1	Promotion of physical activity for adolescents with
2	cystic fibrosis: A qualitative study of UK multi-
3	disciplinary cystic fibrosis teams
4 5	¹ Denford, S., ² Mackintosh, K., ² McNarry, M., ¹ Barker, A.R., ¹ Williams, C.A.; on behalf of the Active Youth Unlimited Group
6 7	¹ Children's Health and Exercise Research Centre, Sport and Health Science, University of Exeter, St Lukes Campus, Exeter, Devon, UK
8	² Sports Science, University of Swansea, Bay Campus, Swansea, UK
9	Corresponding author
10	
11	Dr Sarah Denford
12	Children's Health and Exercise Research Centre
13	St Luke's Campus
14	Baring Court
15	University of Exeter St Lukes Campus
16	Heavitree Road
17	Exeter EX12LU
18	Email: <u>S.Denford@exeter.ac.uk</u>
19	Phone: 01392 725906
20	Word count: 3048

Abstract

22	Background
~~	Duckground

- 23 The Cystic Fibrosis Trust recently published a standards of care document which stated that patients
- 24 should be given a physical activity (PA) programme based on their motivations, fitness, and
- 25 willingness to be active. However, there remains much debate regarding the roles and
- 26 responsibilities for PA promotion, as well as "optimal" recommendations and advice. This study
- 27 aimed to qualitatively explore cystic fibrosis (CF) multidisciplinary teams (MDTs) advice,
- 28 recommendations and practices relating to PA promotion for adolescents with CF.
- 29 Method
- 30 Semi-structured interviews were conducted with fifteen members of CF MDTs (11 physiotherapists,
- 31 two dieticians and two paediatricians). Thematic analysis was used to analyse the data.
- 32 Results
- 33 Major themes identified were: 1) structure of MDTs, 2) recommendations relating to intensities,
- 34 durations and types of PA, and 3) use of exercise testing. Participants reported variation between
- 35 MDTs in terms of who is responsible for promoting and supporting PA, the nature of advice given to
- 36 patients, and the use of exercise testing. Participants consistently lacked confidence in their own or
- 37 others' knowledge to provide standardised recommendations to patients and highlighted that PA
- 38 promotion and support was often overlooked during busy periods.
- 39 Conclusions
- 40 Despite its importance, PA support and promotion is not always prioritised. MDTs lack confidence in
- 41 their ability to promote PA. Standardised advice and training relating to optimal intensities,
- 42 durations and types of PA would provide a baseline from which to individualise advice to each
- 43 patient and could increase confidence in PA promotion among MDTs.

44 Contribution of the paper

- There is a significant lack of confidence among clinical team members in their ability to
- 46 effectively promote physical activity for people with cystic fibrosis.
- Despite the importance of exercise testing and physical activity, its promotion is often
- 48 neglected as a result of factors that could potentially be overcome.
- This study is the first to provide evidence of the urgent need for training and resources to
- 50 support clinical teams promote physical activity.
- 51
- 52 Key words
- 53 Cystic fibrosis; respiratory; youth; qualitative; physical activity; exercise

54 Background

Physical activity (PA) [1, 2] and exercise [3, 4] is widely advocated for adolescents with cystic fibrosis 55 56 (CF). Patients and members of CF multidisciplinary teams (MDTs) consider PA to be a priority in the 57 management of CF [5, 6], recognising both its physiological and psychosocial benefits. Whilst studies 58 have sought to identify whether youth's PA levels differ to age- and sex-matched controls, findings 59 remain equivocal. Indeed, research has identified those with CF to have lower [7], equivalent [8, 9] 60 or even higher [10] PA levels than their healthy counterparts. Given this lack of consensus, it is 61 unsurprising that there also remains debate about optimal intensities, durations and types of PA in 62 adolescents with CF [4].

63 The Cystic Fibrosis Trust recently published a standards of care document which stated that all 64 patients should be made aware of the benefits of PA and/or exercise, and should be prescribed a 65 programme based on their motivations, fitness, and willingness to be active [11]. Recommendations 66 state that patients should be advised to participate in at least 150 minutes of moderate-intensity PA, 67 or 75 minutes of vigorous-intensity PA each week, with resistance training on two or more non-68 consecutive days [11]. The importance of exercise testing for patients over the age of 10 years is also 69 emphasised. Specifically, exercise testing is advocated as an invaluable assessment tool, which can 70 be used to identify PA limitations, aid in disease prognosis, and inform and assess the efficacy of PA 71 prescriptions [11]. The cardiopulmonary exercise test (CPET) is considered the "gold standard" 72 exercise test. However, whilst there are specific recommendations for those with CF these are 73 targeted at adults and there are therefore, no specific recommendations for adolescents with CF. 74 Despite the recognition of the importance of PA, in 2010 a survey of 96 adult and paediatric clinics 75 in the UK found that PA and exercise assessments are currently under-utilised in clinics [5] due to 76 limited time, staff, facilities and equipment. More recently, previous research presenting findings 77 from a series of meetings involving healthcare professionals with an interest in PA for CF found 78 that, even among such a motivated and interested group, over 30% of delegates did not feel

