



# Health-related quality of life and psychological wellbeing are poor in children with bronchiectasis and their parents

To the Editor:

Bronchiectasis is characterised by chronic wet cough, a cycle of inflammation, impaired mucociliary clearance, bacterial colonisation and infection [1]. People with bronchiectasis experience substantial disease burden, including recurrent hospitalisations and impaired quality of life (QoL) [2]. The prevalence and burden of bronchiectasis is increasingly appreciated worldwide [3].

Families with children who have chronic illnesses have a greater likelihood of experiencing poor psychological health [2, 4]. Examining the impact of a childhood illness on the psychological well-being of family members, particularly the primary caregiver, is important as maternal depression may influence nonadherence to therapy and overall morbidity [5, 6]. Among children with bronchiectasis, health-related QoL (HRQoL), parental stress and coping are negatively affected during respiratory exacerbations [2]. However, there is little data on child and parent perception of HRQoL or the psychological wellbeing of parents of children with stable-state bronchiectasis compared with healthy children. A previous report found no difference in anxiety or depression scores but reported poorer physical health QoL in children with bronchiectasis compared with controls [7]. However, this assessment was not undertaken in conjunction with parental reports of psychological health. In this study we sought to determine: 1) self-reported and parent-proxy HRQoL in children with clinically stable bronchiectasis, compared with age-matched peers; and 2) parent or caregivers' psychological well-being.

Children (aged 5–18 years) with clinically stable bronchiectasis were recruited from outpatient clinics at two Australian tertiary hospitals. All parent participants provided written, informed consent, and assent (in children >12 years of age) was also obtained. Children and their parents completed an age-appropriate version of the Pediatric Quality of Life Inventory (PedsQL), a generic HRQoL scale [8]. Items on the PedsQL generate a total score and two summary scores: physical health (physical health subscore) and psychosocial health (emotional, social and school functioning subscores), with higher scores representing better HRQoL. Parents also completed: the Hospital Anxiety and Depression Scale (HADS) and the Center for Epidemiologic Studies Depression Scale (CES-D) [9, 10], with higher scores representing greater depression and anxiety; and the parent-proxy QoL questionnaire of paediatric chronic cough (PC-QoL), with lower scores reflecting greater cough frequency, concerns or worries [11].

Age-matched control children (with no diagnosis of a respiratory condition) were recruited from amongst the children and contacts of staff within the recruiting hospitals, as well as the community. They and their parents completed the same questionnaires (with the exception of the PC-QoL).

The study was approved by the relevant human research ethics committees (HREC/15/QRCH/69 and HREC/15/WCHN/125).



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**Children with bronchiectasis in a stable state have poor HRQoL and their parents report higher levels of anxiety and depression. Parental perception of HRQoL is associated with poorer parental psychological wellbeing.** <http://bit.ly/2lcf3uB>

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Statistical analyses were undertaken using SPSS software (v25.0; IBM Corp., Armonk, NY, USA). Descriptive statistics are presented as mean±SD or median (interquartile range). Categorical variables are reported descriptively using frequency (n) and proportion (%). Differences between groups for continuous data were analysed using the Mann–Whitney U test and the Chi-squared test for categorical data. Relationships between HRQoL and psychological well-being variables were explored using correlation coefficients (Pearson or Spearman’s rank depending on normality distribution), with correlations interpreted as excellent (>0.75), moderate (0.5–0.75), fair (0.25–0.50) and no relationship (0.00–0.25) [12].

41 children with bronchiectasis (mean±SD age 10±4 years, body mass index (BMI) z-score 0.62±1.02) and their 41 parents, and 41 control children and their 41 parents were included in this study. Control children were age-matched, with similar BMI z-scores (0.62±1.01). Most children with bronchiectasis undertook airway clearance therapy daily (73%) and engaged in daily exercise (67%). Mean forced expiratory volume in 1 s (FEV<sub>1</sub>) was 91±16% predicted (range 51–117%).

Children with bronchiectasis had significantly worse self-reported and parent-perceived HRQoL compared with their healthy peers (table 1). In the bronchiectasis group, fair-to-moderate correlations between parent-proxy and child PedsQL physical, psychosocial and total scores were seen ( $r_s$  range 0.36–0.66; all  $p<0.01$ ). There was a fair correlation between disease severity (FEV<sub>1</sub> % pred) and Parent PedsQL physical score ( $r_s=0.482$ ). In the control group, the only statistically significant association was between the parent and child’s PedsQL psychosocial summary score ( $r_s=0.41$ ,  $p=0.009$ ). All others ranged  $r_s=-0.036-0.005$ .

