


# Disease control and psychiatric comorbidity among adolescents with chronic medical conditions: a single-centre retrospective study

Mira Kallio <sup>1,2</sup>, Anna Tornivuori,<sup>1,3</sup> Päivi Miettinen,<sup>1,2</sup> Kaija-Leena Kolho,<sup>1,2,4</sup> Evelyn Culnane,<sup>5</sup> Susan Sawyer,<sup>6,7,8,9</sup> Silja Kosola<sup>1</sup>

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## ABSTRACT

**Background** To investigate disease control, psychiatric comorbidity, substance use and their possible associations in adolescents with chronic medical conditions before transfer to adult healthcare.

**Methods** We collected clinical data from the year preceding transfer of care and psychiatric data from the records of the paediatric hospital in Helsinki, Finland (population base 1.7 million). Participants were grouped into three disease and/or adherence control categories (good, some evidence of concern, poor) based on clinical data from the medical records of the year preceding the transfer of care. Participants completed the Adolescent's Substance Use Measurement Questionnaire before transfer of care and were divided into four risk subgroups accordingly.

**Results** In total, 253 adolescents (mean age 17.3 years, SD 1.2) from six paediatric subspecialties participated in this study. Disease control and/or adherence were rated as good in 28% (n=70), moderate in 42% (n=105) and poor in 30% (n=76) in the year before participants transferred to adult health services. A quarter of participants had at least one psychiatric diagnosis during adolescence. Adolescents with concomitant psychiatric diagnoses more often had poor disease control of their chronic medical condition than adolescents with only a medical condition (44% vs 26%; n=25 of 59 vs 51 of 194, respectively). More than half of adolescents (56%) were abstinent or used substances infrequently; 10% (n=26) reported hazardous substance use.

**Conclusions** Psychiatric comorbidity in adolescents with chronic medical conditions is common. Its negative association with disease control and possible substance use should be considered in the transition process to adult health services.

## INTRODUCTION

The landscape of chronic illness in children and adolescents with chronic medical conditions has changed. Over the past few decades, treatment success has resulted in improved survival of many of these young people, which together with an increased incidence of particular chronic medical disorders in childhood,<sup>1-3</sup> results in increasing numbers

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Adolescents with chronic medical disorders have a higher prevalence of mental health disorders than their peers, but the impact of mental health disorders on disease control prior to transfer to adult healthcare is poorly understood.

## WHAT THIS STUDY ADDS

⇒ Adolescents with chronic medical disorders and comorbid psychiatric diagnoses more frequently have poor control of their medical condition than those without psychiatric comorbidities, which highlights the necessity of a holistic approach to care.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Ensuring that mental health disorders are identified and treated is an important aspect of caring for adolescents and young adults with chronic medical conditions, including at the time they transfer to adult services. Future research to measure the potential impact of adolescent mental health disorders on transfer to adult health service is indicated.

of adolescents requiring regular follow-up in adult health services. Living with a chronic medical condition can pose many challenges during adolescence, not least due to the requirement for regular medication and other treatments, frequent medical appointments and the uncertainty of future treatment such as surgical procedures. These demands for health management and monitoring, together with the impact of the medical condition itself, such as pain and fatigue,<sup>4</sup> can reduce participation in normative activities with effects on peer relationships, extracurricular participation and school attendance.<sup>5</sup>

Chronic medical conditions are associated with increased rates of mental health problems.<sup>6 7</sup> In the USA, 25% of children with epilepsy have anxiety and/or depression compared with the general population aged



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For numbered affiliations see end of article.

## Correspondence to

Dr Mira Kallio; [mira.kallio@hus.fi](mailto:mira.kallio@hus.fi)

12–17 years old, of whom 6% have a current diagnosis of depression and 11% anxiety.<sup>8 9</sup> During a decade of follow-up, 17% of Swedish children with inflammatory bowel disease (IBD) received a diagnosis of any psychiatric disorder compared with 12% of the general population.<sup>10</sup> Population surveys that assess self-reported symptoms of depression or anxiety yield even higher proportions of affected young people.<sup>11</sup> So the proportion of adolescents with chronic medical conditions who struggle with symptoms of mental health disorders is expected to be even higher.

