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ABSTRACT

Although extensive research has investigated the benefits of physical activity in cystic fibrosis, minimal exploration of the experiences for individuals from a qualitative, phenomenological perspective has been carried out. The aim of this study was to explore the subjective experiences of physical activity for individuals with cystic fibrosis. The health-care team, at an Adult Cystic Fibrosis Unit in the United Kingdom, recruited 12 participants to take part. Interview data were analysed using interpretative phenomenological analysis. A central theme of 'self-monitoring' emerged from the accounts and was embedded in the three superordinate themes.

Keywords

cystic fibrosis, exercise behaviour, lived experience, physical activity, self-monitoring

INTRODUCTION

Cystic Fibrosis (CF) is the most common life-limiting autosomal recessively inherited disease in Caucasian populations (Bradley and Morgan, 2011), affecting over 10,000 people in the UK (Cystic Fibrosis Trust, 2013). The disease expresses as a result of a single cell mutation that disrupts salt and water transportation across cell membranes. This leads to the production of thick mucus, which can affect both the digestive and respiratory systems (Gjengedal et al., 2003). As a multisystem disease, it requires complex medical management including daily antibiotic therapy, nutritional attention often including oral enzyme supplements and regular chest physiotherapy to clear secretions from the lungs (Bluebond-Langner, et.al, 2001).

Prognosis for CF has improved substantially over the past five decades. CF used to be a terminal childhood illness but through medical advancements and paramedical support, there has been a dramatic decline in mortality rates in children (Dodge et al., 1997). Harrop (2007) reported that the average life expectancy was around 32 years. Four years later in 2011, the median predicted survival reported by the Cystic Fibrosis Trust was 41.5 years (Cystic Fibrosis Trust, 2011b). Based on the current patterns the projected number of adults living with CF seems set to continue rising.

One treatment modality now encouraged among the CF population is physical activity. Physical activity and exercise are recognized as important elements in maintaining a healthy lifestyle in both health and disease (Thirlaway and Upton, 2009), and a large body of literature has identified numerous physical and psychological advantages in healthy individuals (Wen et al., 2011). Such benefits may also occur in individuals

with CF (Moola et al., 2011). For example, while decreased cardiorespiratory fitness in CF is well established, evidence is building that patients also suffer decreased muscle power, strength and endurance (Selvadurai et al., 2003). Engaging in regular physical activity and increasing physical fitness can aid the development of these areas as well as potentially maximising the ability to fight infection and minimise the detrimental impact of CF. Physical activity has also been associated with enhanced psychological well-being and may offer many quality-of-life benefits for those with CF (Moorcroft et al., 2004). It also boosts perceptions of mastery and normalisation (Moola et al., 2011) as increased physical functioning can minimise the impact of the disease's symptomology. As a result of such acknowledged benefits, efforts to promote regular engagement in physical activity as part of the disease management in CF are being adopted (Swisher and Erickson., 2008).

Many people with CF who engage in regular physical activity describe it as both enjoyable and a preferred treatment modality (Blau et al., 2002; Schneiderman-Walker, 2000). Nevertheless, research suggests that most CF patients are insufficiently active. Moola et al. (2011) report lower frequencies of participation and lower intensities of exertion in comparison to their healthy counterparts. Although not participating in physical activity is potentially depriving those with CF of the benefits associated with such activity (Selvadurai et al., 2002) participating in physical activity may present many barriers. The persistent belief that they are 'not as good', or unable to keep up with others and negative social interactions can cause low self-efficacy, which may result in individuals with CF avoiding physical activity (Moola et al., 2011). The social environment within which individuals engage in physical activity can have a profound effect. Socially enriched environments, which maximise social support through

personal attention and encouragement, have been found to provide greater increases in positive engagement, revitalisation and self-efficacy than socially bland environments which avoid engagement in conversation unrelated to the physical activity and do not direct praise or attention to the individual (Turner et al., 1997). Subsequently, the social environment may also impact on the individual's effort levels and likelihood of them continuing with the activity.

The benefits of regular exercise are both noticeable and measurable over a relatively short period of time, but very quickly lost if people are not physically active. Adherence to physical activity regimens is a key issue in CF (Rogers et al., 2003); however, little is known about the experiences of CF patients who engage in such activity. Within the context of this study the term 'physical activity' was used instead of exercise to encompass all forms of activity such as walking to work, taking the stairs, as well as more organised forms of activity such as taking part in sports or going to the gym. This definition was explained to participants before they took part in the research.

This appears to be a fruitful avenue of research if efforts to promote regular engagement in physical activity as part of the disease management in CF are going to be encouraged. Therefore, the aim of this study was to explore the experience of physical activity for individuals with CF.

