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The experiences of children with bronchiectasis and their parents in a novel play-based therapeutic exercise program: a qualitative analysis.

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Abstract

Objectives: To explore the experiences and perceptions of children with bronchiectasis and their parent's regarding an eight-week play-based therapeutic exercise program.

Design: Qualitative study with inductive content analysis.

Setting: Individual semi-structured interviews were conducted. Interview recordings were transcribed verbatim, and coding was guided by the content. Content categories were established via consensus moderation.

Participants: Ten parent child dyads where children with bronchiectasis were aged 5 – 12 years.

Results: From the perspective of children, the most important components of the program were fun with friends and being active at home as a family. Parents valued the community-based sessions, perceived the program to be engaging and motivating. Parents perceived improvements in their child's endurance, coordination, and physical activity level. They described the home program as fun

31 but noted that finding time was difficult. Both parents and children thought that in-person exercise
32 sessions would be better than exercise sessions delivered online.

33 **Conclusions:** Children who participated in the play-based exercise program, found it fun, motivating
34 and accessible. Parents perceived positive impacts on fitness, coordination and physical activity.

35 Data availability statement: Deidentified data are available upon reasonable request and pending
36 ethics clearance.

37 **Strengths and limitations of this study**

- 38 • This study included children as participants who expressed unique opinions about their
39 participation in the physical activity program highlighting the importance of their inclusion in
40 research focusing on their lived experience.
- 41 • Collaborating with families and co-designing research projects is a current research priority
42 area for children and young people with bronchiectasis.
- 43 • This study had relatively small number of participants, but saturation of data was achieved
44 from the ten parent child dyads.

45 Word count 4573 (with quotes), 2910 (without quotes)

46 **INTRODUCTION**

47 Bronchiectasis unrelated to cystic fibrosis is a chronic lung disease that impacts the daily lives of
48 children, including their schooling, play, and overall wellbeing [1-4]. This pulmonary disorder is
49 diagnosed by identifying the presence of abnormal bronchial dilatation using high-resolution chest
50 computed tomography in the presence of clinical symptoms [5-7]. Children present clinically with a
51 persistent wet cough with or without shortness of breath and poor exercise tolerance [3, 6, 8]. The
52 pathology can alter mucociliary clearance creating a cycle of inflammation and infection which can
53 lead to pulmonary exacerbations [9-11]. The frequency of exacerbation is the only known predictor
54 of long term decline in lung function in children with bronchiectasis [10]. As the global prevalence of
55 bronchiectasis rises, it is recognised as an important cause of chronic respiratory disease, morbidity,
56 and healthcare utilization [12-15].

57 The management of bronchiectasis utilises a multi-disciplinary approach. In children, its goals
58 include improving quality of life, exercise tolerance and lung function whilst reducing the number of
59 exacerbations and hospitalisations [16-18]. Guidelines for the treatment and management of
60 bronchiectasis call for regular exercise, not only as a means of improving aerobic fitness and health-
61 related quality life, but as a self-management tool to reduce the frequency and severity of
62 exacerbations [17]. Yet, the available evidence indicates most children with bronchiectasis are
63 insufficiently active for health benefit with only 6% achieving the recommended 60 minutes of daily
64 moderate to vigorous physical activity (MVPA) [4].

65 Reasons for physical inactivity among children with bronchiectasis are not well understood.
66 However, developmental delays in fundamental movement skill (FMS) proficiency may be a key
67 contributing factor. In a recent study, only 17% of children with bronchiectasis achieved their age
68 equivalency for locomotor skills, while fewer than 9% achieved their age equivalency for object
69 control skills [19]. Importantly, children achieving their age equivalency for locomotor or object
70 control skills exhibited 41% higher levels of MVPA than children not achieving their age
71 equivalency. Collectively, these findings suggest that children with bronchiectasis would

substantially benefit from effective therapeutic programs that improve fundamental movement skill proficiency, promote regular physical activity and increase cardiorespiratory fitness. Yet, to date there is paucity of data on how to achieve this.

The Bronchiectasis: Exercise as Therapy Trial (BREATH) is a multi-centre randomised controlled trial (RCT) designed to evaluate the effects of a novel eight-week, play-based therapeutic exercise program on the frequency of acute exacerbations in children aged 5 to 12 years with radiologically confirmed bronchiectasis. Secondary aims are to assess the program's impact on FMS proficiency, device-measured MVPA, cardiorespiratory fitness, perceived movement competence, health-related quality of life (HR-QoL), and lung function (forced expiratory volume in one second, FEV₁) [20]. Informed by the evidence identifying FMS proficiency as a key determinant of habitual physical activity [21, 22], the program focuses on developing and enhancing children's movement competence, motivation, and aerobic fitness through developmentally appropriate, play-based activities or games tailored to the child's fitness and skill level. The program comprises a combination of supervised and unsupervised exercise therapy sessions. The supervised component consists of eight 60-minute group sessions, completed on a weekly basis, led by a clinical exercise physiologist or physiotherapist. The unsupervised component consists of a home-based, parent-led exercise program, completed two times per week (~ 20 minutes per session), during which children and family members complete two games from their most recent 60-minute supervised group session.

While the trial is focused on the primary and secondary outcomes above, it is important for the ongoing development and sustainability of the program to obtain feedback from participants and their parents/carers. Exploring parent's and children's perspectives on the program provides valuable insight into the utility of the program and drives action required for scale-up and implementation in clinical and community settings. Therefore, the objective of this study was to explore the experiences and perspectives of children with bronchiectasis, and their parents/carers, after participating in the BREATH play-based therapeutic exercise program.

METHODS

Participants

Participants for this study were children enrolled in the BREATH RCT, and their parents/carers. To be eligible, children must have been randomised to the exercise program and participated in at least one exercise session. Written informed consent was obtained from parents/guardians. Ethical approval for this study was received by the Queensland Children's Hospital Human Research Ethics Committee (HREC/19/QCHQ/56049) and NT Health (Reference Number: 2020-3847). The trial was registered with, Australian and New Zealand Clinical Trials Register (ACTRN12619001008112).

Interview guides

Separate interview guides were developed for children and parents (see Supplemental Files 1 and 2). The interview guides included questions related to the acceptability of the program, how it could be improved, and related perceptions of the supervised group exercise sessions and the supplemental unsupervised home-based exercise sessions.

Data collection

Participants completed a single interview via videoconference with a researcher (BK) not involved in the delivery of the exercise program. The child interviews were conducted with a parent present or

1
2 113 nearby. Interviews were digitally recorded, transcribed verbatim, checked for accuracy, and saved for
3 114 subsequent analysis. The transcriptions were deidentified and assigned a unique study identification
4 115 number.

6 116 **Data analysis**

8 117 Data from the interviews were analysed using content analysis with an inductive approach [23, 24].
9 118 Transcripts were read and re-read by a member of the research team (TJ) to guide the establishment
10 119 of a codebook (see Supplemental File 3). Common phrases, words and content from the transcripts
11 120 formed an initial draft of the codebook which was subsequently reviewed and updated by the
12 121 research team (TJ, EB, KO, ST). To test the reliability of the coding scheme, two parent and two
13 122 child transcripts were randomly selected and independently coded by two researchers (TJ and EB).
14 123 Once the codebook was finalised, a member of the research team (TJ) coded the remaining child and
15 124 parent transcripts. After all transcripts were coded the initial code groupings were discussed by
16 125 members of the research team (TJ, EB, ST) and collated to form sub-categories and final content
17 126 categories [25]. Data were managed with NVivo 12 (QSR International Pty. Ltd.).

21 127 **RESULTS**

23 128 **Participant Characteristics**

25 129 From the 17 families eligible to participate, 10 parent-child dyads provided consent and completed
26 130 interviews. Six families could not be contacted, and one family declined due to a busy schedule.
27 131 Children were aged from five to 12 years (median age = 8.2 years, interquartile range IQR = 5.7 –
28 132 9.8). Four of the 10 children were females. All children interviewed had completed seven or eight
29 133 supervised group exercise sessions. Parent interviews ranged from 21 to 46 minutes in duration
30 134 (mean 31 ± 7.2 minutes) and child interviews ranged from 11 to 19 minutes in duration (mean 15.5 ±
31 135 2.5 minutes). The annual household income for families was well distributed across low to high
32 136 income and ranged from \$26,000 to over \$200,000. Parental education ranged from not finishing
33 137 high school to completing post graduate qualifications.

36 138 **Content categories: children**

38 139 Children provided perspectives on the supervised group sessions, unsupervised home-based program,
39 140 and recommendations for future programs. The final content categories were: having fun with family
40 141 and friends; being active at home as a family, and; a preference for in-person sessions. Illustrative
41 142 quotes from participants are presented below for each of the content categories.

44 143 **Fun with friends and family**

46 144 Children described the face-to-face group sessions and the games as fun. Children frequently talked
47 145 about specific games such as balloon tennis or hopscotch they perceived to be fun. Most children
48 146 indicated that they would like to repeat the BREATH program again.

50 147 *'I thought they were really fun, and I liked how they were different ones each*
51 148 *week and sometimes some were the same... I liked doing the hopscotch game.*
52 149 *We went outside and did this ring toss, and the rings were really heavy. I*
53 150 *liked that too.'* Ch03

56 151 *'They were fun, and they involved running around a lot and throwing and*
57 152 *kicking and stuff.'* Ch06

1
2 153 *'They were pretty fun... the one where I do the ball. That was really fun.'*
3 154 *Ch02*

5 155 Children valued having other children participate in the exercise sessions. They especially liked when
6 156 their siblings or friends participated.

