The participating inpatients answered the questionnaires in the presence of a clinical psychologist or a caregiver. The CBCL and the asthma and social support scales were completed by pedagogical employees on a basis of a minimum
observation period of three months. Except for the scales on asthma-related and social support, all questionnaires were administered using a computer-based version. Outpatients and their parents received paper-pencil versions of the questionnaires.

**Statistical Analyses**

Means, medians, range of raw scores, and standard deviations were computed for each variable of interest. Correlations between CBCL scores and quality of life scores as well as between CBCL scores and the extent of support were examined by calculating *Pearson* product-moment correlations with the significance level adjusted for multiple tests (*Bonferroni* correction). According to the GINA classification, four groups of asthma severity were determined. Because the different degrees of severity were not equally distributed, but had peaks in severity grades 1 and 3, we combined asthma severity 1 and 2 (mild asthma) and 3 and 4 (severe asthma) for further analyses. *t*-tests for independent samples were used to analyse group differences between participants with mild and severe asthma in terms of quality of life, need for support and emotional/behavioral symptoms. Again the significance level was adjusted for multiple tests (*Bonferroni*). Multiple regression analyses were used to explore the effects of asthma severity, emotional/behavioral symptoms, and age. Quality of life, need for support due to asthma and need for support due to psychosocial problems were set as response variables. For each of the response variables, a hierarchical multiple regression was computed with stepwise exclusion of independent variables without significant partial correlation (exclusion criterion $p > .15$). All analyses were performed by using the statistical software package SYSTAT 10.2©.
RESULTS

Descriptive data

Table 1 shows the descriptive data. The mean CBCL total score in the study sample (T = 63) was more than one standard deviation above average, compared with the German reference sample. The mean scores for internalising (T=61) and externalising symptoms (T=61) were also above the normal range of the German reference population. The participants judged their quality of life on average as rather good. For all subscales the mean scores of the Ulm Inventory were in the upper range of the scale. Most children and adolescents reported no impairment of quality of life due to asthma symptoms. The mean score of asthma support was 3.2, of social support 3.3 (1: almost no support, 5: persistent intensive support).

The degree of asthma severity were mostly type 1 (25 %) or type 3 (47 %) according to the GINA-classification. As we merged asthma degrees 1 and 2 and asthma degrees 3 and 4, the distribution was as follows: 36 (45%) participants with mild asthma (degree 1 and 2) and 45 (55%) with severe asthma (degree 3 and 4).

Correlations between emotional/behavioral symptoms, quality of life, and need for support

There was a significant negative correlation between emotional symptoms and the quality of life sum score (see table 2). The results reached significance for the CBCL total score ($r = -.36$, $p < .05$) and for the internalising symptom score ($r = -.37$, $p < .05$). Considering the LQ-KID subscales, the most clear and significant association with self-reported psychological well-being was found with the CBCL total score ($r = -.43$, $p < .01$) and with the internalising score ($r = -.49$, $p < .01$). The need for support due to asthma as well as due
to psychosocial problems was significantly correlated with the CBCL total score \((r = .45, p < .01)\) and with the externalising symptom score \((r = .38, p < .05)\), but not with the internalising symptom score. The need for social support was significantly correlated with the CBCL total score \((r = .53, p < .01)\), and both correlations with the CBCL internalising \((r = .36, p < .05)\) and externalising score \((r = .44, p < .01)\) were significant.

Effects of asthma severity

Between-group analyses by \(t\)-tests for independent groups showed no significant differences between patients with mild and severe asthma in terms of psychological symptoms and quality of life. There was a statistical tendency to the effect that children and adolescents with severe asthma received more support due to asthma and due to psychosocial problems than participants with mild asthma \((t=-2.11, p=0.038; t=-2.14, p=0.036)\). However, these results did not reach significance when the test for probability was adjusted for multiple tests.