79	confident discussing PA with patients, only 13% of centres used CPET, and 100% of delegates wanted
80	additional resources and training relating to PA promotion [12]. Further consideration of these
81	issues are crucial to enable clinical staff to have the skills, and confidence needed to support patients
82	to be physically active.

83 Aims

The aim of this study was to qualitatively explore the advice, recommendations and practices of
members of CF MDTs relating to PA for adolescents with CF.

86 Methods

87 Design

In this exploratory study, we used in-depth interviews to explore the advice and recommendations
of MDTs current practice with regard to PA promotion for adolescents with CF.

90 Participant sampling and data collection

91 Participants were recruited via opportunity sampling; physiotherapists, paediatricians, dieticians, 92 and nurses currently on the Cystic Fibrosis Trust email distribution list received an email inviting 93 them to take part in a short telephone interview. Fifteen participants responded to the invitation 94 and provided written informed consent, including eleven physiotherapists (9 female), two 95 consultants (both male) and two dieticians (both female). Using a semi-structured topic guide, 96 participants were asked about their practices relating to PA promotion and exercise testing for 97 adolescents (young people between the ages of 12 and 18 years of age). Participants were asked to 98 think specifically about their practices in relation to this age group (Supplement 1). All interviews 99 were audio recorded and transcribed verbatim. Ethical approval was obtained from the Institutional 100 Ethics Committee (161207/A/03).

101 Data analysis

102 Thematic analysis was used to analyse the data [13] using the software NVivo version 12. After 103 reading and becoming familiar with the transcripts, an initial list of codes were developed 104 independently by two researchers (author one and two). These authors then discussed their 105 independent coding until a consensus was reached, and combined related codes into a series of 106 themes. These themes were then presented to a third author (author 3) who ensured that the 107 themes accurately represent the interview data [14]. Following the six stages of thematic analysis 108 [13], thematic charts were developed for each theme, and corresponding interview text was cut and 109 pasted into each chart [14]. Narratives were developed utilizing these charts [15]. Potential links 110 between the data and existing theories were sought and noted [16]. We actively looked for data that 111 did not fit with our developing narrative, discussed potential explanations, and modified the 112 narrative accordingly. All emerging ideas were noted in the form of a reflective diary. 113 To ensure the validity of our findings, codes, themes and analyses were discussed with the wider 114 research team on multiple occasions [16]. All participants were given the opportunity to comment on the results with four participants responding. All four respondents noted that they were in 115 116 agreement with our presentation of the data. Whilst it is possible that the analysis could have been 117 influenced by our prior training and awareness of the literature, we were conscious of our pre-118 existing knowledge, and every effort was made to ensure that the code and / or the theme were 119 evident in the raw data set.

120 Results

121 Participants

Fifteen (11 physiotherapists, two consultants, and two dieticians) from 15 cystic fibrosis clinics in the
 UK took part in semi-structured interviews with the lead author. Our sample includes male and
 female participants from a wide range of locations in the UK and professional backgrounds. Eleven

participants were from paediatric centres, and four participants worked with both adult andpaediatric patients.

127 Results of the analysis

Results are presented under three headings: i) structure of MDTs; ii) recommendations relating to
intensities, durations and types of PA; and iii) use of exercise testing.

130 Structure of MDTs

- 131 Multidisciplinary teams varied in size and structure, knowledge and passion for the promotion of PA,
- and the roles and responsibilities of each team member with regard to PA promotion (<u>Table 1</u>).
- 133 Whilst the majority of participants reported that the main responsibility for PA promotion lay with
- the physiotherapists, it was considered to be a task for all members of the team. Physiotherapists

135 were viewed as having the time and knowledge to accommodate specific PA issues – but everyone

- should be promoting it (Quote 1). However, even physiotherapist's struggle to fit PA promotion into
- their day, and during busy periods, certain clinical activities (e.g., those focusing on PA promotion)
- 138 would have to be cancelled (Quote 2-5).
- All participants highlighted the need for additional support with at least one person whose time and
- 140 energy could be dedicated to PA promotion. Three of the 15 centres currently had a member of staff
- 141 who was employed specifically to support PA among patients. Such a role was considered to be
- invaluable and a huge benefit to the team and the patients (Quote 6), and the centres without such
- a role described how this would be beneficial (Quote 7).
- 144 Whilst all participants in the current study spoke of their passion for PA, it was recognised that not
- all team members were as knowledgeable or as passionate. This was considered critical for
- successful PA promotion, and it was suggested that those with an exercise background, or personal
- 147 interest in PA, were better placed to promote PA than those who did not have such a background
- 148 (Quote 8-9).