Mental health problems, together with pain and fatigue,<sup>4</sup> can affect disease control, adherence behaviours, and health-related quality of life in children and adolescents with chronic medical conditions.<sup>12 13</sup> For example, depression is associated with higher healthcare costs and emergency department visits in children and adolescents with IBD,<sup>14</sup> but which young people are most at risk is still incompletely understood.

Adolescents living with chronic medical conditions often engage in risk behaviours, such as substance use.<sup>15</sup> Substance use in adolescence is frequently associated with other mental health disorders, and the incidence of both substance use and mental health disorders increases across adolescence and into adulthood.<sup>16–18</sup> This accumulation of risk behaviours and mental health disorders among adolescents and young adults suggests it is important to identify which adolescents with chronic medical disorders are at greatest risk so that they can be appropriately managed, including at the time they transfer to adult health services.

In this study of adolescents with different chronic medical conditions, we aimed to investigate disease control, rates of psychiatric comorbidity and risky substance use and their associations before adolescent care is transferred to adult health services. Our hypothesis was that psychiatric comorbidity is common and associated with poorer disease control and higher rates of substance use.

## METHODS

### Study design

This study is part of an international prospective cohort study named the Bridge, for which the study protocol is available online.<sup>19</sup> In this cross-sectional analysis, we combined retrospective data with questionnaire responses from one study site. The Bridge trial has been registered with ClinicalTrials.gov (ID number NCT04631965).

### Patient and public involvement

Fifteen adolescents with chronic conditions participated in the design of the study questionnaires.

### Participants

Participants were recruited from the New Children's Hospital, Helsinki, Finland (hospital catchment area 1.7 million inhabitants) between September 2017 and

August 2019. In Finland, practically all adolescents with chronic medical conditions are managed by public health services, with few cared for by private doctors. Clinicians from six different paediatric subspecialty clinics (endocrinology, gastroenterology, rheumatology, nephrology and organ transplants, neurology and cardiology) identified adolescents who were expected to transfer to adult clinics within the coming 6–12 months. Inclusion criteria were that participants were aged 15–24 years and had a chronic medical condition that had been diagnosed at least 6 months earlier and was expected to require regular follow-up in adult health services. Eligible participants also needed to have sufficient cognitive and linguistic ability to communicate in Finnish, English or Swedish. Adolescents received a movie ticket (value €10) after completing the survey in acknowledgement of their time.

A research nurse, uninvolved in patient care, personally met 306 consecutive adolescents during their routine hospital visits and provided oral and written information about the Bridge Study.

### Demographics

Background information was obtained from the baseline survey, including gender, residential area, home language and family composition (living with two parents or any other family type).

### Disease control

To determine disease control, we gathered data and laboratory test results from the electronic medical records for the year preceding the final visit at the New Children's Hospital. The final visit was specified as the outpatient appointment where the clinician made a formal referral to the respective adult health service. We divided participants into one of three categories according to the condition for which they were recruited: (1) good disease control and/or adherence; (2) some evidence of concern; and (3) poor disease control and/or adherence or more severe condition (see study protocol for further details).<sup>19</sup> Where appropriate, we used published cut-offs for disease control. For adolescents with diabetes, a mean glycosylated haemoglobin (the mean of all measurements across the year preceding transfer of care)  $\leq 53$  mmol/mol was categorised as good control/adherence, 54–69 mmol/mol was considered evidence of some concern, while  $\geq 70$  mmol/mol was classified as having poor control/adherence. For adolescents with rheumatic disease, the 10-joint Juvenile Arthritis Disease Activity Score was completed. For those with oligoarthritis, cut-off points of  $\leq 0.5$  (good), 0.6–2.8 (some concern) and  $> 2.8$  (poor) were used, while for those with polyarthritis, the cut-off points were  $\leq 0.7$ , 0.8–4 and  $> 4$ , as previously applied.<sup>19–21</sup> For adolescents with IBD, good control/adherence required minimal pain (Visual Analogue Scale, VAS 1–2), at least 80% of faecal calprotectin results  $< 100$   $\mu\text{g/g}$  and always  $< 300$   $\mu\text{g/g}$ , medication unchanged or reduced, and no inpatient care; indicators of some evidence of concern were VAS 3–5,  $< 80\%$  of faecal

calprotectin results within target range or exceeded 300 µg/g even once, but no significant medication changes nor inpatient care; and for poor control/adherence any of the following: VAS ≥6, significant changes in medication, need for corticosteroids and/or commencement of biological medication or an episode of inpatient care. For rare conditions without standard criteria of disease control and/or adherence, experienced clinicians subjectively categorised participants according to their symptoms, clinical and laboratory findings, need for inpatient care and changes in medication. MK first reviewed medical records of every participant, of whom 28 (11%) were difficult to categorise. For these 28 adolescents, SK made an independent assessment of disease control. Six adolescents were categorised differently, and the final grading was based on a consensus between the two reviewers. For some analyses, we combined the three smallest subspecialties (neurology, cardiology and nephrology/organ transplant) into 'others'.