8 157 *'...you can be with people that you know... (therapist) was really nice.'* Ch01

10 158 *'I wasn't alone... I could compete with my brothers.'* Ch06

12 159 *'Why was it fun? 'Because he (brother) got to do activities too and he does*
14 160 *that balloon one too...'* Ch07

16 161 *'It was a bit better because I wasn't just doing all the activities all myself.'*
17 162 *Ch03*

19 163 **Being active at home as a family**

21 164 Children's responses regarding the home program were brief in comparison to their conversations
22 165 about on the supervised group program. Children primarily spoke about their siblings and parents'
23 166 involvement and described the games included in the home program as fun.

25 167 *'You can play with your siblings if you're at home... Sometimes my brother*
27 168 *joined in. It was fun.'* Ch01

29 169 *'There was balloon tennis. For balloon tennis, mum and (sister). For the*
30 170 *yoga poses, dad and mum. I liked having my family involved.'* Ch09

32 171 *'Well, sometimes (brother) would do it with me and mum would sometimes do*
33 172 *a little bit and watch... Yeah, I liked it. It did get tiring for some stuff like*
34 173 *doing - like in the hallway, going up and down doing like frog jumps.'* Ch03

36 174 **In person is better than online**

38 175 Children offered suggestions for future programs regarding the mode of delivery, use of technology,
39 176 and recommendations for future programs. Most (but not all) children expressed a preference for the
40 177 supervised exercise program component to be delivered face-to-face rather than "online" or through
42 178 an exercise "app". However, for the home program, children thought technology could be useful.

44 179 *'...online, for the for the actual game sessions, no.'* Ch02

46 180 *'It would be kind of like strange because you couldn't really - you wouldn't*
47 181 *really be able to demonstrate too well and it's kind of glitchy.'* Ch03

49 182 *'Yeah, an app would be cool and useful. It would probably have like - like*
50 183 *you could like hold it in your hand and it would count how many steps you've*
51 184 *done and could somehow sense your heart rate. Just like a phone or a tablet.'*
53 185 *Ch03*

55 186 *'App with activities, like daily activities, and then it would have like a couple*
56 187 *of weekly.'* Ch02

1
2 188 *'You'd get to watch the activities then do them.'* Ch01
3

4 189 **Content categories: parents**
5

6 190 Parents provided perspectives on the supervised group sessions, unsupervised home-based program,
7 191 perceived impact of the program on their child, and ideas for future programs. The final emergent
8 192 themes were: an engaging and motivating program; parents' perceptions of program impact family
9 193 and friends are important; location, location, location; the home program was fun but finding the time
10 194 was hard, and; apps are fine for home, but face-to-face sessions are preferred. Illustrative quotes from
11 195 participants are presented for each content category.
12
13

14 196 **An engaging and motivating program**
15

16 197 Parents universally expressed positive feelings about the BREATH program. Like the children, they
17 198 thought the exercise sessions were fun and said their child enjoyed the program. Parents valued the
18 199 variety of games and activities included the program and felt that supervised exercise sessions were
19 200 well structured and organised. They perceived that the rapport with the therapist and the variety of
20 201 games motivated and engaged their children to participate in the exercise sessions.
21

22 202 *'It was all very engaging, and she really was motivated by the games because*
23 203 *the games were fun... I think that the venue that we were in was so - like*
24 204 *something that we didn't expect and just the fact that she is in this massive*
25 205 *hall full of games and equipment.'* Par04
26
27

28 206 *'It motivated him and got him interested in doing different things and that, so*
29 207 *I thought it was quite good. All different levels of stuff, like it wasn't just the*
30 208 *same, repetitive things, it was all different stuff... Good variety of activities as*
31 209 *well, it would be different each week, it wasn't repeating in the same sort of*
32 210 *thing each week.'* Par06
33

34 211 *'She did it very well, because I think she's loving all those activities, that's*
35 212 *why, yeah... I think all the activities basically, the whole exercise I think,*
36 213 *because she loves to play, so that's why I think she enjoyed those exercises.'*
37 214 Par08
38
39

40 215 **Perceptions of program impact**
41

42 216 Parents enthusiastically talked about the changes they observed in their child after completing
43 217 BREATH. Parents reported increased fitness and/or endurance, improved coordination, and greater
44 218 participation in physical activity.
45

46 219 *'When he plays baseball, he used to get really, really tired playing baseball.*
47 220 *He would be so puffed out after doing one innings of baseball and sometimes*
48 221 *he'd get that tired he'd have a meltdown because he's autistic. But now he*
49 222 *plays the whole two-and-a-half-hour game without really having a break or*
50 223 *having a meltdown.'* Par01
51
52

53 224 *'Especially like when his cousins come over, they will just run through and*
54 225 *around the house and up and down the house for hours on end, whereas*
55 226 *before he potentially wouldn't have done that.'* Par05
56
57
58
59
60

1
2 227 *'It definitely helped her coordination because now she can do hopscotch.*
3 228 *She's better at aiming with her throws now... I think it's helped her confidence*
4 229 *a little bit too actually. Yes, so even when we're just playing games on the*
5 230 *weekend and stuff like that her coordination has gotten a lot better.'* Par07
6

7
8 231 *'His coordination has definitely improved, like the hand eye coordination,*
9 232 *bouncing balls and hitting things with rackets. A bit of improvement there,*
10 233 *that's for sure... Just in how he plays here at home. Whereas before he'd*
11 234 *maybe get over it pretty quickly because he wasn't that great at it, he had a bit*
12 235 *more skill.'* Par02
13

14 236 *'But to do the weekly exercise program and then see the improvement in him*
15 237 *and since then it's almost like it was a – it was like a trigger for him. So, he*
16 238 *now runs better. He plays better. He throws balls. He kicks balls. He's a lot*
17 239 *more physically coordinated that he was and yeah that was probably one of*
18 240 *the big takeaways for us and something that we've continued to encourage at*
19 241 *home.'* Par05
21

22 242 *'I think she's more active now, but I didn't notice any changes but she's not*
23 243 *getting tired easily basically. So, that also help her, all those exercises.'*
24 244 *Par08*

26 245 **Family and friends are important**

28 246 Parents valued the participation of siblings and friends in BREATH. Parents said that it helped their
29 247 child feel more confident in the initial sessions and made the program more enjoyable overall.

31 248 *'When we were told that we could include the siblings, you know sometimes*
32 249 *people say that, but they really meant it. So, like I said, (sibling) still asks to*
33 250 *go to the sessions, her little brother. I think it just made it more fun, having*
34 251 *her sibling there.'* Par03
36

37 252 *'Participating with his siblings, he's not used to, but it got really good*
38 253 *because they become closer. Him and his brother I know are really close*
39 254 *because they're so close in age, but he got to show (sister) how to play.'*
40 255 *Par01*

42
43 256 *'It was good that there were other kids there. He liked that. I did notice that...*
44 257 *he loves social interaction, absolutely thrives off it, and if he can find a friend*
45 258 *and someone to play with, and someone that likes his games, he's very*
46 259 *happy.'* Par02
47

48 260 *'I think having his sister there made it a fun family experience... (Sister)*
49 261 *loved it as well. She just – yeah, she was excited as he was to go there every*
50 262 *time. There was another little boy there who had bronchiectasis. Yeah, it*
51 263 *made it – it was almost like they saw it as a play date...it was good for them*
52 264 *all to do it, I think.'* Par05
54
55
56
57
58
59

1
2 265 **Location, location, location**

3
4 266 Parents liked that the supervised exercise session were delivered in community halls. They valued the
5 267 spacious venues and the proximity to their home or their child's school.

6
7 268 *'The community centre was actually really good because I had never been*
8 269 *there before but the fact that it was all inside meant that we didn't have to*
9 270 *stop because of the rain.'* Par07

10
11 271 *'The location is very convenient for us because it's only 15 minutes away*
12 272 *from us, so it's very convenient, I cannot complain on that one. We don't*
13 273 *need to travel far, because the option is either go to the other, I think the*
14 274 *hospital, right? Versus the community centre, I prefer the centre because I*
15 275 *know it's only 15 minutes away from our place.'* Par08

16
17
18 276 *'...that's perfect location. It was only just up the road from us, it wasn't a big*
19 277 *push to get there. Like I finished work and got to day care to pick him up from*
20 278 *after school care and then got there generally early most days.'* Par09

21
22 279 **The home program was fun but finding the time was hard**

23
24 280 Parents described the home-based program as fun. They liked the variety of activities and games
25 281 included and thought that the frequency and duration was appropriate. They found the instructions
26 282 helpful and easy to follow. Parents liked that the home programs could be completed with equipment
27 283 they had at home.

28
29
30 284 *'Still to this day we've got a folder where we've kept them, and I still have to*
31 285 *buy balloons because they're like balloon tennis is their favourite. They love*
32 286 *to play it, like all the time, down my hallway, everywhere.'* Par01

33
34 287 *'I like that it gave us some of those activities and things that he did, because*
35 288 *some of them he really enjoyed in the moment. So, it was nice to actually have*
36 289 *a copy of how to do it and how to set it up and stuff like that.'* Par02

37
38
39 290 *'They will play that game as a matter of course. So yeah – and again it's –*
40 291 *it's seeing how the strategies or the activities they were doing in class, for*
41 292 *want of a better word can be – can just become embedded at home and taking*
42 293 *five minutes to play the balloon game or taking five minutes to go downstairs*
43 294 *and kick a football around or do something. So yeah, it was good.'* Par05

44
45 295 However, parents described some barriers to completing the home program. A few parents
46 296 acknowledged that the home program wasn't always a priority. Parents commented that lack of time
47 297 or their own lack of motivation was a barrier to doing the home exercise component.