METHOD

Design

Before recruitment, ethical approval was gained from the relevant research and development offices and National Health Service (NHS) Research Ethics Committees. A semi-structured interview schedule was devised based on guidelines by Smith and Osborn (2008). This aimed to build rapport between the interviewer and participants, where participants would feel comfortable to talk openly about their experiences of physical activity. To achieve this, a funnelling technique was adopted initially focusing on broad questions relating to physical activity and then gradually becoming more specific to the key research aims. Predominantly, the opening section eased the participant into the interview process, allowing them to progressively engage into deep thought about physical activity. Participants were asked about their current levels of physical activity, how such treatment fits into the way they live their lives and finally issues that arise in relation to physical activity. The researcher sought to probe complexities in relation to the reasons they did or did not exercise regularly and the ways they account for this to explore the inner subjectivity of the experiences.

Participants

Due to the rare nature of the disease, a purposive sampling technique was adopted at an Adult CF Unit in a U.K. hospital. The direct care team identified eligible participants based on their lung function (individuals were required to have a predicted lung function of over 30%), age (at least 18 years) and whether the health professionals deemed it suitable within the constraints of the individualised treatment schedule. This assessment acted as a screening tool to ensure that participants' lung function was high

enough to support physical activity. Potential participants were required to engage in at least some level of physical activity. They were contacted via telephone or face-to-face on the CF unit by the physiotherapy team, and given a brief outline of what participation in the study would require and the general aims of the research.

Those who displayed an interest were then given an information sheet, which provided sufficient information to inform a decision on participation. All were given a minimum of 24 hours before any possible interview, which provided time to ask any questions and make decisions. Once consent was obtained each participant was guided through the interview process in a small office at the hospital.

In total, 12 participants were recruited, 6 males and 6 females, with ages ranging from 18 to 46 years. All were of white U.K. origin. The majority of participants were in-patients, who at time of interview, were admitted to the unit for a 2-week course of intravenous antibiotics. One individual took part after a weekly out-patient clinic visit. One participant worked in a very physically active full-time job, three participants worked part-time, two were students and the remaining five participants were unemployed at the time of interview. Three participants described themselves as very active, four described as moderately active and five participants reported low activity levels. The sample was considered homogenous to the extent that all participants had CF and attended the same Adult CF Unit for treatment.

Analysis

Interpretative Phenomenological Analysis (IPA) was deemed an appropriate analytic approach as it considers how participants both make sense of and derive meaning from specific experiences (Smith, 2011). Here, it offered a way of exploring not just the experience of physical activity but how individuals made sense of this within the context of being a CF patient. Analysis was facilitated by Smith and Osborn's (2008) guidelines. Each transcript was read several times to gain familiarity with the content. Next, initial coding was carried out by annotating transcripts with summary statements that related to the research aims. A composite list of all emergent themes from each case was then compiled and reviewed providing a higher level of abstraction. Integration of the individual cases then allowed clusters of themes based on connections between the participants' experiences to be made. Finally these were labelled and represent the super-ordinate themes outlined. Throughout this process the content of potential themes were discussed between the first two authors R.D.S .and J.M.

Validity

Demonstrating rigour and validity within qualitative studies is less clear-cut than within quantitative research (Hansen, 2006). The traditional scientific measures of objectivity and reliability are inappropriate, so an alternative criteria needs to be established in order to illustrate the trustworthiness of qualitative endeavours. For the purpose of this paper the criteria outlined by Yardley (2000) for qualitative health research is drawn upon: *Sensitivity to context* is evidenced by reviewing previous literature findings from the wider field. This allowed the research topic to be contextualised and the importance of the specific aim identified. Additionally, it is shown through the interpretative process where meanings are discussed within specific contexts, which avoids spurious

generalizations. Verbatim quotations facilitate a more nuanced understanding by directly reflecting participants' language. This also adds to transparency. *Transparency* has been achieved by systematically documenting the design and process of analysis adopted. In the presentation of the findings the interpretative commentaries are supported by selected quotations which provide clear links for the reader to establish the trustworthiness of the commentaries. Finally, the *impact and importance* of such findings for health professionals are addressed in the discussion.

In discussing IPA Smith (2011) uses the term '*double hermeneutic*' a process whereby the researcher attempts to make sense of the accounts provided by participants who offer their own interpretations as a process of making meaning of their experience. This acknowledges the subjective stance of the approach and allows researchers to position themselves in relation to the research. This study was conducted by researchers with a background in psychology (with the exception of R.M-B, who is a physiotherapist and acted as a clinical supervisor when the first author was conducting the interviews); it is likely that such discipline knowledge would frame the nature of the interpretation. A researcher writing from a sociological stance, for example, might frame the analysis in a different way, have a different set of objectives and ask different research questions.

