ORIGINAL CONTRIBUTION

T. M. Huurre
H. M. Aro

Long-term psychosocial effects of persistent chronic illness.
A follow-up study of Finnish adolescents aged 16 to 32 years

■ **Abstract** 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) in their life situation, psychosocial well-being and health habits at age 32 years. 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.

■ **Key words** persistent chronic illness – psychosocial health – adolescents – longitudinal studies

T. M. Huurre (✉) · H. M. Aro
National Public Health Institute
Department of Mental Health
and Alcohol Research
Mannerheimintie 166
00300 Helsinki, Finland
E-Mail: taina.huurre@ktl.fi

Introduction

Many cross-sectional studies have found that children and adolescents with chronic illness and disabilities are at increased risk of psychosocial problems. Chronically ill children and adolescents have been reported to have lower self-esteem, poorer body image and more problems in psychological well-being, behaviour, and social adjustment than those without chronic conditions [8, 13, 15, 30, 35]. Although there is some evidence that chronic illness and disability may put children and adolescents at psychosocial risk, it may not necessarily cause problems in psychosocial functioning [23, 31].

Patterson and Blum [23], in their review of biomedical and psychosocial literature of chronic illnesses and disabilities, pointed out the sources of risk encountered by children with chronic conditions as well as protective factors that can modify risk. They identified risk and protective factors at four multiple levels: the condition, the child, the family, and the community. Certain characteristics of the chronic conditions, such as uncertain prognosis, an invisible condition and chronic pain have been found to create higher risk for problems. Independent of characteristics of the chronic condition, there is evidence that individual factors are associated with developmental outcomes. Male gender, low self-esteem, poor psychological health, poor school achievement, and a lower sociable temperament of the child have been found to predispose to risk. Also, unhealthy health habits (smoking and alcohol use) have been identified as important factors. At the family level, family flexibility, adaptive coping, social integration, positive meanings ascribed to the conditions, good communication, and clear boundaries appear to be protective factors. In addition, formal and informal networks and support in the community have been found to be associated with good developmental outcomes of chronically ill subjects.

Conflicting views about the effects of childhood and adolescence psychosocial problems on transition to adulthood and adult functioning have been presented. The problems may be transient, i. e. diminish or completely resolve as the individual grows older. However, the problems may also persist into adulthood and may even become more severe. Their severity may remain unchanged, but their social significance may develop new dimensions in adult life [24].

Only a few studies have been carried out on the long-term consequences of prolonged illness [7, 12, 18, 19, 21, 24]. Some of these studies have found no effect of adolescence chronic illness on young adult's psychological well-being [7, 12, 18], educational level or marital status [7, 12], while others have found a higher risk for problems in psychological well-being [19, 24], educational qualifications [24], and employment [12, 24]. In addition to male gender [7, 24], characteristics of the chronic conditions (a severe and visible physical illness, chronic illness associated with limitations in daily life) have been found to create higher risk for developmental problems [18, 19, 21].

The purpose of this study was to investigate whether adults with persistent chronic illness at ages 16, 22, and 32 years differ from their healthy peers in their life situation, psychosocial well-being, and health habits at age 32 years.

Methods

■ Subjects

The original study population included all ninth-grade secondary school pupils in the spring of 1983 in Tampere, an industrial and university city of 166,000 inhabitants, situated in southern Finland. The study was conducted in three phases. In the first phase, in 1983, 2194 pupils (96.7 %), with a mean age of 15.9 years (SD 0.3 years) completed questionnaires during school hours.

In the second phase, questionnaires were mailed to the same study cohort in the spring of 1989, when the subjects were about 22 years old. From the original study population, four had died, 18 could not be identified because of inappropriate completion or missing identification numbers, and the addresses of 33 could not be found (17 of whom were known to have moved abroad). Thus, the follow-up cohort included 2139 individuals (97 %), and the response rate was 77.4 % (N = 1656).

In the third phase, in 1999, postal questionnaires were sent to the same study population at the age of 32. The cohort included 1,609 persons (97 %), and the response rate was 78.4 % (n = 1262). From those who participated in the follow-up at age 22, one could not be identified because of inappropriate identification, and the addresses of 35 were not available.