48
49
50 298 *'We knew what we had to do. It's more home management of finding the time*
51 299 *to do it... there was nothing we disliked. It's just our innate laziness trying to*
52 300 *find times to do the things.'* Par05

53
54 301 *'We didn't do it as often as we should and that's because of the time... We*
55 302 *always did it once before because obviously, the day before, we were going to*

1
2 303 *the next session... we couldn't do it very often because it's just too much*
3 304 *other things, you know?' Par04*
4

5 305 *'I tried begging, I tried pleading. He's not a fan. As soon as it was called*
6 306 *homework, he was very much not interested. Even with the encouragement of*
7 307 *the stickers and the whole getting to show off the next time when we went*
8 308 *there anything. He was just yeah - he was not very interested in doing it at*
9 309 *all.'* Par02
10
11

12 310 **Apps are fine for home, but face-to-face sessions are preferred**

13
14 311 Parents provided feedback and suggestions in relation to the mode of delivery and use of technology.
15 312 There were strong opinions that exercise sessions delivered through a digital platform such as
16 313 telehealth would not work for their child since parent involvement was crucial. Nevertheless, parents
17 314 saw value in the use of an online platform or app for the management of the home-based exercise
18 315 program.
19

20 316 *'I think if it was over a Zoom call or anything like that, he would just not be*
21 317 *so engaged. So, I kind of liked the fact that it had real people.'* Par09
22
23

24 318 *'Personally, I don't think it would probably work for us...given that that's just*
25 319 *not his thing, doing it like over the phone or telehealth or whatever. Maybe*
26 320 *an app would be all right. But it'd still need that face-to-face, I think,*
27 321 *interaction, with the actual going to a group and doing that. I think it needs*
28 322 *that.'* Par02
29

30 323 *'Telehealth would not work ever with (child), no way. We did the dance Zoom*
31 324 *classes during the lockdowns and yeah, you know... Oh, she loses the interest*
32 325 *like you know, she can just move away herself from the situation.'* Par04
33
34

35 326 *'...maybe if you had an app or something for the older kids where they can*
36 327 *just do it on their own maybe, so they didn't have to have mum and dad there*
37 328 *or something.'* Par07
38

39 329 *'...if we have an app to basically listed all the exercises that we needed to do*
40 330 *for a specific day, I think that would be easier instead of the paper base.*
41 331 *Especially we're now on modern technology as well.'* Par08
42
43

44 332 **DISCUSSION**

45
46 333 Our study explored children's and parent's experiences and perceptions of an eight-week
47 334 developmentally appropriate play-based therapeutic exercise program for children with non-cystic
48 335 fibrosis bronchiectasis (BREATH program). Children and parents provided unique yet
49 336 complementary perspectives about the BREATH program. Children thought that including family
50 337 members and friends in the program made it more engaging. They valued being physically active at
51 338 home with family members and preferred in-person exercise sessions to telehealth or online sessions.
52 339 Parents expressed broader viewpoints than children. Parents described BREATH as an engaging and
53 340 motivating exercise program and felt that it had visible positive impacts on their child's
54 341 cardiovascular fitness, coordination level, and participation in physical activity. Like children,
55 342 parents indicated a preference for face-to-face sessions over telehealth or app-based exercise
56
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60

1
2 343 programs. The community-based location and inclusion of family members and friends were
3 344 considered important strengths. They described the supplemental home program as fun but
4 345 acknowledged that finding time to complete the program was challenging.
5

6 346 The delivery of the program in readily accessible community-based venues such as council halls was
7 347 highly valued by parents. Therapeutic exercise programs are typically delivered in health services,
8 348 outpatient settings, or academic institutions. Thus, parents' strong endorsement of community halls
9 349 as a venue for delivering the program represents an important finding. The families' preference for
10 350 exercise programs delivered locally is consistent with the results of a recent qualitative study that
11 351 identified supportive physical activity environments as a facilitator to physical activity in children
12 352 with bronchiectasis [26]. In this present study, parents liked that the community venues were close to
13 353 home or school, they felt that it was an excepted place where exercise occurs and appreciated the
14 354 physical space inside the venues. Multiple systematic reviews highlight that physical environmental
15 355 factors are consistently associated with physical activity [27-30]
16
17
18

19 356 Both children and parents thought that the inclusion of siblings and friends in the exercise sessions
20 357 was fun and motivating, especially at the start of the program. These findings are consistent with the
21 358 results of a recent systematic review of 26 qualitative studies exploring children's perspectives on
22 359 what they like about physical activity, why it is important, and the factors that influence their
23 360 physical activity [31]. The review identified enjoyment of physical activity, being active with friends,
24 361 and being encouraged by their friends as salient influences on children's physical activity. Being
25 362 physically active with their families and parental support were also identified as important influences.
26 363 In a different study, children and young people with cystic fibrosis were a subset of participants
27 364 interviewed to explore their perceptions of physical activity [32]. Children with cystic fibrosis
28 365 reported that they enjoyed physical activity and linked it to health benefits. Similar to the present
29 366 study, they identified peers and family as enablers for physical activity. Collectively, the findings
30 367 from these studies support the concept that making therapeutic exercise programs open to family
31 368 members and friends is an effective strategy to increase enjoyment, engagement and support
32 369 motivation.
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36 370 Parents perceived that their child directly benefited from participating in the program. Parents openly
37 371 talked about visible improvements in their child's endurance, level of coordination, and physical
38 372 activity participation. Previous exercise studies in children with bronchiectasis tend to focus on
39 373 specific activities or components of movement such sit to stand [33], balance [34] and walk testing
40 374 [35]. In a different approach to activities and exercise a recent study investigated the efficacy of
41 375 aerobic video game exercises and breathing video game exercises in children with bronchiectasis
42 376 [36]. The parents' observations from our study reflect the goals of the BREATH program which
43 377 focuses on developing and enhancing children's confidence and motivation to engage in physical
44 378 activity through developmentally appropriate, play-based activities targeting aerobic fitness and
45 379 fundamental movement skills. The perceived improvements in coordination and endurance are
46 380 consistent with the results of the BREATH pilot RCT [22]. In this study, relative to usual care
47 381 controls, children receiving the play-based therapeutic exercise program exhibited significant
48 382 improvements in cardiovascular fitness, locomotor skills and object control skills [22]. The perceived
49 383 increase in physical activity after completing the program is consistent with the findings of a
50 384 previous study conducted in children with bronchiectasis which reported fundamental movement
51 385 skill proficiency to be associated with higher levels of daily MVPA [4]. While the empirical
52 386 evaluation of the BREATH program on frequency of exacerbations, aerobic fitness, fundamental
53 387 movement skills, physical activity, quality of life and lung function is ongoing, the findings of our
54 388 qualitative study indicates that the program is on track.
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2 389 When asked to consider a hypothetical scenario where the BREATH exercise program was delivered
3 390 via the internet or smart phone, both parents and children indicated a preference for face-to-face
4 391 exercise sessions over telehealth. Digital healthcare encompasses telehealth, phone contact, text
5 392 messaging, digital applications (or apps) and is increasingly part of the healthcare landscape [37].
6 393 Unsurprisingly, there was a sharp increase in digital healthcare during the COVID-19 pandemic
7 394 which has prompted discussion as to its continued role and future innovations [38]. In the current
8 395 study, parents and children clearly expressed their preference for face-to-face exercise sessions,
9 396 citing the positive experience of engagement with other children and the therapist. Parents and
10 397 children did, however, see a role for of an app or online platform for completing the supplemental
11 398 home exercise program, which many parents described as difficult to prioritise. Families preferred an
12 399 app or mobile-health (m-health) platform that would be specifically tailored to children with
13 400 bronchiectasis. It is important to consider these preferences when designing exercise programs to
14 401 increase fitness, movement competence, and habitual physical activity in children with
15 402 bronchiectasis.
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19 403 This study has both strengths and limitations. A strength of the current study is the inclusion of
20 404 children as participants. Children expressed unique opinions about their participation in the
21 405 BREATH program which highlights the importance of their inclusion in research focused on their
22 406 lived experience. Collaborating with families and co-designing research projects is a current research
23 407 priority area for children and young people with bronchiectasis [39]. The study followed established
24 408 content analysis guidelines and utilised a rigorous collaborative process to data analysis. Limitations
25 409 include, the relatively small number of participants interviewed and the omission of perspectives
26 410 from the therapists delivering the program. Children who participated in the exercise sessions but did
27 411 not participate in the interviews study may have offered different perspectives. However, saturation
28 412 of data was reached from the parent child dyads that were interviewed and the views of the therapists
29 413 were not a focus of the study.
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33 414 In summary, we explored the experiences and perceptions of families who participated in an eight-
34 415 week play-based therapeutic exercise program to reduce the frequency of acute exacerbations in
35 416 children with bronchiectasis. The findings suggest that the children who participated in the BREATH
36 417 program demonstrated improvements in fitness, coordination, and physical activity participation, and
37 418 found the program fun, motivating and accessible.
38

39 419 **Conflict of Interest**

40
41 420 The authors declare that the research was conducted in the absence of any commercial or financial
42 421 relationships that could be construed as a potential conflict of interest.
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44

45 422 **Author Contributions**

46
47 423 ST oversaw the design and conduct of the study. ABC, VG, GBM and TJ supported the recruitment.
48 424 BK interviewed the participants. TJ reviewed the transcripts, coded and drafted the manuscript. ST,
49 425 EB, K-AO'G, and TJ analysed the data. All authors had a role in informing coding and analysis of
50 426 the data collected, read, and approved the final manuscript.
51

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53
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55 429 Queensland Advancing Research Fellowship and a Royal Australasian College of Physicians' Early
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430 Career Fellowship (2022REF00054). ABC is supported by a senior NHMRC practitioner fellowship
431 (1058213).