149 Recommendations relating to intensities, durations and types of PA

150 Participants described how they are required to make recommendations in relation to various 151 aspects of PA, including type, intensity, frequency and duration, and dealing with infection control 152 (Table 2). In making such recommendations, some physiotherapists referred to guidelines written for 153 people without chronic conditions, such as physiotherapy guidelines (Quote 1). None of our 154 participants were aware of existing guidelines that are specific to people with CF (Quote 2-3). 155 As a result, participants' specific recommendations (i.e., intensity, frequency and duration) of PA 156 varied – both between participants, and within participants for different patients. Although the 157 difference between PA and exercise was not always explicitly mentioned, there was recognition that 158 for some patients, PA was more appropriate than exercise. However, most importantly, 159 recommendations were always individualised to the patient taking into consideration their needs 160 and preferences. 161 Participants' recommendations relating to the intensity and duration of PA sessions were based on 162 maximum heart rate (Quote 4); levels of intensity (Quote 5); and degrees of breathlessness (Quote 163 6). Recommendations relating to duration of PA sessions included a minimum duration (Quote 7), specific targets (Quote 8); and upper and lower limits (Quote 9). However, participants noted that 164 165 any recommendations should be dependent on baseline PA levels (Quote 10). 166 In terms of types of PA, a combination of cardiovascular, strength and flexibility training was 167 considered optimal (Quote 11). Specific activities, such as running, yoga, Pilates, Zumba, 168 trampolining and walking the dog were all mentioned (Quote 12) as examples of activities that could 169 be performed by young people with CF. Such examples were intended to highlight the range of 170 activities available to young people rather than being an exhaustive list of all activities endorsed by 171 the team. The majority of the participants (13 of 15) did not feel that there were any limitations to 172 what participants could do. Only two participants mentioned any caution and these related to high-

intensity interval training (HIIT) and plyometric training (Quote 13-14). These cautions were based
on clinical experience rather than formal recommendations.

175 It was noted that recommendations should be individualised on the basis of PA goals or simply in 176 terms of what the patient enjoys doing. Very few participants explicitly mentioned the difference 177 between PA and exercise, however, those who were aware of the distinction suggested that, for 178 some patients, PA may be a more realistic option. Other participants alluded to this without 179 explicitly referring to PA rather than exercise, and just promoted moving more (Quote 15). 180 Ultimately, it was noted that the needs and preferences of the patient are crucial - even if they are 181 not considered to be optimal (Quote 16). 182 Use of exercise testing 183 Exercise testing was viewed as positive, but the type of test used, the interpretation of the results, and the way in which the results were used to inform treatment varied between clinics (Table 3). 184

185 Participants referred to the importance of exercise testing for informing exercise plans and for

prognostic purposes (Quote 1). Three or six minute step tests were commonly used (Quote 2),

187 though these were considered to be sub-optimal in comparison with cardiopulmonary exercise

188 testing (CPET), which was considered to be gold standard (Quote 3).

189 Common barriers and limitations to exercise testing included patient refusal (Quote 4), the test not

assessing maximal capacity (Quote 5), and space and time limitations (Quote 6). Interpretation of

191 test results was often confusing, with many participants unsure what a specific result meant (Quote

192 <u>7).</u>

193 There was considerable variation in the way in which the test results were used. In one centre,

194 exercise test results formed the basis of exercise programs (Quote 8), other centres used the results

to provide achievable goals (Quote 9), and other centres would simply keep test scores on record

196 (Quote 10). One participant verbalised this variance, highlighting that better knowledge of how to

197 use results of an exercise test is necessary (Quote 11).