### Psychiatric diagnosis and treatment

Psychiatric diagnoses and treatment details were collected from the electronic medical records of the Helsinki University Hospital, which is the only public provider of adolescent psychiatric care in the study catchment area. Data were collected from ages 13 to 18 years, the age range of adolescent psychiatry in the study area. These data were collected separately from the disease control data, and in a different order of patients. Psychiatric diagnoses were divided into four categories: (1) mood disorders; (2) anxiety disorders; (3) others and (4) multiple diagnoses (ie, diagnosis from at least two different diagnostic categories). The New Children's Hospital has no general guideline regarding psychiatric assessment, and adolescents may have received referrals to adolescent psychiatry from community healthcare centres and student health services. Outpatient appointments with mental health professionals over these 6 years were divided into three categories: (1) no appointments; (2) one to three appointments and (3) more than three appointments. We also recorded the age at first psychiatric diagnosis, any admissions for psychiatric inpatient care and, if so, the number of days spent in psychiatric inpatient care.

### Substance use

Participants completed the Adolescent Substance Use Measurement (ADSUME), a brief measure that was developed and validated in Finland to evaluate adolescent substance use and its possible consequences during the previous year. ADSUME is reliable when compared with validated adult questionnaire The Alcohol Use Disorders Identification Test (AUDIT) and may even be superior in detecting hazardous substance use among adolescents.<sup>22</sup> We calculated a total score (0–31 points) of the first nine questions (online supplemental appendix 1) to yield a numerical score, which we used in analyses. We also divided participants into subgroups according

to guidelines from the Finnish Institute for Health and Welfare: (1) abstinence or experimental use, 0–3 points; (2) recurring use, 4–6 points; (3) risky use, 7–9 points; and (4) hazardous use, 10 points or more.<sup>23</sup>

### Data analysis

Categorical data are presented as frequencies (with percentages). For continuous variables, means and SDs or medians (with IQR) are used. Associations between disease control, psychiatric diagnoses and family composition were compared using Fisher's exact test (two-sided). To evaluate the associations between categorical data and continuous variables, we used non-parametric tests (Mann-Whitney U and Kruskal-Wallis). Finally, ordinal logistic regression with disease control as the dependent variable was conducted. Data analyses were performed using IBM SPSS Statistics V.25 and a p value of <0.05 was considered significant.

### RESULTS

In total, 279 (91.2%) adolescents consented to participate, and 253 (82.7%) adolescents completed the baseline survey after a maximum of two reminders. Demographic and clinical data of the 253 study participants are summarised in tables 1 and 2. The mean age at diagnosis of the medical condition was 9.0 years (SD 5.3) and the mean age at first psychiatric diagnosis was 13.7 years (SD 2.7). Age at transfer differed greatly between subspecialties: rheumatology patients were the youngest to transfer (mean age 16.2 years) and gastroenterology were the oldest (mean age 19.0 years;  $p < 0.001$  for difference between groups).

Among all study participants, 27.7% ( $n=70$ ) were categorised as having good disease control and/or adherence, 41.5% ( $n=105$ ) were rated as having some evidence of concern, and 30.0% ( $n=76$ ) were classified as having poor disease control and/or adherence (or more severe condition) during the year preceding the transfer of care. Only 16% of adolescents with gastroenterological diseases and 14% of adolescents with diabetes had good disease control (mean of 4.6 measurements). Among adolescents with rheumatological disease, 39% had good disease control, while it was 48% in the group of 'others'. Gender and age at diagnosis showed no association with different disease control groups. Older age at transfer of care was associated with poorer disease control ( $p=0.045$ ).