432 **Acknowledgments**

433 We thank the parents and children who participated in the BREATH trial and interviews.

For peer review only

434 Supplemental File 1: Interview Guide developed for children

Topic	Questions and prompts
BREATH exercise program questions	<p>You did the BREATH program at (<i>interest location</i>). You were joined by (<i>insert siblings, friends</i>).</p> <ul style="list-style-type: none"> • Tell me what you thought about the games and activities? <ul style="list-style-type: none"> ○ What did you like about the games/activities? Why? ○ What parts did you think were fun? ○ What didn't you like about the program? Why? ○ What parts did you think were boring? ○ What would you change? • What did you think about how long each session went for? • What did you think about the having the sessions at (<i>insert location</i>)? • What was it like having your (friend/sibling there)? • Have you noticed any changes to the way your body feels or moves since doing the exercise program? <ul style="list-style-type: none"> ○ What are those changes? • Have you noticed that it is easier or harder to keep up with your friends when you are playing? • Do you get tired when you are playing or running around? <ul style="list-style-type: none"> ○ Did this tiredness change after you did the games/exercise program?
Home activity program	<ul style="list-style-type: none"> • What did you think about the home programs? <ul style="list-style-type: none"> ○ What did you like about your home programs? ○ What was fun? ○ What didn't you like about the home programs? ○ What was boring? ○ What did you think about the types of activities? ○ What did you think about how long your home activities went for? • What would you change about the home programs? • Who did the home programs with you? <ul style="list-style-type: none"> ○ What was that like? ○ How many times a week did you do the home activities? • Would it be helpful to have an app or other online support? <ul style="list-style-type: none"> ○ What would that look like?
Future programs	<ul style="list-style-type: none"> • Would you do the games and exercise program again? • Would you recommend that other children do the games/ activity sessions? <ul style="list-style-type: none"> ○ Can you tell my why/why not? • >10yo: How do you feel an ideal program would be delivered?

- Group sessions, one-on-one, home-based, combination, remote, online coaching, apps
- Would you recommend that friends/siblings be included
- Timing. Before or after school, on the weekends, or in the holidays?
- Frequency. More/less than once a week
- Types of activities
- Setting. At home, in the community, at a health centre.
- <10yo: Would you do the BREATH program again? Would you want to try anything different?
- >10yo: Do you have any thoughts how this would work if we delivered this online via a smart phone or iPad?

Sweeping
question

Is there anything else you would like to add before we finish?

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437 Supplemental File 2: Interview Guide developed for parents

Topic	Questions and prompts
BREATH exercise program questions	<p>Your child participated in the bronchiectasis research project that included games/exercise sessions at (<i>interest location</i>). They were joined by (<i>insert siblings, friends</i>).</p> <ul style="list-style-type: none"> • Tell me what you thought about the BREATH program? <ul style="list-style-type: none"> ○ What did you like about the program? ○ What could we have done better? • What did you think about the types of activities? • What did you think about the length of each session? (<i>approx. 1hr</i>) • What did you think about the length of the whole program? (<i>8 weeks</i>) • What did you think about the location? • How did your child feel about participating in the exercise program? <ul style="list-style-type: none"> ○ What did they like? ○ What did they dislike? ○ What parts of the sessions did you child find easy? ○ What parts of the sessions did your child find hard or difficult? • Have you noticed any changes in your child's movement skills or coordination level? <ul style="list-style-type: none"> ○ What type of changes in movement skills or coordination did you observe? ○ Did they improve? Did they stay the same? Did they decline? • Have you noticed any changes in their fitness since participating in the games/exercise sessions? <ul style="list-style-type: none"> ○ Did their fitness improve? Did it stay the same? Did their fitness decline? • Is there any change to their tiredness or fatigue? <ul style="list-style-type: none"> ○ Do they become more fatigued with physical activity? No change? Less fatigued with physical activity? • The BREATH program is designed to include siblings, friends or other children with bronchiectasis. Describe how the inclusion of other children influenced your child?
Home activity program	<ul style="list-style-type: none"> • What did your home program sessions look like? <ul style="list-style-type: none"> ○ Who was usually involved in the home games and activities? ○ Did you use any particular strategies to manage the home program (e.g. sibling and parent involvement, supervision, competition, rewards, music)? • What did you think about the home programs? <ul style="list-style-type: none"> ○ What did you like about the home program?

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- What did you dislike about the home program?
 - What did you think about the length of each home program?
 - What did you think about how often you were asked to do the home program?
 - What did you think about the types of activities?
 - Was it difficult to motivate you child to do the home program? If so, in what way?
 - What did you think about the paper handouts you were provided for the home program?
 - How often did you do the home program?
- Future programs
- Describe what you think would be an ideal program.
 - Group sessions, one-on-one, home-based, combination, remote, online coaching, apps
 - Timing. Would BREATH be suited closer to the diagnosis of bronchiectasis.
 - Frequency. More/less than once a week
 - Length of program, is 8 weeks, too long, too short or the right about of time?
 - Types of activities
 - Setting. At home, in the community, at a health centre.
 - Timing. Before or after school, on the weekends, or in the holidays?
 - Do you have any thoughts how this would work if we delivered over the internet or smart phone app?
 - Would a program like BREATH be valuable for other children with bronchiectasis?
- Sweeping question Do you have any other comments you would like to add before we finish?
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439 Supplemental File 3: Codebook to support content analysis of child and parent interview

Topic	Topic Sub Grouping	Initial Code
BREATH Program	Location	Community
		Home
		Hospital
		Inside
		Other location
		Outside
		Proximity (to home/school)
		Research Centre
		School
		Travel time
	Feelings about program	Adaptable
		Bad
		Boring
		Challenging
		Difficult
		Dislike
		Easier
		Fun / enjoyment
		Games-based
		Good
		Happy
		Hard or harder
		Helpful
		Improve
		Individualised
		Interesting
		Like
		Play- based
		Rapport (therapist, or others at sessions)
	Social / socialise	
	Structured	
	Variety	
	Logistics	Communication therapist
Communication written		
Equipment support		
Organisation		
Support People	Child	
	Friend	
	Parent	
	Sibling	
	Therapist	
Timing of diagnosis	Other people (not listed above)	
	Appropriate as was	
	Prefer closer to diagnosis	
		Prefer further from diagnosis

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Changes in participant

Symptoms

Breathless
Coughing
Tired / fatigue / exhausted

Other changes

Ability
Confidence
Co-ordination
Fitness
Motivation
No change
Participation
Reducing Medicine
Skills- balance
Skills- ball
Skills- exercise (and activities)
Skills- jumping
Skills- Play
Skills- running
Skills- throwing
Tried (or trying)

Duration and Frequency BREATH

Frequency F2F Sessions

Appropriate as was
Prefer more frequent
Prefer less frequent

Duration of F2F sessions

Appropriate as was
Prefer longer
Prefer shorter

Duration of BREATH program

Appropriate as was
Prefer longer
Prefer shorter

Home program

Frequency of home sessions

Appropriate as was
Prefer more frequent
Prefer less frequent

Duration of home sessions

Appropriate as was
Prefer longer
Prefer shorter

Management of home program

Competition
Equipment
Parent involvement
Reminders
Rewards
Sibling involvement
Supervision

Sentiment towards home program

Bad
Boring
Challenging
Child autonomy

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		Difficult
		Dislike
		Easier
		Fun
		Games-based
		Good
		Happy
		Hard or harder
		Helpful
		Improve
		Interesting
		Like
Future Programs	Mode	Face to face
		Group based
		Individual with therapist
		Using tech (like an APP) for games sessions
		Using tech (like an APP) for home program
	Time /timing	Afternoon
		Day
		Evening
		Holidays
		Morning
		School Term
		Weekend
	Recommend to others	Comment

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Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	Page 1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 1, starting line 19

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	Page 2, starting lines 47 - 96
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	Page 3, starting line 94

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	Page 4, starting 117
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	Page 4, line 111
<p>Context - Setting/site and salient contextual factors; rationale**</p>	Page 3, lines 99 to 101
<p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	Page 3, line 99
<p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	Page 3, starting line 102
<p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	Page 4, starting line 111

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3	Data collection instruments and technologies - Description of instruments (e.g.,	Page 3, lines
4	interview guides, questionnaires) and devices (e.g., audio recorders) used for data	106 to Page 4,
5	collection; if/how the instrument(s) changed over the course of the study	line 126.
6		
7	Units of study - Number and relevant characteristics of participants, documents,	Page 4, starting
8	or events included in the study; level of participation (could be reported in results)	line 129
9		
10	Data processing - Methods for processing data prior to and during analysis,	Page 4, lines
11	including transcription, data entry, data management and security, verification of	111 to 126
12	data integrity, data coding, and anonymization/de-identification of excerpts	
13		
14	Data analysis - Process by which inferences, themes, etc., were identified and	Page 4, lines
15	developed, including the researchers involved in data analysis; usually references a	117 to 126
16	specific paradigm or approach; rationale**	
17		
18	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness	Page 4, lines
19	and credibility of data analysis (e.g., member checking, audit trail, triangulation);	117 to 126
20	rationale**	

Results/findings

23	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and	Page 4, lines
24	themes); might include development of a theory or model, or integration with	129 to page 8,
25	prior research or theory	line 333
26		
27		Page 4, lines
28	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts,	129 to page 8,
29	photographs) to substantiate analytic findings	line 333

Discussion

33	Integration with prior work, implications, transferability, and contribution(s) to	
34	the field - Short summary of main findings; explanation of how findings and	
35	conclusions connect to, support, elaborate on, or challenge conclusions of earlier	Page 9, lines
36	scholarship; discussion of scope of application/generalizability; identification of	335 to page 11
37	unique contribution(s) to scholarship in a discipline or field	420
38		
39		Page 11, lines
40	Limitations - Trustworthiness and limitations of findings	410 to 415

Other

44	Conflicts of interest - Potential sources of influence or perceived influence on	Page 11, line
45	study conduct and conclusions; how these were managed	422 to 423
46		
47	Funding - Sources of funding and other support; role of funders in data collection,	Page 12, line
48	interpretation, and reporting	430 to 435

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

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The experiences of children with bronchiectasis and their parents in a novel play-based therapeutic exercise program: a qualitative analysis.