Some additional information on reported chronic illness was included from earlier school surveys of the same children in 1981 and 1982.

The subjects were asked whether they had any of seven common chronic illnesses including asthma, allergic rhinitis, other allergies, allergic skin conditions, other skin conditions, migraine, or diabetes mellitus. Open-ended questions were used to collect information about other illnesses. The subjects were also asked whether the condition limited daily activities (yes/no). Among the 1262 participants in the third phase, 296 (24 %), reported a persistent long-term illness at the three phases of the study. Allergic conditions including asthma, allergic rhinitis, and other allergies were treated as allergic spectrum illness, and a subject was assigned to the persistent illness group if any of these conditions was present at the three phases of the study. Two groups of persistent chronic illness were constructed for comparison: 1) participants who reported as school children that they had a chronic illness limiting their daily life (n = 52); and 2) subjects with a persistent chronic illness without any limitations in daily activities (n = 244). The healthy control group consisted of 401 (32 %) subjects who had not reported any chronic illness at ages 16, 22, and 32 years. Those participants who had experienced resolution of their health problems or a new onset of illness between ages 16 and 32 years (n = 543, 43 %) were excluded from this analysis. Twenty-two cases with no information of the presence of chronic illness were also excluded from the analysis.

The group of participants with persistent chronic illness had the following conditions: allergy (n = 249; 84 %), non-allergic skin condition (n = 10), migraine (n = 29), diabetes mellitus (n = 5), and others (n = 9). Of the 296 participants with chronic illness, six had more than one illness.

Comparisons were made between those who participated in all three questionnaires and those who participated in the first survey but not in the follow-up (n = 932) in characteristics and answers at baseline. The results showed that boys dropped out more often than girls (62 % vs 38 %). Furthermore, pupils who dropped out from the follow-up had lower poor school performance than stable pupils (boys: mean 7.2, SD 0.9 vs. 7.5 SD 0.9; girls: mean 7.6 SD 0.9 vs 7.9 SD 0.9). No significant differences were found in chronic illnesses, parental SES, somatic complaints and health status among non-participants and participants. These analyses suggest that the dropout should not bias the results concerning long-term consequences of chronic illness.

Measures

The questionnaires comprised questions about health status, personal characteristics, health behaviours, fam-

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ily background, life situation, as well as social relationships and support.

The symptom checklist showing acceptable reliability (1, 22) had been used earlier in a nationwide Finnish study on juvenile health habits [27] and in an adult population study [4]. The following symptoms were included in the sum score of somatic complaints: abdominal pain, loss of appetite, headache, difficulty in falling asleep at night or wakefulness during the night, nausea or vomiting, dizziness, tremor of hands, diarrhoea or irregular bowel function, excessive perspiration without physical effort, heartburn or other stomach acid problems, breathlessness, and palpitations. The sum score was obtained by totalling the following ratings for each item: 0 = never, 1 = sometimes, 2 = quite often, 3 = often or continuously.

The self-esteem scale was a modified version of that developed for Finnish students [2, 14]. It consisted of seven self-assertions on a five-point scale showing internal reliability of 0.79 among females and 0.77 among males as measured by Cronbach's alfa coefficient in adolescents [3]. The students rated their general health status on a scale from 1 (very good) to 5 (very poor). The school pupils' self-reported average of grades in the school report was used as a measure of school performance (range 4–10). The General Health Questionnaire (GHQ–12) was used as a measure of psychological distress [11]. In addition, depression was measured using the short 13-item Beck Depression Inventory (S-BDI, 6). The Finnish version of the instrument, for use in epidemiologic surveys, also includes introductory questions and an additional positive choice of answer for each item, which do not affect the rating of depression [20]. Subjects with S-BDI scores of five or higher were classified as depressed [6].

The Alcohol Use Disorders Identification Test (AUDIT) was used as the screening instrument of alcohol use [5]. The measurement of social support was based on a modified version of Vaux and Harrison's Social Support Resources [34].