The idiographic nature of the study, dictates that the findings should not be indiscriminately generalised, but they can make a meaningful contribution towards understanding the nuances of engaging in physical activity with CF. Accounts may also resonate with other studies in the area of physical activity, and as such contribute to developing a literature-base.

FINDINGS

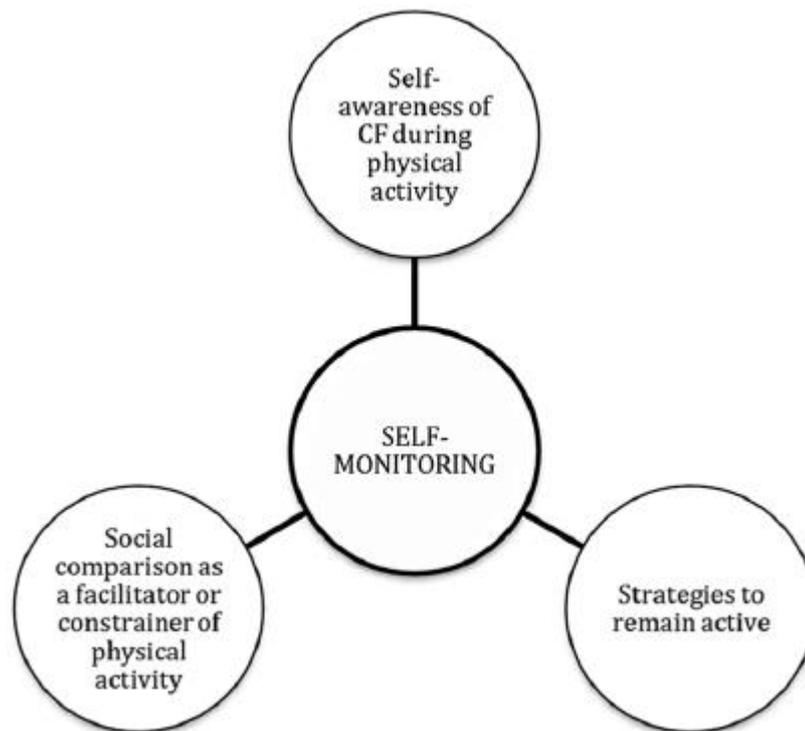
Three super-ordinate themes were identified: ‘self-awareness of CF during physical activity’, ‘social comparison as a facilitator or constrainer of physical activity’ and ‘strategies to remain physically active’. Each theme is outlined below, with a tagged quotation to allow the reader to stay close to the participants’ own words.

When conducting the analysis, it became evident that there was a divergence between the ways in which the participants’ accounts related to these themes. There seemed to be a divide within the group to the extent to which they monitored their social environment when engaging in physical activity and the impact this had on their feelings and behaviour. For example, some were concerned about what others may think of their physical appearance such as seeing scars from surgery, or how they would react if they coughed a lot (a typical consequence of physical exertion for those with CF). *‘It is more about what they could be thinking of me you know’* is a quote from the interviews to illustrate this. Yet others, who may also encounter the same things, reacted to them in a different way, making statements such as, *‘I switch off really’* and *‘not take too much notice’* when discussing the presence of others during physically activity. It was observed that different levels of what we have labelled here as ‘self-monitoring’ was taking place.

Distinguishing between these two groups and their levels of self-monitoring was considered an important part of the analytic process to in order to capture not just the experience of physical activity but how individuals made sense of this within the context of being a CF patient. Subsequently, a central theme ‘self-monitoring’ was used which mediated all three super-ordinate themes. (See Figure 1).

Participants were grouped as either high self-monitors who appeared more responsive to social and interpersonal cues and reported monitoring and regulating their behaviours (eight individuals were labelled as this) or low self-monitors. Low self-monitors did not display the same concern for social appropriateness, and their behaviours seemed less affected by those around them (four individuals were placed in this group). The idea of self-monitoring is discussed in further detail within the interpretative commentaries for each theme below.

“INSERT FIGURE 1 HERE”



Self-awareness of CF during physical activity - ‘I know my body. I know what my body can do’

Each participant showed some level of awareness of their capabilities when it came to engaging in physical activity with CF. This is encapsulated by the quotation ‘I know

my body. I know what my body can do'. Despite this, the four low self-monitoring participants continued to engage in activity. Marc describes how in the gym he feels:

a little conscious like sometimes but you know, I switch off really and say 'well I'm doing what I want to do' and I get down, I know my regime and I just stick to that really.