Predictors of quality of life and need for support

Multiple regression analyses were calculated to explore the relationship between psychological symptoms, asthma severity, quality of life and asthma and social support (see table 3). To control for effects due to age, this variable was also included in the regression model. As to quality of life, the CBCL internalising score accounted for most of the variance and was the only significant predictor of quality of life within the model. The need for support due to asthma was significantly predicted by the CBCL externalising score, asthma severity and age. With respect to social support, the CBCL internalising and externalising scores accounted for most of the variance.
DISCUSSION
This study examined the effects of emotional and behavioral symptoms and disease severity on quality of life and on the need for support of children and adolescents with asthma. Our primary hypothesis that psychological factors explain significantly more variance of quality of life than asthma severity was confirmed by our data. Therefore our study was able replicate the findings of Vila et al. in a sample with higher manifestations of emotional and behavioral symptoms (Vila and others 2003). The most obvious association in our study was found between psychological well-being and the internalising score of the CBCL. This result could be expected because internalising symptoms are related to an impairment of psychological well-being and quality of life. A correlation between internalising symptoms and an obvious impairment of quality of life was also found by Sawyer et al. in a sample of children and adolescents with mental disorders (Sawyer and others 2002). Considering the effects of asthma severity on quality of life, previous findings have been inconsistent (Juniper 1995; Sawyer M.G. and others 2000; Annett 2001). However, a decrease of quality of life was found to be more obvious when asthma symptoms had occurred recently (Merikallio and others 2005). So a sample effect may be responsible for the differing findings. All participants in our study received continuing medical treatment and patient education. Most of them were free of asthma symptoms at the time of assessment. This may explain the absence of differences between the patients with mild asthma and those with severe asthma in quality of life. Furthermore, most children and adolescents in our study judged their quality of life as being rather good despite of their chronic disease, as did other clinical samples of chronically ill children.
(Annett 2001; Warschburger and others 2004). This may be attributed to a successful adjustment to the disease. In accordance with Eksi and others (1995) we found no correlation between asthma severity and emotional and behavioral symptoms, indicating that comorbid psychological problems exist independently of asthma. However, psychological problems were found to impair the management of asthma (Rietveld and Creer 2006). Our results are consistent with these findings. Besides age and asthma severity, externalising symptoms were related to the need for support due to asthma. Adherence problems of patients with externalising symptoms may explain this correlation. The need for support due to psychosocial problems was related to externalising symptoms as well as to internalising symptoms, suggesting that the kind of support was judged differently by caregivers depending on the prevailing psychological symptoms.

Some methodical limitations of this study have to be mentioned. In order to assess emotional and behavioral symptoms we used the Child Behaviour Checklist. This instrument is useful for gaining indications of psychiatric disorders but it is not possible to confirm psychiatric diagnosis from its results. In further studies, specific effects of manifest mental disorders may be determined by using standardised clinical interviews. Besides psychopathology, other factors have been found to impair quality of life, such as social skills or recent stressful life events, that were not included in this study (Bastiaanssen and others 2005). Further studies should also consider these aspects. The need for support was judged by caregivers on a uni-dimensional scale. More objective and differentiating measures, e.g. a measure of time taken to support the child, could deliver more information about the influence of psychological problems on support for asthma management. Because of the cross-sectional design of the study, no statements about causal direction of effects can be made.

However, as far as we know, so far only Vila and others (2003) have combined measures of quality of life, psychological symptoms and disease severity. Our findings correspond
essentially to the results of this study though we had a highly selected sample and a rather small sample size. This may support our findings despite of the limitations described.

Conclusions

The quality of life of asthmatic children and adolescents who receive appropriate medical treatment is more impaired by psychological factors than by disease severity. Considering that behavior problems of children and adolescents with asthma make asthma management more difficult, an optimal treatment of patients with asthma should address the issue of comorbid emotional and/or behavioral symptoms. Screening for emotional/behavioral symptoms could be useful for identifying children and adolescents who need an additional mental health service and a more comprehensive treatment. Within the scope of liaison services, clinical child psychologists or child psychiatrists should be involved in the treatment if screening results or direct observations indicate a psychiatric disorder. In order to respond adequately to the needs of children and adolescents with asthma and psychological problems, the children should receive a multidisciplinary treatment. Further investigations should focus on the development and evaluation of structured intervention programs.

Conflict of interests: none

Ethical approval for this observation study was obtained from the local institutional review board.
References


Table 1: Descriptive data on behavior, quality of life, need for support, and asthma severity in the study group

<table>
<thead>
<tr>
<th></th>
<th>n</th>
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<th>SD</th>
<th>median</th>
<th>min</th>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>CBCL&lt;sup&gt;a&lt;/sup&gt; total T-score</td>
<td></td>
<td>63</td>
<td>9.1</td>
<td>64</td>
<td>40</td>
<td>82</td>
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<tr>
<td>CBCL&lt;sup&gt;a&lt;/sup&gt; internalising T-score</td>
<td></td>
<td>61</td>
<td>10.3</td>
<td>62</td>
<td>36</td>
<td>79</td>
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<tr>
<td>CBCL&lt;sup&gt;a&lt;/sup&gt; externalising T-score</td>
<td></td>
<td>61</td>
<td>10.1</td>
<td>61</td>
<td>35</td>
<td>82</td>
</tr>
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**quality of life (QL):**