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Keywords: respiratory, chronic disease, pediatrics, exercise, qualitative analysis

Abstract

Objectives: To explore the experiences and perceptions of children with bronchiectasis and their parent's regarding an eight-week play-based therapeutic exercise program.

Design: Qualitative study with inductive content analysis.

Setting: Individual semi-structured interviews were conducted. Interview recordings were transcribed verbatim, and coding was guided by the content. Content categories were established via consensus moderation.

Participants: Ten parents and ten children with bronchiectasis aged 5 – 12 years.

Results: From the perspective of children, the most important components of the program were fun with friends and being active at home as a family. Parents valued the community-based sessions, perceived the program to be engaging and motivating. Parents perceived improvements in their child's endurance, coordination, and physical activity level. They described the home program as fun

31 but noted that finding time was difficult. Both parents and children thought that in-person exercise
32 sessions would be better than exercise sessions delivered online.

33 **Conclusions:** Children who participated in the play-based exercise program, found it fun, motivating
34 and accessible. Parents perceived positive impacts on fitness, coordination and physical activity.

35 Data availability statement: Deidentified data are available upon reasonable request and pending
36 ethics clearance.

37 **Strengths and limitations of this study**

- 38 • This study included children as participants who expressed unique opinions about their
39 participation in the physical activity program highlighting the importance of their inclusion in
40 research focusing on their lived experience.
- 41 • Collaborating with families and co-designing research projects is a current research priority
42 area for children and young people with bronchiectasis.
- 43 • This study had relatively small number of participants, but saturation of data was achieved
44 from the ten parent child dyads.

45 Word count 4573 (with quotes), 2910 (without quotes)

46 **INTRODUCTION**

47 Bronchiectasis unrelated to cystic fibrosis is a chronic lung disease that impacts the daily lives of
48 children, including their schooling, play, and overall wellbeing [1-4]. This pulmonary disorder is
49 diagnosed by identifying the presence of abnormal bronchial dilatation using high-resolution chest
50 computed tomography in the presence of clinical symptoms [5-7]. Children present clinically with a
51 persistent wet cough with or without shortness of breath and poor exercise tolerance [3, 6, 8]. The
52 pathology can alter mucociliary clearance creating a cycle of inflammation and infection which can
53 lead to pulmonary exacerbations [9-11]. The frequency of exacerbation is the only known predictor
54 of long term decline in lung function in children with bronchiectasis [10]. As the global prevalence of
55 bronchiectasis rises, it is recognised as an important cause of chronic respiratory disease, morbidity,
56 and healthcare utilization [12-15].

57 The management of bronchiectasis utilises a multi-disciplinary approach. In children, its goals
58 include improving quality of life, exercise tolerance and lung function whilst reducing the number of
59 exacerbations and hospitalisations [16-18]. Guidelines for the treatment and management of
60 bronchiectasis call for regular exercise, not only as a means of improving aerobic fitness and health-
61 related quality life, but as a self-management tool to reduce the frequency and severity of
62 exacerbations [17]. Yet, the available evidence indicates most children with bronchiectasis are
63 insufficiently active for health benefit with only 6% achieving the recommended 60 minutes of daily
64 moderate to vigorous physical activity (MVPA) [4].

65 Reasons for physical inactivity among children with bronchiectasis are not well understood.
66 However, developmental delays in fundamental movement skill (FMS) proficiency may be a key
67 contributing factor. In a recent study, only 17% of children with bronchiectasis achieved their age
68 equivalency for locomotor skills, while fewer than 9% achieved their age equivalency for object
69 control skills [19]. Importantly, children achieving their age equivalency for locomotor or object
70 control skills exhibited 41% higher levels of MVPA than children not achieving their age
71 equivalency. Collectively, these findings suggest that children with bronchiectasis would

substantially benefit from effective therapeutic programs that improve fundamental movement skill proficiency, promote regular physical activity and increase cardiorespiratory fitness. Yet, to date there is paucity of data on how to achieve this.

The Bronchiectasis: Exercise as Therapy Trial (BREATH) is a multi-centre randomised controlled trial (RCT) designed to evaluate the effects of a novel eight-week, play-based therapeutic exercise program on the frequency of acute exacerbations in children aged 5 to 12 years with radiologically confirmed bronchiectasis. Secondary aims are to assess the program's impact on FMS proficiency, device-measured MVPA, cardiorespiratory fitness, perceived movement competence, health-related quality of life (HR-QoL), and lung function (forced expiratory volume in one second, FEV₁) [20]. Informed by the evidence identifying FMS proficiency as a key determinant of habitual physical activity [21, 22], the program focuses on developing and enhancing children's movement competence, motivation, and aerobic fitness through developmentally appropriate, play-based activities or games tailored to the child's fitness and skill level. The program comprises a combination of supervised and unsupervised exercise therapy sessions. The supervised component consists of eight 60-minute group sessions, completed on a weekly basis, led by a clinical exercise physiologist or physiotherapist. The unsupervised component consists of a home-based, parent-led exercise program, completed two times per week (~ 20 minutes per session), during which children and family members complete two games from their most recent 60-minute supervised group session.

While the trial is focused on the primary and secondary outcomes above, it is important for the ongoing development and sustainability of the program to obtain feedback from participants and their parents/carers. Exploring parent's and children's perspectives on the program provides valuable insight into the utility of the program and drives action required for scale-up and implementation in clinical and community settings. Therefore, the objective of this study was to explore the experiences and perspectives of children with bronchiectasis, and their parents/carers, after participating in the BREATH play-based therapeutic exercise program.

METHODS

Participants

Participants for this study were children enrolled in the BREATH RCT, and their parents/carers. To be eligible, children must have been randomised to the exercise program and participated in at least one exercise session. Written informed consent was obtained from parents/guardians. Ethical approval for this study was received by the Queensland Children's Hospital Human Research Ethics Committee (HREC/19/QCHQ/56049) and NT Health (Reference Number: 2020-3847). The trial was registered with, Australian and New Zealand Clinical Trials Register (ACTRN12619001008112).

Interview guides

Separate interview guides were developed for children and parents (see Supplemental Files 1 and 2). The interview guides included questions related to the acceptability of the program, how it could be improved, and related perceptions of the supervised group exercise sessions and the supplemental unsupervised home-based exercise sessions.

Data collection

Participants completed a single interview via videoconference with a researcher (BK) not involved in the delivery of the exercise program. The child interviews were conducted with a parent present or

1
2 113 nearby. Interviews continued until no new insights were identified and key concepts became
3 114 repetitive [23] Interviews were digitally recorded, transcribed verbatim, checked for accuracy against
4 115 the original recording, and saved for subsequent analysis. The transcriptions were deidentified and
5 116 assigned a unique study identification number.

7 117 **Data analysis**

9 118 Data from the interviews were analysed using content analysis with an inductive approach [24, 25].
10 119 Transcripts were read and re-read by a member of the research team (TJ) to guide the establishment
11 120 of a codebook (see Supplemental File 3). Common phrases, words and content from the transcripts
12 121 formed an initial draft of the codebook which was subsequently reviewed and updated by the
13 122 research team (TJ, EB, KO, ST). To test the reliability of the coding scheme, two parent and two
14 123 child transcripts were randomly selected and independently coded by two researchers (TJ and EB).
15 124 Once the codebook was finalised, a member of the research team (TJ) coded the remaining child and
16 125 parent transcripts. After all transcripts were coded the initial code groupings were discussed by
17 126 members of the research team (TJ, EB, ST) and collated to form sub-categories and final content
18 127 categories [26]. Data were managed with NVivo 12 (QSR International Pty. Ltd.).

22 128 **Patient and public involvement statement**

24 129 The parents of children involved in this study initiated discussions with their respiratory physicians
25 130 regarding participation in the intervention component of the randomised controlled trial. These
26 131 physicians, who are part of the research team, recommended a post-intervention qualitative study to
27 132 investigate the experiences and perceptions of the participating families. Two parents who
28 133 participated in the intervention sessions were asked about the study's value and the potential
29 134 effectiveness of conducting interviews via videoconference. Participants were not involved in
30 135 recruitment or dissemination plans.

33 136 **RESULTS**

35 137 **Participant Characteristics**

37 138 From the 17 families eligible to participate, 10 parent-child dyads provided consent and completed
38 139 interviews. Six families could not be contacted, and one family declined due to a busy schedule.
39 140 Children were aged from five to 12 years (median age = 8.2 years, interquartile range IQR = 5.7 –
40 141 9.8). Four of the 10 children were females. All children interviewed had completed seven or eight
41 142 supervised group exercise sessions. Parent interviews ranged from 21 to 46 minutes in duration
42 143 (mean 31 ± 7.2 minutes) and child interviews ranged from 11 to 19 minutes in duration (mean $15.5 \pm$
43 144 2.5 minutes). The annual household income for families was well distributed across low to high
44 145 income and ranged from \$26,000 to over \$200,000. Parental education ranged from not finishing
45 146 high school to completing post graduate qualifications.