The classification of parental and current socioeconomic status was based on a standard classification of occupations [9, 10]. The measurement of parental socioeconomic status in childhood was based on the father's occupation, if available, or the mother's. If the occupation was unknown, the assignment of social class was based on the parent's education.

The research was approved by the Ethics Committees of Tampere University Hospital and National Public Health Institute of Finland.

Statistical analyses

Differences between the three groups (with limiting chronic illness, chronic illness without limitations,

healthy controls) in demographic characteristics and health status were analysed comparing proportions using the chi-square test and comparing the means using the one-way analysis of variance, including post hoc tests using Scheffé procedure.

Group differences in psychological well-being and health habits were analysed by logistic regression models for dichotomous outcomes using the logistic procedure to produce maximum likelihood estimates. The means were analysed using two-way analysis of variance (GLM Univariate), including post hoc tests using Scheffé procedure. The effect of gender and parental SES were statistically controlled in these analyses. The interactions of gender and parental SES with outcome measures were also analysed. Owing to the small number of adults with limiting chronic illness, gender-specific analyses were done on groups of adults with any chronic illness, including those with limiting and non-limiting chronic illness, and adults without chronic illness, controlling for parental SES.

Results

Demographic characteristics and health status

The group of adults with limiting chronic illness (LCI) and those with chronic illness without limitations in daily life (CI) included more females than males (LCI: females 69 % vs. males 31 %; CI: females 55 % vs. males 45 %). Gender distribution was equal in the group of healthy controls. No significant differences were found between the groups in parental socioeconomic status (Table 1).

Mean health status ratings and mean number of somatic complaints differed significantly among the three groups. Adults who had persistent chronic conditions which limited their daily life reported poorer health status and more somatic complaints than those with chronic conditions without any limitations and healthy subjects at the ages 16, 22 and 32. Furthermore, subjects with chronic conditions without limitations reported significantly poorer health status and more somatic complaints compared with healthy controls at the ages of 22 and 32 (Table 1).

Life situation

Adults with persistent chronic illness did not differ from healthy controls in current socioeconomic status, university education, and working status (working, unemployment). Adults with limiting chronic illness were less often married or cohabiting than those with chronic illness without limitations and healthy controls (LCI 65 %, CI 73 %, HC 78 %, p < 0.05). Adults with chronic illness

Table 1 Demographic characteristics and health status of subjects with and without limiting chronic illness and healthy controls

	Limiting chronic illness (LCC) (n = 52)	Chronic illness without limitations (CC) (n = 244)	Healthy controls (HC) (n = 401)
Gender %			
Females	69.2	55.3	49.6
Males	30.8	44.7	50.4[a]
Socioeconomic status %			
White-collar	67.3	53.9	53.6
Blue-collar	32.7	46.1	46.4
Health status, mean (SD)			
Age 16	2.2 (0.8)	1.8 (0.7)	1.7 (0.7)[b]
Age 22	2.2 (0.7)	1.8 (0.6)	1.6 (0.6)[c]
Age 32	2.2 (0.7)	1.9 (0.7)	1.8 (0.6)[d]
Somatic complaints, mean (SD)			
Age 16	5.3 (3.5)	3.9 (3.1)	3.5 (3.1)[e]
Age 22	6.0 (4.0)	4.6 (3.3)	3.5 (2.9)[f]
Age 32	6.4 (4.9)	5.5 (3.6)	4.5 (3.3)[g]

[a] $\chi^2 = 7.86$, df = 2, $p < 0.05$,
one-way ANOVA: [b] $F = 12.9$, $p < 0.001$; [c] $F = 20.0$, $p < 0.001$; [d] $F = 13.6$, $p < 0.001$;
[e] $F = 8.1$, $p < 0.001$; [f] $F = 18.8$, $p < 0.001$; [g] $F = 10.8$, $p < 0.001$

had children almost as often as those without chronic illness (Table 2).

Psychosocial well-being

At the age of 32 years, adults with limiting chronic illness showed higher depressive symptom scores, higher prevalence of depression, and lower self-esteem than healthy subjects or those with chronic illness without limitations. There was a trend that males with any chronic illness also reported more psychological dis-

tress than healthy males (mean 1.9, SD 2.5 vs. mean 1.4, SD 2.5; $p = 0.06$, Table 3).