198 Discussion

199 This is the first study to explore, in-depth, the practices, advice and recommendations of members 200 of MDTs relating to PA and exercise testing for youth with CF. Our findings complement and extend 201 previous work that has explored the use of exercise testing [5] and PA promotion [12] by presenting 202 detailed information on challenges faced by MDTs, as well as highlighting areas in which additional 203 training and support is urgently needed. This study provides urgently needed evidence that action 204 must to be taken to ensure physical activity recommendations are informed by evidence and 205 guidelines, and that staff feel confident in the recommendations they provide. Multi-disciplinary teams 206 207 Whilst the majority of participants acknowledged that PA promotion was considered to be a whole 208 team role, in accord with previous research [5, 12] there was recognition that it was largely 209 undertaken by the physiotherapists. However, participants described that their time-constraints and 210 work-load often leave them at full capacity, and PA sessions are consequently sacrificed. Tomlinson 211 et al. [12] highlighted a range of highly-skilled tasks undertaken by MDTs in relation to PA promotion 212 - above and beyond physiotherapy duties. Not only does this take considerable time, it also requires 213 significant knowledge and training. The current study concurs with Tomlinson et al. [12] suggesting 214 that physiotherapists do not feel confident to promote PA. Within the current study, it was 215 suggested that those with an exercise background, or personal interest in PA were better placed to 216 promote PA than those who did not have such a background. Participants suggested that patients 217 would benefit if MDTs incorporated an exercise specialist tasked solely with the promotion and 218 prescription of PA for patients. Nonetheless, funding restrictions and limited budgets mean that

219 developing such a role may not be possible; however, at the very least, protected time and adequate

training is required for such a role to be carried out efficiently.

221 Recommendations

222 The Cystic Fibrosis Trust Standards of Care and Good Clinical Practice for the Management of CF [11] 223 state that, for individuals with CF, recommendations should include 150 minutes of moderate-224 intensity PA, or 75 minutes of vigorous-intensity PA per week. Those who are inactive and/or are 225 limited in their physical capacity to exercise should be encouraged to accumulate 10-minute bouts of 226 PA throughout the day [11]. It should be noted that this generic guideline is based on adult PA 227 recommendations with no differences for paediatric patients. However, healthy children and 228 adolescents have different guideline compare to adults. This distinction should be recognised by the 229 CF community. 230 Whilst participants in the current study did not specifically mention the Cystic Fibrosis Trust 231 standards of care, their advice and recommendations given were complimentary, although variation 232 between centres exists. This may suggest that certain members of MDTs are not aware of the advice 233 relating to PA in the standards of care, particularly members of the team who are not 234 physiotherapists. Therefore, informing or educating members of MDTs of this advice may be

234 physiotherapists. Therefore, informing or educating members of MDTs of this advice may be235 beneficial.

236 Participants' suggested intensities for physical activity were significantly varied. In line with the 237 standards of care recommendations, participants highlighted the relationship between intensity and 238 duration, noting that higher-intensity PA should be of a shorter duration. However, 239 recommendations for an "optimal" duration of PA ranged from thirty minutes per day to one hour 240 per day, and from three sessions per week to two and a half to five hours per week. Whilst specific 241 advice relating to the type, intensity, and duration of PA were slightly different between clinics, in 242 line with the Trust's Standards of Care [11], all participants described the need to consider patients' motivations and goals, circumstances, fitness, and willingness to be active when prescribing PA. 243 244 Consideration of enjoyment is essential for long-term, sustainable PA behaviour change [17], as well

as having an impact on patient's quality of life. Indeed, pleasurable PA with family members or peersis likely to lead to greater satisfaction and feelings of normalcy [18].

Participants recommended a range of strength, cardiovascular and flexibility work. In line with the
Cystic Fibrosis Trust Standard of Care [11], Yoga and Pilates was also considered to be useful.
Participants were cautious about the use of HIIT, suggesting that this should only be recommended
for those with a certain level of fitness. Plyometric training was also avoided. As some studies have
demonstrated positive effects of HIIT in CF [19, 20], further research into the relative benefits of
such training for certain patients may be beneficial.

253 Our study is the first to show that participants have individual understanding of what "optimal" PA 254 recommendations comprise; however, all participants acknowledge the need to tailor PA programs 255 to the individual patient. However, participants were aware of the futility of recommending 256 "optimal" PA programmes, particularly for participants not at all interested in PA. This is often an 257 obstacle to progress; too much emphasis is often placed on the "best" training program and is likely 258 to hinder the patient who is aiming simply to be more active. Whilst identifying the best way to 259 optimise health from PA is important, this is not useful for patients who are not willing or able to 260 achieve the level of PA needed. It is arguably more important to prescribe PA that patients can and 261 will achieve over what is optimal.

262 Our findings show that there is an element of uncertainty surrounding the recommended intensity 263 and duration of PA for people with CF. Whilst standards do exist [11], the quality of evidence is rated 264 low-to-moderate, indicating that further research is needed to standardise PA advice and 265 recommendations [2, 4]. Additional training for members of the MDTs is clearly required to enhance 266 confidence in prescribing and discussing PA with patients, as well as combining "optimal" 267 recommendations with patients' individual motivations and circumstances. Initiatives such as 268 "Exercise is Medicine", and the growing enthusiasm for broadening medical curriculum have made 269 substantial progress in addressing some of these issues and building necessary skills [21].