49 147 **Content categories: children**

50 148 Children provided perspectives on the supervised group sessions, unsupervised home-based program,
51 149 and recommendations for future programs. The final content categories were: having fun with family
52 150 and friends; being active at home as a family, and; a preference for in-person sessions. Illustrative
53 151 quotes from participants are presented below for each of the content categories.

56 152 **Fun with friends and family**

1
2 153 Children described the face-to-face group sessions and the games as fun. Children frequently talked
3 154 about specific games such as balloon tennis or hopscotch they perceived to be fun. Most children
4 155 indicated that they would like to repeat the BREATH program again.

6 156 *'I thought they were really fun, and I liked how they were different ones each*
7 157 *week and sometimes some were the same... I liked doing the hopscotch game.*
8 158 *We went outside and did this ring toss, and the rings were really heavy. I*
10 159 *liked that too.'* Ch03

12 160 *'They were fun, and they involved running around a lot and throwing and*
13 161 *kicking and stuff.'* Ch06

15 162 *'They were pretty fun... the one where I do the ball. That was really fun.'*
16 163 Ch02

18 164 Children valued having other children participate in the exercise sessions. They especially liked when
20 165 their siblings or friends participated.

22 166 *'...you can be with people that you know... (therapist) was really nice.'* Ch01

24 167 *'I wasn't alone... I could compete with my brothers.'* Ch06

26 168 *'Why was it fun? 'Because he (brother) got to do activities too and he does*
27 169 *that balloon one too...'* Ch07

29 170 *'It was a bit better because I wasn't just doing all the activities all myself.'*
31 171 Ch03

33 172 **Being active at home as a family**

34 173 Children's responses regarding the home program were brief in comparison to their conversations
35 174 about on the supervised group program. Children primarily spoke about their siblings and parents'
37 175 involvement and described the games included in the home program as fun.

39 176 *'You can play with your siblings if you're at home... Sometimes my brother*
40 177 *joined in. It was fun.'* Ch01

42 178 *'There was balloon tennis. For balloon tennis, mum and (sister). For the*
43 179 *yoga poses, dad and mum. I liked having my family involved.'* Ch09

45 180 *'Well, sometimes (brother) would do it with me and mum would sometimes do*
47 181 *a little bit and watch... Yeah, I liked it. It did get tiring for some stuff like*
48 182 *doing - like in the hallway, going up and down doing like frog jumps.'* Ch03

50 183 **In person is better than online**

51 184 Children offered suggestions for future programs regarding the mode of delivery, use of technology,
52 185 and recommendations for future programs. Most (but not all) children expressed a preference for the
53 186 supervised exercise program component to be delivered face-to-face rather than "online" or through
54 187 an exercise "app". However, for the home program, children thought technology could be useful.

57 188 *'...online, for the for the actual game sessions, no.'* Ch02

1
2 189 *'It would be kind of like strange because you couldn't really - you wouldn't*
3 190 *really be able to demonstrate too well and it's kind of glitchy.'* Ch03
4

5 191 *'Yeah, an app would be cool and useful. It would probably have like - like*
6 192 *you could like hold it in your hand and it would count how many steps you've*
7 193 *done and could somehow sense your heart rate. Just like a phone or a tablet.'*
8 194 Ch03
9

10
11 195 *'App with activities, like daily activities, and then it would have like a couple*
12 196 *of weekly.'* Ch02
13

14 197 *'You'd get to watch the activities then do them.'* Ch01
15

16 198 **Content categories: parents**

17
18 199 Parents provided perspectives on the supervised group sessions, unsupervised home-based program,
19 200 perceived impact of the program on their child, and ideas for future programs. The final emergent
20 201 themes were: an engaging and motivating program; parents' perceptions of program impact family
21 202 and friends are important; location, location, location; the home program was fun but finding the time
22 203 was hard, and; apps are fine for home, but face-to-face sessions are preferred. Illustrative quotes from
23 204 participants are presented for each content category.
24 204
25

26 205 **An engaging and motivating program**

27
28 206 Parents universally expressed positive feelings about the BREATH program. Like the children, they
29 207 thought the exercise sessions were fun and said their child enjoyed the program. Parents valued the
30 208 variety of games and activities included the program and felt that supervised exercise sessions were
31 209 well structured and organised. They perceived that the rapport with the therapist and the variety of
32 210 games motivated and engaged their children to participate in the exercise sessions.
33

34 211 *'It was all very engaging, and she really was motivated by the games because*
35 212 *the games were fun... I think that the venue that we were in was so - like*
36 213 *something that we didn't expect and just the fact that she is in this massive*
37 214 *hall full of games and equipment.'* Par04
38 214
39

40 215 *'It motivated him and got him interested in doing different things and that, so*
41 216 *I thought it was quite good. All different levels of stuff, like it wasn't just the*
42 217 *same, repetitive things, it was all different stuff... Good variety of activities as*
43 218 *well, it would be different each week, it wasn't repeating in the same sort of*
44 219 *thing each week.'* Par06
45 219
46

47 220 *'She did it very well, because I think she's loving all those activities, that's*
48 221 *why, yeah... I think all the activities basically, the whole exercise I think,*
49 222 *because she loves to play, so that's why I think she enjoyed those exercises.'*
50 223 Par08
51 223

52 224 **Perceptions of program impact**

53
54 225 Parents enthusiastically talked about the changes they observed in their child after completing
55 226 BREATH. Parents reported increased fitness and/or endurance, improved coordination, and greater
56 227 participation in physical activity.
57 227
58

1
2 228 *'When he plays baseball, he used to get really, really tired playing baseball.*
3 229 *He would be so puffed out after doing one innings of baseball and sometimes*
4 230 *he'd get that tired he'd have a meltdown because he's autistic. But now he*
5 231 *plays the whole two-and-a-half-hour game without really having a break or*
6 232 *having a meltdown.'* Par01

8
9 233 *'Especially like when his cousins come over, they will just run through and*
10 234 *around the house and up and down the house for hours on end, whereas*
11 235 *before he potentially wouldn't have done that.'* Par05

12
13 236 *'It definitely helped her coordination because now she can do hopscotch.*
14 237 *She's better at aiming with her throws now... I think it's helped her confidence*
15 238 *a little bit too actually. Yes, so even when we're just playing games on the*
16 239 *weekend and stuff like that her coordination has gotten a lot better.'* Par07

18
19 240 *'His coordination has definitely improved, like the hand eye coordination,*
20 241 *bouncing balls and hitting things with rackets. A bit of improvement there,*
21 242 *that's for sure... Just in how he plays here at home. Whereas before he'd*
22 243 *maybe get over it pretty quickly because he wasn't that great at it, he had a bit*
23 244 *more skill.'* Par02

25
26 245 *'But to do the weekly exercise program and then see the improvement in him*
27 246 *and since then it's almost like it was a – it was like a trigger for him. So, he*
28 247 *now runs better. He plays better. He throws balls. He kicks balls. He's a lot*
29 248 *more physically coordinated that he was and yeah that was probably one of*
30 249 *the big takeaways for us and something that we've continued to encourage at*
31 250 *home.'* Par05

32
33 251 *'I think she's more active now, but I didn't notice any changes but she's not*
34 252 *getting tired easily basically. So, that also help her, all those exercises.'*
35 253 *Par08*

37 254 **Family and friends are important**

39 255 Parents valued the participation of siblings and friends in BREATH. Parents said that it helped their
40 256 child feel more confident in the initial sessions and made the program more enjoyable overall.

42
43 257 *'When we were told that we could include the siblings, you know sometimes*
44 258 *people say that, but they really meant it. So, like I said, (sibling) still asks to*
45 259 *go to the sessions, her little brother. I think it just made it more fun, having*
46 260 *her sibling there.'* Par03

48
49 261 *'Participating with his siblings, he's not used to, but it got really good*
50 262 *because they become closer. Him and his brother I know are really close*
51 263 *because they're so close in age, but he got to show (sister) how to play.'*
52 264 *Par01*

53
54 265 *'It was good that there were other kids there. He liked that. I did notice that...*
55 266 *he loves social interaction, absolutely thrives off it, and if he can find a friend*

1
2 267 *and someone to play with, and someone that likes his games, he's very*
3 268 *happy.* ' Par02
4

5 269 *'I think having his sister there made it a fun family experience... (Sister)*
6 270 *loved it as well. She just – yeah, she was excited as he was to go there every*
7 271 *time. There was another little boy there who had bronchiectasis. Yeah, it*
8 272 *made it – it was almost like they saw it as a play date...it was good for them*
9 273 *all to do it, I think.* ' Par05
10
11

12 274 **Location, location, location**

13
14 275 Parents liked that the supervised exercise session were delivered in community halls. They valued the
15 276 spacious venues and the proximity to their home or their child's school.

16
17 277 *'The community centre was actually really good because I had never been*
18 278 *there before but the fact that it was all inside meant that we didn't have to*
19 279 *stop because of the rain.* ' Par07
20

21 280 *'The location is very convenient for us because it's only 15 minutes away*
22 281 *from us, so it's very convenient, I cannot complain on that one. We don't*
23 282 *need to travel far, because the option is either go to the other, I think the*
24 283 *hospital, right? Versus the community centre, I prefer the centre because I*
25 284 *know it's only 15 minutes away from our place.* ' Par08
26
27

28 285 *'...that's perfect location. It was only just up the road from us, it wasn't a big*
29 286 *push to get there. Like I finished work and got to day care to pick him up from*
30 287 *after school care and then got there generally early most days.* ' Par09
31

32 288 **The home program was fun but finding the time was hard**

33
34 289 Parents described the home-based program as fun. They liked the variety of activities and games
35 290 included and thought that the frequency and duration was appropriate. They found the instructions
36 291 helpful and easy to follow. Parents liked that the home programs could be completed with equipment
37 292 they had at home.