In this cohort, 23.3% of adolescents ( $n=59$ ) had a psychiatric diagnosis, of whom 37.2% ( $n=22$ ) had at least two different diagnoses. Anxiety disorders were most common ( $n=38$ ), comprising 15.0% of all participants and 64.4% of adolescents with a psychiatric diagnosis. Females were over-represented in anxiety disorders and males in the 'other psychiatric diagnosis' group. Nine adolescents (3.6%) received inpatient psychiatric care, with a median of 22 days (range 9–956 days) per person. Age at medical diagnosis and age at psychiatric diagnosis showed no association ( $p=0.32$ ).

**Table 1** Demographic and clinical data of 253 adolescents

	N	%
Gender		
Male	118	46.6
Female	132	52.2
Other	3	1.2
Paediatric subspecialty		
Diabetes	92	36.4
Rheumatology	66	26.1
Gastroenterology	45	17.8
Cardiology	19	7.5
Neurology	18	7.1
Kidney or liver disease with/without transplant	13	5.1
Lives with		
Mother and father	158	62.5
Other than with two parents	95	37.5
Disease control*		
Good control and/or adherence	70	27.7
Some evidence of concern	105	41.5
Poor control and/or adherence or more severe condition	76	30.0
Psychiatric diagnoses	<b>59</b>	<b>23.3</b>
Anxiety disorders	38	15.0
Mood disorders	18	7.1
Others†	26	10.3
Many diagnoses	22	8.7
Outpatient visits in adolescent psychiatry		
None	159	62.8
1–3	36	14.2
More than 3	58	22.9
Median ADSUME total scores (IQR)‡	<b>3</b>	<b>(0–6)</b>
Females	2	(0–6)
Males	3	(0–6)
ADSUME risk category‡	<b>N</b>	<b>%</b>
Abstinence or experimental use (0–3 points)	142	56.1
Recurring use (4–6 points)	57	22.5
Risky use (7–9 points)	27	10.7
Hazardous use (10 points or more)	26	10.3

\*Data available for 251 adolescents as transfer of two adolescents was delayed.

†Others: for example, conduct disorder, attention deficit-hyperactivity disorder, psychotic disorder, eating disorders, developmental disorders.

‡One response missing.

ADSUME, Adolescent Substance Use Measurement.

More than half of participants (n=142, 56.1%) were abstinent or reported only experimental substance use (table 1). Approximately half of the adolescents reported using alcohol in the last year. The median ADSUME total score was 3.0 and the maximum score was 27 points.

**Table 2** Demographic and clinical data (n=253)

	Mean, years (median)	SD
Age at first medical diagnosis	9.0 (10.1)	5.3
Age at first psychiatric diagnosis	13.7 (14.3)	2.7
Age when completing the ADSUME	17.2 (16.8)	1.2
Age at transfer of care	17.3 (17.1)	1.2
Diabetes	17.2	0.7
Rheumatology	16.2	0.5
Gastroenterology	19.0	0.9
Others	17.8	1.2
Time between ADSUME and transfer of care	0.2 (0.0)	0.4
Time between medical diagnosis and transfer of care	8.3 (7.4)	8.3
Time between psychiatric diagnosis and transfer of care	4.0 (3.2)	4.0

ADSUME, Adolescent Substance Use Measurement.

Table 3 and figure 1 summarise the associations between disease control, psychiatric diagnoses, substance use and family composition. Adolescents with psychiatric diagnoses more often had poor disease control and/or adherence or more severe disease/condition

**Table 3** Family composition, disease control and substance use, by psychiatric diagnosis (n=253). P < 0.05 is considered as significant.

	No psychiatric diagnosis (n=194) N (%)	Psychiatric diagnosis (n=59) N (%)	P value
Living with two parents	128 (66)	30 (51)	<b>0.05</b>
Disease control*			
Good control and/or adherence	59 (30)	11 (19)	0.13
Some evidence of concern	84 (43)	21 (37)	0.45
Poor control and/or adherence or more severe condition	51 (26)	25 (44)	<b>0.01</b>
ADSUME score, median (IQR)†	3 (0–6)	0 (0–6)	0.56