270 Exercise testing

271 Previous research found that, whilst MDTs valued the use of exercise testing, it was often under-272 utilised, with less than 40% and 30% of paediatric and adult patients, respectively, having had an 273 exercise test in the past 12 months [5, 12]. Whilst the majority of participants in the current study 274 reported using exercise testing with their patients, the type of test, interpretation and use of the 275 results differed between centres. The three and six-minute step test and the modified shuttle test 276 were reported by participants as standard practice, but the CPET was considered to be gold-standard 277 despite only being used by a small number of MDTs. Participants stated time, space, and patient 278 refusal were the biggest barriers to exercise testing, thereby highlighting the need for specific time 279 to be allocated to this annual test. Moreover, MDTs often lacked a comprehensive understanding of 280 the results of the exercise tests and were therefore limited in how they utilised them to inform 281 patient-specific treatment, likely exacerbating patient refusals as the merit of the tests was not 282 evident. In the majority of cases, test results were stored and used as a comparator for future test 283 results. Indeed, participants highlighted the need for normative data in both healthy and CF peers to 284 facilitate comparisons and goal-setting strategies for their younger participants. These findings not 285 only indicate that further training is required for MDTs in relation to how data from all exercise tests 286 are interpreted and used within clinics, but also for the need for further research to provide 287 reference data. This is crucial if the use of exercise testing within clinics is to be maximised [12].

288 Implications for policy and practice

Our study has a number of implications for policy and practice. First, our study highlights the need for the development of standardised recommendations relating to PA promotion for young people with CF. This would include evidence-based advice relating to the type, intensity, and frequency of PA for young people with CF, as well as recommendations for supporting PA behaviour change in this population. Second, training is required to ensure clinical teams are familiar with, and confident in their ability to adhere to, the recommendations. Third, considerable investment will be needed to

ensure clinical teams have the time and funding to dedicate to the promotion of this critical aspect
of treatment. Finally, additional training and support is required to ensure consistency in the
conduct, interpretation, and use of exercise testing.

298 Strengths and limitations

299 A key strength of the study is the use of qualitative methods to provide a rich account of MDTs 300 current practices with regard to PA promotion, and the challenge they face. To enhance the 301 trustworthiness of our study, we used multiple coders and asked respondents to validate our 302 findings. During analysis, we triangulated our emerging results and the existing literature. However, 303 our findings must be interpreted with a number of limitations in mind. First, our study was based on 304 a small sample of 15 participants (11 physios, 2 doctors and 2 dieticians). As this is not fully 305 representative of a UK cystic fibrosis clinic, relevant voices (e.g., nurses, exercise specialists etc) may 306 have been missed. Secondly, all participants were from UK hospitals, thus may reduce the 307 transferability of the results beyond this area. Furthermore, our use of opportunity sampling may 308 have led to a biased sample of people who were interested in PA. Whilst there was still considerable 309 variation in the practices, advice and recommendations given by our participants, we suggest that 310 the richness of the data could have been improved with the inclusion of additional teams members; 311 including those less enthusiastic about PA promotion. Potentially important information about the 312 barriers to PA promotion could have been missed from those who chose not to participate; thus 313 additional research and training is needed.

314 Conclusion

Despite the known importance of PA and exercise testing, both are often under-utilised in CF clinics. The present study shows that MDTs vary greatly in terms of who is responsible for PA promotion, the advice and recommendations that are given to patients, and how exercise tests are used and interpreted. Although physiotherapy standards exist [11], their relevance to adolescents is unclear.

- 319 Our findings highlight the need for changes to both policy and practice, with further training
- 320 required for those responsible for PA promotion in individuals with CF, in order to develop standards
- 321 of care that are widely accepted for this specific population.

- 323 Acknowledgements
- 324 We would like to thank the Cystic Fibrosis Trust for funding this study. We would also like to thank
- 325 all the practitioners who volunteered their valuable time to participate in this study.
- 326 Ethical approval
- 327 Ethical approval was provided by the University of Exeter Sport and Health Science Ethics Committee
- 328 (161207/A/03).
- 329 Funding
- 330 This work was funded by the Cystic Fibrosis Trust. Grant number SRC 008.
- 331 Conflict of interest statement
- 332 The authors declare no conflict of interest