38
39
40 293 *'Still to this day we've got a folder where we've kept them, and I still have to*
41 294 *buy balloons because they're like balloon tennis is their favourite. They love*
42 295 *to play it, like all the time, down my hallway, everywhere.* ' Par01
43

44 296 *'I like that it gave us some of those activities and things that he did, because*
45 297 *some of them he really enjoyed in the moment. So, it was nice to actually have*
46 298 *a copy of how to do it and how to set it up and stuff like that.* ' Par02
47

48
49 299 *'They will play that game as a matter of course. So yeah – and again it's –*
50 300 *it's seeing how the strategies or the activities they were doing in class, for*
51 301 *want of a better word can be – can just become embedded at home and taking*
52 302 *five minutes to play the balloon game or taking five minutes to go downstairs*
53 303 *and kick a football around or do something. So yeah, it was good.* ' Par05
54
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56
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60

1
2 304 However, parents described some barriers to completing the home program. A few parents
3 305 acknowledged that the home program wasn't always a priority. Parents commented that lack of time
4 306 or their own lack of motivation was a barrier to doing the home exercise component.

6 307 *'We knew what we had to do. It's more home management of finding the time*
7 308 *to do it... there was nothing we disliked. It's just our innate laziness trying to*
9 309 *find times to do the things.'* Par05

11 310 *'We didn't do it as often as we should and that's because of the time... We*
12 311 *always did it once before because obviously, the day before, we were going to*
13 312 *the next session... we couldn't do it very often because it's just too much*
14 313 *other things, you know?'* Par04

16 314 *'I tried begging, I tried pleading. He's not a fan. As soon as it was called*
17 315 *homework, he was very much not interested. Even with the encouragement of*
18 316 *the stickers and the whole getting to show off the next time when we went*
19 317 *there anything. He was just yeah - he was not very interested in doing it at*
20 318 *all.'* Par02

23 319 **Apps are fine for home, but face-to-face sessions are preferred**

25 320 Parents provided feedback and suggestions in relation to the mode of delivery and use of technology.
26 321 There were strong opinions that exercise sessions delivered through a digital platform such as
27 322 telehealth would not work for their child since parent involvement was crucial. Nevertheless, parents
28 323 saw value in the use of an online platform or app for the management of the home-based exercise
29 324 program.

31 325 *'I think if it was over a Zoom call or anything like that, he would just not be*
32 326 *so engaged. So, I kind of liked the fact that it had real people.'* Par09

35 327 *'Personally, I don't think it would probably work for us...given that that's just*
36 328 *not his thing, doing it like over the phone or telehealth or whatever. Maybe*
37 329 *an app would be all right. But it'd still need that face-to-face, I think,*
38 330 *interaction, with the actual going to a group and doing that. I think it needs*
39 331 *that.'* Par02

41 332 *'Telehealth would not work ever with (child), no way. We did the dance Zoom*
42 333 *classes during the lockdowns and yeah, you know... Oh, she loses the interest*
43 334 *like you know, she can just move away herself from the situation.'* Par04

46 335 *'...maybe if you had an app or something for the older kids where they can*
47 336 *just do it on their own maybe, so they didn't have to have mum and dad there*
48 337 *or something.'* Par07

51 338 *'...if we have an app to basically listed all the exercises that we needed to do*
52 339 *for a specific day, I think that would be easier instead of the paper base.*
53 340 *Especially we're now on modern technology as well.'* Par08

55 341 **DISCUSSION**

Our study explored children's and parent's experiences and perceptions of an eight-week developmentally appropriate play-based therapeutic exercise program for children with non-cystic fibrosis bronchiectasis (BREATH program). Children and parents provided unique yet complementary perspectives about the BREATH program. Children thought that including family members and friends in the program made it more engaging. They valued being physically active at home with family members and preferred in-person exercise sessions to telehealth or online sessions. Parents expressed broader viewpoints than children. Parents described BREATH as an engaging and motivating exercise program and felt that it had visible positive impacts on their child's cardiovascular fitness, coordination level, and participation in physical activity. Like children, parents indicated a preference for face-to-face sessions over telehealth or app-based exercise programs. The community-based location and inclusion of family members and friends were considered important strengths. They described the supplemental home program as fun but acknowledged that finding time to complete the program was challenging.

The delivery of the program in readily accessible community-based venues such as council halls was highly valued by parents. Therapeutic exercise programs are typically delivered in health services, outpatient settings, or academic institutions. Thus, parents' strong endorsement of community halls as a venue for delivering the program represents an important finding. The families' preference for exercise programs delivered locally is consistent with the results of a recent qualitative study that identified supportive physical activity environments as a facilitator to physical activity in children with bronchiectasis [27]. In this present study, parents liked that the community venues were close to home or school, they felt that it was an accepted place where exercise occurs and appreciated the physical space inside the venues. Multiple systematic reviews highlight that physical environmental factors are consistently associated with physical activity [28-31]

Both children and parents thought that the inclusion of siblings and friends in the exercise sessions was fun and motivating, especially at the start of the program. These findings are consistent with the results of a recent systematic review of 26 qualitative studies exploring children's perspectives on what they like about physical activity, why it is important, and the factors that influence their physical activity [32]. Although the studies included in the review focused on healthy, typically developing children, being active with friends, and being encouraged by their friends as salient influences on children's physical activity. Being physically active with their families and parental support were also identified as important influences. In a different study, children and young people with cystic fibrosis were a subset of participants interviewed to explore their perceptions of physical activity [33]. Children with cystic fibrosis reported that they enjoyed physical activity and linked it to health benefits. Similar to the present study, they identified peers and family as enablers for physical activity. Collectively, the findings from these studies support the concept that making therapeutic exercise programs open to family members and friends is an effective strategy to increase enjoyment, engagement and support motivation.

Parents perceived that their child directly benefited from participating in the program. Parents openly talked about visible improvements in their child's endurance, level of coordination, and physical activity participation. Previous exercise studies in children with bronchiectasis tend to focus on specific activities or components of movement such sit to stand [34], balance [35] and walk testing [36]. In a different approach to activities and exercise a recent study investigated the efficacy of aerobic video game exercises and breathing video game exercises in children with bronchiectasis [37]. The parents' observations from our study reflect the goals of the BREATH program which focuses on developing and enhancing children's confidence and motivation to engage in physical activity through developmentally appropriate, play-based activities targeting aerobic fitness and

1
2 388 fundamental movement skills. The perceived improvements in coordination and endurance are
3 389 consistent with the results of the BREATH pilot RCT [22]. In this study, relative to usual care
4 390 controls, children receiving the play-based therapeutic exercise program exhibited significant
5 391 improvements in cardiovascular fitness, locomotor skills and object control skills [22]. The perceived
6 392 increase in physical activity after completing the program is consistent with the findings of a
7 393 previous study conducted in children with bronchiectasis which reported fundamental movement
8 394 skill proficiency to be associated with higher levels of daily MVPA [4]. While the empirical
9 395 evaluation of the BREATH program on frequency of exacerbations, aerobic fitness, fundamental
10 396 movement skills, physical activity, quality of life and lung function is ongoing, the findings of our
11 397 qualitative study indicates that the program is on track.

14 398 When asked to consider a hypothetical scenario where the BREATH exercise program was delivered
15 399 via the internet or smart phone, both parents and children indicated a preference for face-to-face
16 400 exercise sessions over telehealth. Digital healthcare encompasses telehealth, phone contact, text
17 401 messaging, digital applications (or apps) and is increasingly part of the healthcare landscape [38].
18 402 Unsurprisingly, there was a sharp increase in digital healthcare during the COVID-19 pandemic
19 403 which has prompted discussion as to its continued role and future innovations [39]. In the current
20 404 study, parents and children clearly expressed their preference for face-to-face exercise sessions,
21 405 citing the positive experience of engagement with other children and the therapist. Parents and
22 406 children did, however, see a role for of an app or online platform for completing the supplemental
23 407 home exercise program, which many parents described as difficult to prioritise. Families preferred an
24 408 app or mobile-health (m-health) platform that would be specifically tailored to children with
25 409 bronchiectasis. It is important to consider these preferences when designing exercise programs to
26 410 increase fitness, movement competence, and habitual physical activity in children with
27 411 bronchiectasis.

31 412 This study has both strengths and limitations. A strength of the current study is the inclusion of
32 413 children as participants. Children expressed unique opinions about their participation in the
33 414 BREATH program which highlights the importance of their inclusion in research focused on their
34 415 lived experience. Collaborating with families and co-designing research projects is a current research
35 416 priority area for children and young people with bronchiectasis [40]. The study followed established
36 417 content analysis guidelines and utilised a rigorous collaborative process to data analysis. Limitations
37 418 include, the relatively small number of participants interviewed and the omission of perspectives
38 419 from the therapists delivering the program whom could be included in future research. Children who
39 420 participated in the exercise sessions but did not participate in the interviews study may have offered
40 421 different perspectives. However, saturation of data was reached from the parent child dyads that were
41 422 interviewed and the views of the therapists were not a focus of the study.