<table>
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<tr>
<th></th>
<th>n</th>
<th>mean</th>
<th>SD</th>
<th>median</th>
<th>min</th>
<th>max</th>
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<tr>
<td>LQ-KID&lt;sup&gt;b&lt;/sup&gt; (range 0-100)</td>
<td>81</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>- physical well-being</td>
<td></td>
<td>77.9</td>
<td>15.4</td>
<td>81.0</td>
<td>33.0</td>
<td>100</td>
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<td>- psychological well-being</td>
<td></td>
<td>71.3</td>
<td>17.4</td>
<td>75.0</td>
<td>14.0</td>
<td>97.0</td>
</tr>
<tr>
<td>- disease- and therapy-related distress</td>
<td></td>
<td>82.1</td>
<td>15.1</td>
<td>83.0</td>
<td>33.0</td>
<td>100</td>
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<tr>
<td>- family relations</td>
<td></td>
<td>82.6</td>
<td>24.3</td>
<td>88.0</td>
<td>0</td>
<td>100</td>
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<td>- general QL</td>
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<td>68.5</td>
<td>21.9</td>
<td>75.0</td>
<td>25.0</td>
<td>100</td>
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<tr>
<td>- asthma-related QL</td>
<td></td>
<td>80.5</td>
<td>20.4</td>
<td>91.7</td>
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<td>100</td>
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<td>- sumscore</td>
<td></td>
<td>77.0</td>
<td>13.0</td>
<td>80.8</td>
<td>37.4</td>
<td>97.4</td>
</tr>
</tbody>
</table>

**asthma support (range 1-5)** | 81 | 3.2  | 1.3 | 3      | 1   | 5   |

**social support (range 1-5)** | 3.3 | 1.1  | 3   | 1      | 5   |

**Asthma severity (GINA<sup>c</sup>)**

<table>
<thead>
<tr>
<th></th>
<th>mild</th>
<th>severe</th>
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<tbody>
<tr>
<td>1</td>
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<sup>a</sup> Child Behaviour Checklist  
<sup>b</sup> Quality of life self-report questionnaire  
<sup>c</sup> Global Initiative against Asthma
Table 2: Pearson correlations between emotional/behavioral symptoms and quality of life, asthma, and social support (N = 81).

<table>
<thead>
<tr>
<th></th>
<th>CBCL&lt;sup&gt;a&lt;/sup&gt;</th>
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<tr>
<td></td>
<td>total</td>
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<td>external</td>
</tr>
<tr>
<td>LQ-KID&lt;sup&gt;b&lt;/sup&gt;:</td>
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<td>-.30</td>
<td>-.19</td>
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<td>- psychological well-being</td>
<td>-.43**</td>
<td>-.49**</td>
<td>-.23</td>
</tr>
<tr>
<td>- disease- and therapy-related distress</td>
<td>-.13</td>
<td>-.15</td>
<td>-.03</td>
</tr>
<tr>
<td>- family relations</td>
<td>-.23</td>
<td>-.12</td>
<td>-.25</td>
</tr>
<tr>
<td>- general quality of life</td>
<td>-.25</td>
<td>-.27</td>
<td>-.12</td>
</tr>
<tr>
<td>- asthma related quality of life</td>
<td>-.04</td>
<td>-.01</td>
<td>-.07</td>
</tr>
<tr>
<td>- quality of life sumscore</td>
<td>-.36*</td>
<td>-.37*</td>
<td>-.22</td>
</tr>
<tr>
<td>asthma support</td>
<td>.45**</td>
<td>.27</td>
<td>.38*</td>
</tr>
<tr>
<td>social support</td>
<td>.53**</td>
<td>.36*</td>
<td>.44**</td>
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<sup>a</sup> Child Behaviour Checklist  <b>Quality of life self-report questionnaire

*p < .05; **p < .01
Table 3: Results of multiple regression analyses for variables predicting quality of life, asthma support and social support (N = 81)

<table>
<thead>
<tr>
<th>response variable:</th>
<th>LQ-KID&lt;sup&gt;b&lt;/sup&gt; sumscore</th>
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<th>social support</th>
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<tr>
<td></td>
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<tr>
<td></td>
<td>standard coefficient</td>
<td>coefficient</td>
<td>coefficient</td>
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<tr>
<td>CBCL&lt;sup&gt;a&lt;/sup&gt; internalising</td>
<td>-.37 -3.52 0.001</td>
<td>.27 &lt; 1 ns</td>
<td>.26 2.54 0.013</td>
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<td>CBCL&lt;sup&gt;a&lt;/sup&gt; externalising</td>
<td>-.22 &lt; 1 ns</td>
<td>.43 4.4 0.000</td>
<td>.37 3.67 0.000</td>
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<tr>
<td>asthma severity</td>
<td>-.15 &lt; 1 ns</td>
<td>.23 2.38 0.020</td>
<td>.14 &lt; 1 ns</td>
</tr>
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<td>age</td>
<td>.04 &lt; 1 ns</td>
<td>-.31 -3.18 0.002</td>
<td>-.06 &lt; 1 ns</td>
</tr>
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</table>

R² (df) | .12 (1/79) | .25 (3/77) | .24 (2/78)

<sup>a</sup> Child Behaviour Checklist  
<sup>b</sup> Quality of life self-report questionnaire
Figure 1: Theoretical model of interrelations between main variables

- Emotional and behavioral symptoms
- Asthma severity
- Quality of life
- Need for social support
- Need for asthma support