Nearly three times as many parents of children with bronchiectasis reported symptoms of anxiety (49%) compared with parents of healthy controls (17%) ( $p=0.009$ ). In parents of children with bronchiectasis, worse HRQoL (PedsQL total score) was associated with poorer parental psychological health (HADS depression and CES-D, both  $r_s>-0.45$ ,  $p<0.01$ ). Similarly, poorer PC-QoL was significantly associated with anxiety ( $r_s=-0.40$ ,  $p=0.03$ ) and depression on the CES-D ( $r_s=-0.32$ ,  $p=0.01$ ) but did not relate to depression on HADS ( $r_s=-0.17$ ,  $p=0.33$ ).

Our study is novel for several reasons. Firstly, we report on both parent-proxy and child QoL concurrently, while previous studies reported either child or parent-proxy reports and found poor HRQoL in stable-state [7] and during an exacerbation [2]. Our finding of a significant association between parent and child reports of HRQoL, suggests that, while not equivalent, in the absence of a validated disease-specific measure for children, self-report or parent-proxy measures of HRQoL may be used depending on child’s age and capacity, and reasonably reflect disease impact. This may be less applicable to a healthy population; our few correlations between parental and healthy child QoL are consistent with previous findings [13].

Secondly, the higher prevalence of anxiety and depression in parents of children with stable-state bronchiectasis compared with controls, is consistent with reports of parents of children with cystic fibrosis (CF) [14]. Poorer parental psychological health may be related to the high treatment burden of their children, with nearly 75% of child participants with bronchiectasis in this study engaged in regular airway clearance therapy and exercise. High treatment burden is recognised in adults with bronchiectasis [15].

TABLE 1 Health-related quality of life and psychological well-being responses in bronchiectasis compared with age-matched controls, children and parent participants

	Bronchiectasis	Controls	p-value
<b>Children</b>			
Males:females n	23:18	20:21	0.557 <sup>#</sup>
PedsQL physical	75 [63–91]	88 [84–94]	0.002 <sup>¶</sup>
PedsQL psychosocial	17 [16–19]	63 [47–78]	<0.001 <sup>¶</sup>
PedsQL total	67.4 [58.7–81.5]	88 [85–95]	<0.001 <sup>¶</sup>
<b>Parents</b>			
PedsQL physical	75 [54.7–90.6]	94 [88–100]	<0.001 <sup>¶</sup>
PedsQL psychosocial	17 [15–18]	62 [51–73]	<0.001 <sup>¶</sup>
PedsQL total	65.8 [54.1–80.7]	95 [88–101]	<0.001 <sup>¶</sup>
HADS anxiety	20 [49]	7 [17]	0.009 <sup>#</sup>
HADS depression	13 [32]	1 [2]	0.001 <sup>#</sup>
CES-D	23 [56]	1 [2]	<0.001 <sup>#</sup>

Data are presented as median [interquartile range] or n (%), unless otherwise stated. PedsQL: Pediatric Quality of Life Inventory; HADS: Hospital Anxiety and Depression Scale; CES-D: Centre for Epidemiologic Studies Depression Scale. <sup>#</sup>: Chi-squared test; <sup>¶</sup>: Mann–Whitney U test.

This finding is important given the known association between anxiety, depression and treatment adherence described in other respiratory populations [5, 6]. While our small dataset did not allow an evaluation of this relationship, future exploration of the link between treatment burden, adherence and the psychological health of parents of children with bronchiectasis, and a comparison of this to children with CF is warranted.

The poorer parental psychological well-being reported by parents of children with bronchiectasis highlights the importance of a “whole-of-family” approach to screening and management for bronchiectasis, including current recommendations for psychosocial interventions for families of children with bronchiectasis [3]. Adolescents with CF are twice as likely to report depression and/or anxiety if a parent has psychological distress [14]. Whether parental psychological distress serves as a precursor to the development of child psychological distress is unclear.

The small participant numbers in this study may serve to under- or overestimate the degree of impairment in HRQoL experienced by children with bronchiectasis, as well as the prevalence of parental psychological distress. Children with bronchiectasis in this study had mild disease, with exacerbation frequency or antibiotic prescription unknown; in addition, only stable-state children with bronchiectasis were included. Therefore, the extent these findings apply to those with severe disease, or with an acute exacerbation, are unclear. In the absence of information regarding exacerbations and hospitalisations, their contribution to poorer HRQoL are unknown. Participants with bronchiectasis were recruited from two geographical and climatic regions, whilst control participants came from geographically disparate locations. Whether environmental and cultural differences influence QoL or psychological well-being cannot be accounted for.

In comparison with their healthy peers, children with bronchiectasis have poor HRQoL and their parents report higher levels of anxiety and depression. Attention to, and strategies to improve, HRQoL and parental psychological well-being are warranted in this patient group.

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