- 334[1]Hebestreit, H., et al., Quality of life is associated with physical activity and fitness in cystic
- *fibrosis.* BMC Pulmonary Medicine, 2014. **14**: p. 26.
- Bradley, J., Moran, F, *Physical training for Cystic Fibrosis*. Cochrane Databse of Systematic
 Reviews, 2008. 23(1): p. CD002768.
- 338 [3] Radtke, T.B., C; Kriemler, S, *Physical Activity and Exercise Training in Lung Transplant*
- 339 Recipients with Cystic Fibrosis: 'What We Know, What We Don't Know and Where to Go'.
- 340 Lung, 2016. **194**(1): p. 177-8.
- Radtke. T; Nolan, S.J.H., H; Kriemler S, *Physical exercise training for cystic fibrosis* Pediatric
 Respiritory Review 2016. **19**: p. 42-45.
- 343 [5] Stevens, D., et al., *A survey of exercise testing and training in UK cystic fibrosis clinics*. Journal
 344 of Cystic Fibrosis, 2010. 9(5): p. 302-6.
- Rowbotham, N., et al., *Question CF: A James Lind Alliance Priority Setting Partnership in cystic fibrosis.* Journal of Cystic Fibrosis, 2017. 16(Supplement 1): p. S38.
- 347 [7] Nixon, P.A., D.M. Orenstein, and S.F. Kelsey, *Habitual physical activity in children and*
- 348 *adolescents with cystic fibrosis.* Medicine and Science in Sports and Exercise, 2001. **33**(1): p.
 349 30-35.
- Britto, M.T., et al., *Comparison of physical activity in adolescents with cystic fibrosis versus age-matched controls*. Pediatric Pulmonology, 2000. **30**(2): p. 86-91.
- 352 [9] Mackintosh, K.A., et al., *Physical Activity and Sedentary Time Patterns in Children and*
- 353 Adolescents With Cystic Fibrosis and Age- and Sex-Matched Healthy Controls. Journal of
- 354 Physical Activity and Health, 2018. **15**(2): p. 82-88.
- 355 [10] Selvadurai, H.C., et al., Gender differences in habitual activity in children with cystic fibrosis.
- 356 Archives of Disease in Childhood, 2004. **89**(10): p. 928-33.
- 357 [11] Cystic Fibrosis Trust., *Standards of care and good clinical practice for the physiotherapy*
- 358 *management of cystic fibrosis. Third edition.* 2017, The Cystic Fibrosis Trust.

- 359 [12] Tomlinson, O.S., J; Denford, S; Barker, A; Oades, P; Williams, C, Promotion of exercise in the
- 360 management of cystic fibrosis Summary of national meetings. European Journal for Person
 361 Centered Healthcare, 2018. 6 (2): .
- 362 [13] Braun, V. and V. Clarke, What can "thematic analysis" offer health and wellbeing
- 363 *researchers?* International Journal of Qualitative Studies on Health and Well-Being, 2014. 9.
- 364 [14] Miles, M.B., & Huberman, A.M, *Qualitative Data Analysis: An expanded source book, 2nd* 365 *edition* 1994, Thousand Oaks: Sage Publications
- Ritchie, J. and L. Spencer, *Qualitative data analysis for applied policy research*. The
 qualitative researcher's companion, 2002. 573: p. 305-329.
- 368 [16] Yardley, L., *Dilemmas in qualitative health research*. Psychology & Health, 2000. 15(2): p.
 369 215-228.
- 370 [17] Segar, M.L., Guerin, E., Phillips, E., Fortier, M, *From a vital sign to vitality: Selling exercise so*371 *patients want to buy it.* Translational Journal of the American College of Sports Medicine,
 372 2016. 1(11): p. 97-102.
- Fereday J; MacDougall, C.S., M; Darbyshire, P; Schiller, W., "There's nothing I can't do--I just
 put my mind to anything and I can do it": a qualitative analysis of how children with chronic
- 375 *disease and their parents account for and manage physical activity* BMC Pediatric 2009.
- **1**(9): p. 1.
- 377 [19] Gruber, W.O., D.M; Braumann, K.M; Beneke, R, Interval exercise training in cystic fibrosis -
- 378 *effects on exercise capacity in severely affected adults.* Journal of Cystic Fibrosis, 2014. **13**(1):
- p. 86-91.
- 380 [20] Cox, N., et al., *Exercise assessment and training in cystic fibrosis: Can less achieve more?*381 Journal of Cystic Fibrosis, 2017. 16(6): p. 649-650.
- 382 [21] Cheng, S., et al., *Physical activity continuum throughout the lifespan: Is exercise medicine or*383 *what?* Journal of Sport and Health Science, 2016. 5(2): p. 127-128.