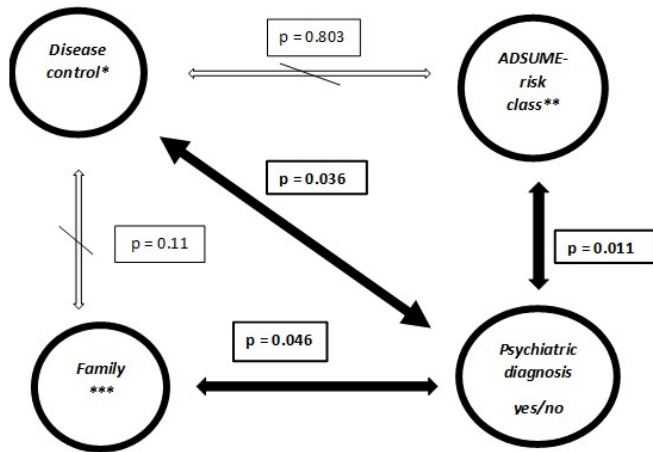
Other factors compared using Fisher's exact test; ADSUME median scores compared using the Mann-Whitney U test. Bold values signifies P < 0.05.

\*Transfer of two adolescents has been delayed.

†One response missing.

ADSUME, Adolescent Substance Use Measurement.





**Figure 1** Associations between disease control, psychiatric diagnoses, substance use (ADSUME) and family composition.  $P < 0.05$  is considered significant. \*Good control and/or adherence, some evidence of concern or poor control and/or adherence or more severe condition. \*\*Abstinence or experimental use, repetitive use, risky use or hazardous use. \*\*\*Living with mother and father or with someone else (for example, with only one parent, mixed family or any other third party). ADSUME, Adolescent Substance Use Measurement.

than adolescents without psychiatric diagnoses ( $p=0.01$ ). Hazardous substance use was more frequent among adolescents with psychiatric diagnoses (8% vs 19%), but total ADSUME points showed no direct association with psychiatric diagnoses nor disease control. Adolescents who lived with two parents ( $n=158$ , 62.5%) had fewer psychiatric diagnoses than adolescents living in other kinds of families ( $p=0.05$ ). In ordinal regression, only psychiatric diagnoses were significant for disease control (table 4).

## DISCUSSION

In this cross-sectional study of adolescents with chronic medical conditions, nearly one-third were assessed to have poor disease control in the year preceding transfer

to adult health services and almost a quarter had received a psychiatric diagnosis during adolescence. Adolescents with a comorbid psychiatric diagnosis more frequently had poor control of their medical condition than those without a psychiatric diagnosis.

In our study, 23% of the adolescents received a mental health diagnosis between the ages of 13 and 18 years. Adolescents living with two parents had fewer psychiatric diagnoses than their peers living in other kinds of families. The protective effect of living in a nuclear family when considering psychiatric morbidity has also been reported among the general population of children and adolescents.<sup>24 25</sup> Overall, the prevalence of psychiatric diagnoses was higher in our study than in other diagnostic studies.<sup>8 10</sup> Regular assessment by medical professionals might have contributed to unnecessary referrals aided by the relative ease of referral to public mental health professionals. However, as the portion of adolescents with three or more outpatient visits in the department of adolescent psychiatry is comparable with the proportion of adolescents with a psychiatric diagnosis, overdiagnosis seems unlikely.

In this study, 22.5% of adolescents reported using substances regularly, while a further 21.0% were categorised as risky or hazardous users. This is consistent with national Finnish data that found 15%–24% of students aged 17–18 years old reported monthly binge drinking.<sup>26</sup> Conversely, only 1% of adolescents in our cohort had used cannabis during the past year, in comparison with 8%–12% of students aged 17–18 years old in Finland.<sup>26</sup> Although alcohol consumption has decreased among adolescents in many developed countries, adolescent binge drinking and the accompanying risky behaviour remain significant public health problems.<sup>27</sup>

The association between poor disease control and psychiatric comorbidity found in our study may be bidirectional: mental health problems may affect self-management resources and thus worsen disease control, while living with a severe disease may increase the emotional burden experienced. The burden of a

**Table 4** Results of ordinal regression with disease control (good, moderate or poor) as the dependent variable.  $P < 0.05$  is considered as significant.