The overall and gender-specific analyses showed no significant differences between those with chronic illness and those without chronic illness in family relations, numbers of confidants, size of social networks, perceived available social support and feelings of loneliness.

Health habits

No statistical differences appeared in mean alcohol consumption scores between those with persistent chronic illness and those without chronic illness (LCI: mean 6.5, SD 5.6, CI: mean 5.8, SD 4.8, HC: mean 6.0, SD 5.1). In overall analyses, the proportion of daily smokers showed no difference between adults with chronic illness and those without chronic illness (LCI: 14 %, CI: 23 %, HC: 19 %). Gender-specific analyses showed that reported daily smoking was significantly more common among healthy males than among those with any chronic illness (26 % vs. 18 %, $p < 0.05$). Among females, daily smoking was more common among those with chronic illness (24 % vs. 11 %, $p < 0.05$).

The proportions of daily smokers were further analysed at ages 16 and 22. At age 16, no significant gender differences were found in the proportion of daily smokers between those with any chronic illness and those without chronic illness (females with AI 16 % vs. HC females 14 %; males with AI 15 % vs. HC males 21 %). When the subjects were 22 years old, the findings were in agreement with results obtained at age 32 years. Among females, females with chronic illness reported daily smoking more often than healthy controls (AI: 30 % vs. HC: 19 %, $p < 0.05$). Among males, healthy sub-

Table 2 Life situation of adults with limiting chronic illness (LCI), with chronic illness without limitations (CI), with any chronic illness (AI) and healthy controls (HC) at age 32 years

	LCI[a] (n = 52)	CI[a] (n = 244)	HC[a] (n = 401)	Males AI[b] (n = 125)	Males HC[b] (n = 202)	Females AI[b] (n = 171)	Females HC[b] (n = 199)
Current socioeconomic status %							
White collar	78.8	75.3	72.2	69.2	60.0	80.9	85.2
Blue collar	22.0	24.7	23.3	30.8	40.0	19.1	14.8
University education %	21.2	26.7	24.8	25.8	24.8	25.6	24.7
Working status %							
Working	71.2	73.3	75.6	85.6	87.1	63.5	63.8
Unemployed	3.8	7.0	6.2	5.0	4.0	7.5	8.2
Unemployed during last 10 years	58.8	53.3	50.8	47.5	43.5	59.2	58.1
Marital status %							
Married or cohabiting	65.4	73.1	78.3*	67.7	76.7	74.7	79.8
Having children	55.8	59.9	59.6	55.6	56.6	61.8	62.8

[a] Analyses were controlled for gender and parental SES using logistic regression models
[b] Analyses were controlled for parental SES using logistic regression models
* $p < 0.05$

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Table 3 Psychological well-being of adults with limiting chronic illness (LCI), with chronic illness without limitations (CI), with any chronic illness (AI) and healthy controls (HC) at age 32 years

	LCI[a] (n = 52)	CI[a] (n = 244)	HC[a] (n = 401)	Males AI[b] (n = 125)	Males HC[b] (n = 202)	Females AI[b] (n = 171)	Females HC[b] (n = 199)
Self-esteem[c]							
Mean (SD)	15.4 (5.67)	13.7 (4.54)	13.7 (4.87)[d]	13.6 (4.6)	12.7 (4.6)	14.4 (5.0)	14.6 (5.0)
Psychological distress[c]							
Mean (SD)	2.4 (2.84)	2.0 (2.62)	1.7 (2.70)	1.9 (2.5)	1.4 (2.5)[e]	2.1 (2.8)	2.0 (2.9)
Depressive symptoms[c]							
Mean (SD)	3.0 (3.22)	1.7 (2.58)	1.7 (2.68)[f]	1.6 (2.4)	1.4 (2.6)	2.2 (3.2)	2.0 (2.8)
Depression %							
Depressed	28.8	12.3	12.5[g]	12.8	10.4	17.0	14.6
Non-depressed	71.2	87.7	87.5	87.2	89.6	83.0	85.4