385 Table 1: Structure of MDTs

Quote 1	"I think all of us should be, in the CF team. I think the Physio's are the main ones with
	their experience and the time to hopefully to be seeing these patients for exercise but I
	think all of the team have a role to play to discuss activity with their patients" (Female
	Physiotherapist).
Quote 2	"We try and do three exercise sessions a week, but we've got a hundred and fifty children
	so it's not enough. It works out that we're doing an exercise session once every three or
	four months with someone"(Female physiotherapist)
Quote 3	<i>"It's not just the initial promotion, it's the continuing support for that. And we just don't</i>
	have the time"(Male Consultant)
Quote 4	"Our activity levels are very much dictated by our in-patient service. So if we have lots of
	in-patients then we'll have to cancel community visits for our out-patients" (Female
	Physiotherapist).
Quote 5	"We're struggling to manage to do lots of exercise sessions especially in the winter as well
	we have got a very restricted gym at the hospitalWe are restricted with not enough
	bodies and not enough space (Male Physiotherapist)
Quote 6	"[The role] is invaluable. I think really having the time and the expertise and, you know,
	being able to work individually with each patient – as an individual to work out a really
	tailored exercise plan. Yeah it's crucial" (Female Dietician)
Quote 7	"I think it is in an ideal world, if we could have a qualified person who is there to promote
	exercise so whether they've got a Physio or physiology, or PT [personal trainer], or
	coaching background. I think, I've been to European conferences, and they have in Wales a
	person whose job is to just to teach and do exercise with the adolescents" (Female
	Physiotherapist)
Quote 8	"I don't think there's a huge understanding from I mean one of the reasons I got my job
L	

	was because I had the exercise experience and so I work in a team of Physio's and I was
	shocked that they didn't know what I would call basic gym weight exercises" (Male
	Physiotherapist)
Quote 9	"A wee bit harsh what I'm going to say, but I think that it's all very well to advocate it, but
	I think you have to participate in an activity yourself, because I don't think it's a good thing
	for me to say 'you need to be doing all this exercise' if I'm sat on my bum and not doing
	anything. And I think if you're an inactive person to be advocating activity I think the
	patients will see right through you. So it's a hard one I think everybody's responsible but I
	would rather it would be somebody that can actually enthuse a patient than somebody
	that says well you know you're meant to be exercising with someone less than enthusiastic
	about it" (Female Physiotherapist)

Quote 1	"Well to fit in with the Association of Physiotherapist Guidelines, we say thirty minutes of
	out of breath exercises five times a week" (Female Physiotherapist)
Quote 2	"Yeah I don't think we have any sort of sets of protocols or advice. We will often do it
	dependent onwhat their endurance is like with exercise, what they can tolerate at the
	time" (Female Physiotherapist)
Quote 3	"I'm not aware that there are CF Trust directions for exercise within CF I guess if we had
	some sort of consensus around what would be the recommended levels of activity for
	someone with CF" (Female Physiotherapist)
Quote 4	"So we would say between 60 and 80 percent of their max heart rate" (Male
	Physiotherapist)
Quote 5	"It needs to be at half an hour at least and be high-intensity for it to be classed as a
	Physio session" (Female Physiotherapist)
Quote 6	<i>"I do sort of explain that ideally they need to be getting out of breath you know</i>
	increasing their respiratory rate and the heart rate" (Female Physiotherapist)
Quote 7	"I would suggest that they try and be active at least 5 or 10 minutes a day" (Female
	Physiotherapist)
Quote 8	<i>"If you're over five, an hour of activity a day and with a lot of that being exercise to a</i>
	more moderate or intense level" (Female Physiotherapist)
Quote 9	<i>"I would say we would suggest two and a half hours to five hours a week but then that's</i>
	additive so that they can say well I actually go for a walk with the dog on a Monday"
	(Female Physiotherapist)
Quote 10	"If they're starting at a baseline of zero they are not expected to go out and play football
	three times a week at a really high level but just trying to set more realistic goals for
	them that's anything more than what they are doing already so that it's achievable"

388Table 2: Recommendations relating to intensity, duration and types of physical activity