	Estimate	SE	Wald	df	P value	95% CI	
						Lower	Upper
Threshold: poor to moderate dc	-2.963	1.718	2.975	1	0.085	-6.330	0.404
Threshold: moderate to good dc	-1.111	1.708	0.423	1	0.516	-4.459	2.237
Male vs female	-0.147	0.240	0.377	1	0.539	-0.617	0.323
Two parents vs other family	0.359	0.246	2.116	1	0.146	-0.125	0.842
Psychiatric dg vs no dg	0.636	0.291	4.794	1	<b>0.029</b>	0.067	1.206
Age (continuous)	-0.158	0.096	2.675	1	0.102	-0.347	0.031

Pseudo- $r^2$ : Cox and Snell 0.046, Nagelkerke 0.052.

Bold values signifies  $P < 0.05$ .

dc, disease control; dg, diagnosis.

chronic condition also includes a sense of interrupted social maturation for which substance use can sometimes present as a means of catching up although adolescents are aware of the harmful effects of substance use.<sup>28</sup>

Considering the modest proportion of adolescents with good disease control before transfer of care, additional strategies may be required to optimise health outcomes in adolescents whose disease is challenging to treat, who lack motivation or skills for self-management, or have mental health or substance use problems.<sup>29 30</sup> The treatment of anxiety and depression in adolescents is expected to improve symptoms and positively influence disease control and healthcare utilisation,<sup>31–33</sup> while some adolescents will need concurrent transition of psychiatric and medical care. A child's illness is a significant stressor for parents,<sup>34</sup> and family psychosocial support and interventions to minimise financial hardship also warrant consideration. Our data affirm the importance of regularly discussing substance use and its effects with adolescents with chronic medical conditions especially given its potential effect on specific medical conditions, such as a reduced seizure threshold in adolescents with epilepsy or hypoglycaemia in adolescents with diabetes.<sup>35 36</sup>

A strength of this study is the high response rate of adolescents recruited from six different hospital departments to intentionally span a range of conditions, increasing the generalisability of our results. However, this also provided some challenges, especially regarding how disease control was defined as by definition, this differs by medical condition. Although the same researcher collected data on disease control and psychiatric diagnoses, we attempted to reduce bias by collecting these data on separate occasions, using separate files, and in different patient order. While we needed to categorise disease control subjectively in adolescents with rare diseases, the likelihood of misclassification was reduced by having two independent reviewers. As we had access to all electronic medical records in the study catchment area, including psychiatry, we were able to use specific psychiatric diagnoses and estimate disease control of medical conditions based on clinical and laboratory findings. While psychiatric diagnoses were made by the psychiatry department, standardised assessments were not routinely used. Further, some psychiatric diagnoses may have been missed if the adolescent had moved to or from another hospital district. The public health system in Finland results in adolescents receiving the same treatment regardless of socioeconomic status, with provision of psychiatric care in the private sector uncommon. In countries without public healthcare, associations between mental health problems and poor disease control may be even more significant than in our study.

## CONCLUSIONS

In conclusion, psychiatric morbidity and poor disease control of chronic medical conditions are prevalent and closely intertwined among adolescents, reinforcing the

importance of collaboration between medical and psychiatric care.<sup>37</sup> Maximising mental health before adolescents transfer to adult health services appears especially important given the associations of both poor mental health and the transfer of care itself with unsatisfactory adherence to treatment and increased rates of emergency visits and hospitalisation.<sup>12 38 39</sup>

## Author affiliations

<sup>1</sup>Pediatric Research Center, New Children's Hospital, Helsinki, Finland

<sup>2</sup>Department of Pediatrics, Helsinki University Hospital and University of Helsinki, Helsinki, Finland

<sup>3</sup>Nursing Science, University of Turku, Turku, Finland

<sup>4</sup>Faculty of Medicine and Health Technology, Tampere University, Tampere, Finland

<sup>5</sup>Transition Support Service, Royal Children's Hospital, Parkville, Victoria, Australia

<sup>6</sup>Department of Adolescent Medicine, Royal Children's Hospital, Parkville, Victoria, Australia

<sup>7</sup>Department of Paediatrics, The University of Melbourne, Parkville, Victoria, Australia

<sup>8</sup>Centre for Adolescent Health, Murdoch Children's Research Institute and the Royal Children's Hospital, Parkville, Victoria, Australia

<sup>9</sup>Health Services, Murdoch Children's Research Institute, Melbourne, Victoria, Australia

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#### ORCID iD

Mira Kallio <http://orcid.org/0000-0003-0188-5341>

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