[a] Analyses were controlled for gender and parental SES using logistic regression models for dichotomous and two-way analysis of variance for continuous outcome variables

[b] Analyses were controlled for parental SES using logistic regression models for dichotomous and two-way analysis of variance for continuous outcome variables

[c] Higher score = poorer self-esteem, more psychological distress and depressive symptoms

[d] Differences between LCI and CI, p = 0.07; LCI and HC, p < 0.05

[e] Differences between males with AI and males HC, p = 0.06

[f] Differences between LCI and CI, p < 0.05; LCI and HC, p < 0.01; g differences between LCI, CI and HC, p < 0.05

jects tended to report daily smoking more often than males with chronic illness (36 % vs 27 %, p = 0.12).

The results showed no interaction effects between gender and parental SES for any outcome measures (life situation, psychosocial well-being and health habits).

Discussion

This follow-up study was planned to assess the effect of persistent chronic illness experienced in adolescence on the adult life situation, psychosocial well-being, and health habits. Only a few studies have attempted to investigate the long-term consequences of chronic illness [7, 12, 18, 19, 21, 24].

Our results show that when the chronic illness was associated with perceived limitations in daily life, problems arose in psychological well-being. This result is similar to that of Orr et al. [21], who studied non-fatal physical illness lasting longer than three months (such as asthma, hay fever, orthopaedic disorders, and diabetes mellitus) and found more psychosocial problems among those with persisting medical problems associated with at least some impairment in daily living. The finding is also in agreement with the cross-sectional studies of Cadman et al. [8] and a previous study of ours [15]. Cadman et al. [8] found, in their representative sample of children and adolescents with a variety of chronic conditions in Canada, the highest risk for psychiatric disorders and social adjustment problems among those children and adolescents with both chronic illness and associated disability. In our previous study, the highest scores of depressive and distress symptoms were also found among adolescents with lim-

iting chronic illness, compared to healthy controls and those with visual impairment [15].

Our results showed no significant differences between adults with any persistent chronic illness (mainly non-severe allergic conditions) and healthy controls in psychosocial well-being. The finding of a good social adaptation (educational, employment, social class, psychical exercise) agrees with previous follow-up studies of asthma and respiratory diseases [16, 29].

Pless et al. [24] found marked gender differences in the psychosocial characteristics of young adults with chronic illness, showing more psychosocial problems among males with chronic physical disorders compared with healthy males. We also found that males with chronic illness had higher psychological distress scores than healthy males, though the differences were not marked and not found in other areas of psychological well-being. However, this raises the question whether a physical illness is a greater source of stress for men.

The results of this study, in agreement with those of Kokkonen [17], indicate that the presence of chronic illness does not deter adults from potentially harmful health habits, even though the group with chronic illness, which mainly consisted of subjects with allergic conditions, could be expected to have been exposed to more health education by care providers than their peers without chronic illness. Females with chronic illness reported daily smoking even more often than females without chronic illness.

This study has several strengths and limitations. The strengths of the study include a non-selective representative sample of subjects, a good response rate to the questionnaires, and a longitudinal design. The majority of subjects with persistent chronic conditions suffered

from allergic conditions, which are the most common chronic illnesses in children in Finland [32], but may not necessarily place major demands on a young person transitioning to adulthood. In order to study more severe conditions we also analysed the group of subjects with limiting chronic conditions. Unfortunately, we had no detailed information about the ways in which chronic illness was limiting daily life. The members in the limiting illness group also remained small for detailed analyses. The limiting chronic illness group included more females than males which is in line with earlier studies which have also found that females experience or report chronic illness more often as limiting than males do [25, 26]. Furthermore, all data were based on self-report; the chronic illness diagnosis could not be verified independently. Our prevalences were, however, similar to previous prevalence studies of allergic diseases in Finland [28, 33].

In conclusion, this study showed no differences between adults with any persistent chronic illness (mainly non-severe allergic conditions) and healthy controls in psychosocial well-being. However, more attention in health care should be paid to psychological well-being among those with a long-term illness limiting their daily life. It is also important to improve health habit counselling for females with chronic illness within health care.

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