	(Male Consultant)
Quote 11	"We try and do a bit of cardio, a bit of strength work and some core or postural stuff so a
	bit of everything really" (Female Physiotherapist)
Quote 12	"We do a muscular skeletal assessment as part of the annual assessment which checks
	for pain, back pain and core stability as well. And with it, you know girls and mums if
	that's an issue we'll try and sort of promote Pilates and Yoga" (Female Physiotherapist)
Quote 13	<i>"I just have to be careful promoting HIIT sessions because if they're kind of not very fit I</i>
	don't want them to get injured really and that's the best way to do it in a HIIT session
	with no warm up and straight in. Full on high impact kind of stuff it does get you fit but
	you've got to have a certain level of fitness to begin with" (Female physiotherapist)
Quote 14	"The only ones I would refuse to do with patients are plyometrics and heavy high-
	intensity because plyometrics, unless I know the patient and I've worked with them for a
	while, I don't think their joints can cope because they are very prone to arthropathy and
	the impact, because of malnutrition, on the bones, well, I just wouldn't want to risk it
	with them" (Male Physiotherapist)
Quote 15	"We might focus slightly less on the exercise corner of our triangle and look at more
	physical activity and trying to maintain a base of activity so they're not taking the car
	everywhere, they're not getting a lift to every opportunity they are doing walking the
	dog, the lower level activities and still getting them some cardio benefits" (Male
	Physiotherapist)
Quote 16	"[The patient's choice of activity] might not be optimal, but it is a start. And it is better
	than not being able to do anything. It gives us something to work with. So it might not
	have the health benefits that we know comes with being active, but if they enjoy it, if
	they are still moving and being active and interacting with peers, then yes they are
	getting benefit from it. And it is a starting point" (Female Physiotherapist)
	<u> </u>

Quote 1	Exercise is an important component of the patient's overall health and prognosis and
20000 -	
	when we do the exercise tests, it is the actual standard, but it's not just the adherence
	to standards that we're looking to achieve it's a really useful outcome for looking at
	prognostics for health" (Male Physiotherapist)
Quote 2	"At the moment with the, well it's the three-minute step test, which I don't think is a
	brilliant exercise test" (Female Physiotherapist)
Quote 3	"We don't do sort of the formal CPETs or exercise testing, but that would probably give
	us some better results" (Female Physiotherapist)
Quote 4	"A lot of people refuse to do [the modified shuttle], so it's not a good uptake" (Female
	Physiotherapist)
Quote 5	"We used to do the shuttle walk, modified shuttle walk, but we often found that they'd
	get to the end of it and they'll be able to keep going it wasn't like an accurate test"
	(Female Physiotherapist)
Quote 6	"I've just started doing some exercise tests. We've had trouble doing things because of
	space and time" (Female Physiotherapist)
Quote 7	"We've not got any direct comparisons for the younger age range. So that kind of limits
	what we can deduce. We obviously know the lower the value the less well they've done,
	but I think perhaps those things would be useful for trying to help us guide and inform
	patients on what they should be doing and where they dip compared to sort of the
	relative population. That's what the family want to know after we've done any exercise
	or any tests or any sort of intervention they and rightly so they want to be informed
	they want to know where that, what that actually means" (Male Physiotherapist)
Quote 8	"So we get a summary from control, and the person that runs the test, so whether they
	were limited by ventilation or deconditioning, and what their metabolic equivalents
l	

	were at each level, and heart rate, and prescribed sort of exercise based on that"
	(Female Physiotherapist)
Quote 9	We will do a yearly as a minimum exercise test so we will always try and encourage
	them to do better than their last test or use that as a goal" (Female Physiotherapist)
Quote	"We keep that data and it will all go on their, it will be their annually for all the team to
10	look at" (Female Physiotherapist)
Quote	"I think you'll find quite a large variance as to what different people are using and if
11	they, if they're then what are they doing with that information because as I said it's all
	very good collecting data for data's sake but we need to know what the practical
	applications of what people are doing with that information when they collect, when
	they get the information back from an exercise test what do they then actually do with
	that?" (Male Consultant)

393 Supplementary material

394 Semi-structured interview schedule

1. How important do you think physical activity is for adolescents with CF?

a. Why?

- 2. Who should be promoting physical activity for adolescents with CF?
- 3. How do you encourage adolescents to be physically active?
 - a. What information or issues do you consider when promoting physical activity?
 - b. How do you encourage those who are not motivated?
 - c. How effective do you think these approaches are? Why?
- 4. Can you give me an example of how you encourage adolescents to be physically active?
- 5. What advice do you give adolescents in relation to physical activity?
 - a. Type?
 - b. Frequency?
 - c. Intensity?
 - d. Anything else?
- 6. Do you use exercise testing?
 - a. When / with who?
 - b. What test do you use?
 - c. How do you use the results?
- 7. What factors best enable you to promote physical activity?
- 8. What do you think the biggest barriers are to adolescents with CF being physically active?
 - a. How would you help them overcome this?
- 9. In which situations / for which patients (if any) are you least likely to promote PA?
 - a. Why?
- 10. Is there anything you feel you need to improve physical activity promotion?

a. Is there any more information / training that would be useful?

11. Would any organisational or cultural changes facilitate the promotion of physical activity?

12. Is there anything else you want to say?

395