45 423 In summary, we explored the experiences and perceptions of families who participated in an eight-
46 424 week play-based therapeutic exercise program to reduce the frequency of acute exacerbations in
47 425 children with bronchiectasis. The findings suggest that the children who participated in the BREATH
48 426 program demonstrated improvements in fitness, coordination, and physical activity participation, and
49 427 found the program fun, motivating and accessible.

52 428 **Conflict of Interest**

54 429 The authors declare that the research was conducted in the absence of any commercial or financial
55 430 relationships that could be construed as a potential conflict of interest.

1
2 431 **Author Contributions**
3

4 432 ST oversaw the design and conduct of the study. ABC, VG, GBM and TJ supported the recruitment.
5 433 BK interviewed the participants. TJ reviewed the transcripts, coded and drafted the manuscript. ST,
6 434 EB, K-AO'G, and TJ analysed the data. All (guarantor) authors had a role in informing coding and
7 435 analysis of the data collected, read, and approved the final manuscript.
8

9
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18

19
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21

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Supplemental Table 1: Interview Guide developed for children

Topic	Questions and prompts
BREATH exercise program questions	<p>You did the BREATH program at (<i>interest location</i>). You were joined by (<i>insert siblings, friends</i>).</p> <ul style="list-style-type: none"> • Tell me what you thought about the games and activities? <ul style="list-style-type: none"> ○ What did you like about the games/activities? Why? ○ What parts did you think were fun? ○ What didn't you like about the program? Why? ○ What parts did you think were boring? ○ What would you change? • What did you think about how long each session went for? • What did you think about the having the sessions at (<i>insert location</i>)? • What was it like having your (friend/sibling there)? • Have you noticed any changes to the way your body feels or moves since doing the exercise program? <ul style="list-style-type: none"> ○ What are those changes? • Have you noticed that it is easier or harder to keep up with your friends when you are playing? • Do you get tired when you are playing or running around? <ul style="list-style-type: none"> ○ Did this tiredness change after you did the games/exercise program?
Home activity program	<ul style="list-style-type: none"> • What did you think about the home programs? <ul style="list-style-type: none"> ○ What did you like about your home programs? ○ What was fun? ○ What didn't you like about the home programs? ○ What was boring? ○ What did you think about the types of activities? ○ What did you think about how long your home activities went for? • What would you change about the home programs? • Who did the home programs with you? <ul style="list-style-type: none"> ○ What was that like? ○ How many times a week did you do the home activities? • Would it be helpful to have an app or other online support? <ul style="list-style-type: none"> ○ What would that look like?
Future programs	<ul style="list-style-type: none"> • Would you do the games and exercise program again? • Would you recommend that other children do the games/ activity sessions? <ul style="list-style-type: none"> ○ Can you tell my why/why not? • >10yo: How do you feel an ideal program would be delivered? <ul style="list-style-type: none"> ○ Group sessions, one-on-one, home-based, combination, remote, online coaching, apps

- Would you recommend that friends/siblings be included
- Timing. Before or after school, on the weekends, or in the holidays?
- Frequency. More/less than once a week
- Types of activities
- Setting. At home, in the community, at a health centre.

- <10yo: Would you do the BREATH program again? Would you want to try anything different?
- >10yo: Do you have any thoughts how this would work if we delivered this online via a smart phone or iPad?

Sweeping
question

Is there anything else you would like to add before we finish?

Supplemental Table 2: Interview Guide developed for parents

Topic	Questions and prompts
BREATH exercise program questions	<p>Your child participated in the bronchiectasis research project that included games/exercise sessions at (<i>interest location</i>). They were joined by (<i>insert siblings, friends</i>).</p> <ul style="list-style-type: none"> • Tell me what you thought about the BREATH program? <ul style="list-style-type: none"> ○ What did you like about the program? ○ What could we have done better? • What did you think about the types of activities? • What did you think about the length of each session? (<i>approx. 1hr</i>) • What did you think about the length of the whole program? (<i>8 weeks</i>) • What did you think about the location? • How did your child feel about participating in the exercise program? <ul style="list-style-type: none"> ○ What did they like? ○ What did they dislike? ○ What parts of the sessions did your child find easy? ○ What parts of the sessions did your child find hard or difficult? • Have you noticed any changes in your child's movement skills or coordination level? <ul style="list-style-type: none"> ○ What type of changes in movement skills or coordination did you observe? ○ Did they improve? Did they stay the same? Did they decline? • Have you noticed any changes in their fitness since participating in the games/exercise sessions? <ul style="list-style-type: none"> ○ Did their fitness improve? Did it stay the same? Did their fitness decline? • Is there any change to their tiredness or fatigue? <ul style="list-style-type: none"> ○ Do they become more fatigued with physical activity? No change? Less fatigued with physical activity? • The BREATH program is designed to include siblings, friends or other children with bronchiectasis. Describe how the inclusion of other children influenced your child?
Home activity program	<ul style="list-style-type: none"> • What did your home program sessions look like? <ul style="list-style-type: none"> ○ Who was usually involved in the home games and activities? ○ Did you use any particular strategies to manage the home program (e.g. sibling and parent involvement, supervision, competition, rewards, music)? • What did you think about the home programs? <ul style="list-style-type: none"> ○ What did you like about the home program? ○ What did you dislike about the home program?

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Future programs

- What did you think about the length of each home program?
- What did you think about how often you were asked to do the home program?
- What did you think about the types of activities?
- Was it difficult to motivate you child to do the home program? If so, in what way?
- What did you think about the paper handouts you were provided for the home program?
- How often did you do the home program?
- Describe what you think would be an ideal program.
 - Group sessions, one-on-one, home-based, combination, remote, online coaching, apps
 - Timing. Would BREATH be suited closer to the diagnosis of bronchiectasis.
 - Frequency. More/less than once a week
 - Length of program, is 8 weeks, too long, too short or the right about of time?
 - Types of activities
 - Setting. At home, in the community, at a health centre.
 - Timing. Before or after school, on the weekends, or in the holidays?
- Do you have any thoughts how this would work if we delivered over the internet or smart phone app?
- Would a program like BREATH be valuable for other children with bronchiectasis?

Sweeping question

Do you have any other comments you would like to add before we finish?

Supplemental Table 3: Codebook to support content analysis of child and parent interview

Topic	Topic Sub Grouping	Initial Code
BREATH Program	Location	Community
		Home
		Hospital
		Inside
		Other location
		Outside
		Proximity (to home/school)
		Research Centre
		School
		Travel time
	Feelings about program	Adaptable
		Bad
		Boring
		Challenging
		Difficult
		Dislike
		Easier
		Fun / enjoyment
		Games-based
		Good
		Happy
		Hard or harder
		Helpful
		Improve
		Individualised
		Interesting
		Like
		Play- based
		Rapport (therapist, or others at sessions)
		Social / socialise
	Structured	
	Variety	
	Logistics	Communication therapist
		Communication written
		Equipment support
		Organisation
Support People	Child	
	Friend	
	Parent	
	Sibling	
	Therapist	
Timing of diagnosis	Other people (not listed above)	
	Appropriate as was	
	Prefer closer to diagnosis	
	Prefer further from diagnosis	

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4	Changes in		
5	participant	Symptoms	Breathless
6			Coughing
7			Tired / fatigue / exhausted
8		Other changes	Ability
9			Confidence
10			Co-ordination
11			Fitness
12			Motivation
13			No change
14			Participation
15			Reducing Medicine
16			Skills- balance
17			Skills- ball
18			Skills- exercise (and activities)
19			Skills- jumping
20			Skills- Play
21			Skills- running
22			Skills- throwing
23			Tried (or trying)
24			
25			
26	Duration and		
27	Frequency		
28	BREATH	Frequency F2F Sessions	Appropriate as was
29			Prefer more frequent
30			Prefer less frequent
31		Duration of F2F sessions	Appropriate as was
32			Prefer longer
33			Prefer shorter
34		Duration of BREATH program	Appropriate as was
35			Prefer longer
36			Prefer shorter
37		Frequency of home sessions	Appropriate as was
38	Home program		Prefer more frequent
39			Prefer less frequent
40		Duration of home sessions	Appropriate as was
41			Prefer longer
42			Prefer shorter
43		Management of home program	Competition
44			Equipment
45			Parent involvement
46			Reminders
47			Rewards
48			Sibling involvement
49			Supervision
50		Sentiment towards home	
51		program	Bad
52			Boring
53			Challenging
54			Child autonomy
55			Difficult
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		Dislike
		Easier
		Fun
		Games-based
		Good
		Happy
		Hard or harder
		Helpful
		Improve
		Interesting
		Like
Future Programs	Mode	Face to face
		Group based
		Individual with therapist
		Using tech (like an APP) for games sessions
		Using tech (like an APP) for home program
	Time /timing	Afternoon
		Day
		Evening
		Holidays
		Morning
		School Term
		Weekend
	Recommend to others	Comment

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Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 1, starting line 19

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 2, starting lines 47 - 96
Purpose or research question - Purpose of the study and specific objectives or questions	Page 3, starting line 94

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Page 4, starting 117
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 4, lines 111 - 112
Context - Setting/site and salient contextual factors; rationale**	Page 3, lines 99 to 101
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 3, lines 99 to 101
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 3, starting line 101
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 3, starting line 111

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 3, lines 106 to Page 4, line 127.
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 4, starting line 129
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 4, lines 111 to 127
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 4, lines 117 to 127
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 4, lines 117 to 127

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 4, lines 147 to page 9, line 340
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Page 4, lines 147 to page 9, line 340

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Page 10, lines 342 to page 11 422
Limitations - Trustworthiness and limitations of findings	Page 11, lines 418 to 422

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 11, lines 418 to 422
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 12, lines 437 to 442

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:
O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

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