Although their appearance and physical symptoms might attract the attention of others, these individuals were less responsive to their reactions and instead focused on what they wanted to achieve. Angela recounts regularly having coughing fits when walking, which had led passers-by to stop and comment:

The best one is 'you need to give up smoking'. Yeah, that's the best one. And I'd often say, if it was only that easy, I'd start smoking to give up, you know and (.) or they go, 'You want to go the doctor about that cough'...Some people look at you terrified as if to say, 'Oh my God! Are you alright?' But (.) I think I've heard it all. You know, I've got to the stage now where I'm coughing, you know, and there's nothing I can do about it.

Here, Angela is accepting of her CF and its accompanying symptoms. For those in the high self monitoring group, this did not appear to be the case. James explains how he is very self-conscious about his appearance. This generates a sense of vulnerability that prevents him participating in a form of physical activity that he used to enjoy:

I would like (.) to swim more. I'm very body conscious and because of having a stoma and I am very aware that I have quite a large chest and I have a lot of scars on my torso and having my feeding tube and having a line on my chest and from having IV drugs, and I think it's very different (.) how I look outside with my clothes on and how I look without them. And I think if I swim, I feel very exposed.

For James the self-monitoring leaves him feeling 'exposed', and unable to engage in the social situations where others might see him. This sense of embodiment experienced from the physical scars of CF is highly constraining in relation to physical activity.

All eight participants considered to be at the higher end of the self-monitoring continuum described feeling self-conscious about engaging in physical activity in front of others. In addition to concerns about physical appearance, they often referred to the physical symptoms of the disease such as coughing increasing when engaging in physical activity. For this group, awareness of CF became a barrier to exercise.

Kate describes:

I've noticed, sort of when I'm walking the dogs, if I do like a really steep hill...I start coughing because it's physio it's almost...But if I'm with someone they're like, 'Oh you're okay? You're okay?' and that's embarrassing as well and you know like, don't fuss. It's like, 'I'm coughing. I'm fine.' You don't need to fuss over it. But it's just. When exertion, it does make me cough... And it's just the embarrassment of that. Because sometimes with my coughing, if I'm coughing and coughing and coughing, it

makes me sick. And if that does, touch wood that's never happened in front of anyone, but if that did, I would die.

The powerful analogy Kate uses here, preferring 'to die' than be sick in front of someone, illustrates the intensity of emotion this scenario raised for her. The phrase emphasises how socially 'terminal' such an incident might be and consequently could lead to the 'death' of her engagement in this physical activity. It also indicates that, like James, self-awareness of CF during physical activity can be due to an imagined event or scenario often associated with how participants feel others *may* perceive them. In this way the theme of self-awareness is linked to next theme of social comparison.

Social Comparison as a facilitator or constrainer of physical activity – 'I can't do as much as other people can'

Although most participants relayed accounts of comparing their capacity for physical activity with others, again there was a divergence in how low and high self-monitors made sense of this. Nia states:

if anything, it makes me feel more normal because everyone should do exercise, really, so, I think it's seeing that everyone should do it kind of makes me...yeah, makes me feel normal as I go a lot, "You should do exercise as well," you know, we're both getting different benefits out of it. But, you know, everyone's doing it then.

For the low self-monitors physical activity acted as a normaliser, enabling them to feel 'just like anybody else'. Comparing themselves to others was positive here.

In contrast, social comparison proved a self-diminishing process for the high self-monitors, drawing attention to the fact that they feel less able than others in terms of physical activity, and ‘stand out’ as different. This is illustrated by Kate, who recalls that she feels:

...just embarrassment really that I can't do it. I can't do as much as other people can. That's it really. If I was perfectly healthy, I think I probably would, because I enjoy going swimming and stuff and I enjoy sort of dancing but it's just that I can't do it. So I just don't even try.

The comparison with others who are ‘perfectly healthy’ leads Kate to change her narrative from someone who ‘can’t do as much’ as others to someone who ‘can’t do it’. Consequently she does not ‘even try’. Like James (in the previous theme) we observe the possibility of physical activity being shut down due to a perceived embarrassment of how others might react. Carley provides a further insight into this:

Just, it makes me feel like I seem lazy to the other people. So, not embarrassed. It is more about what they could be thinking of me you know. They'll say, 'Well' you're at the gym, why aren't you doing anything?' You just stand there watching. While other people are really going for it...It makes me a bit angry.

This account again illustrates how the participants in this group talk of being affected by the imagined gaze of others. For Carley she *feels* like she would ‘seem lazy to other people’. It is not clear if her anger is toward herself or her illusory audience.

What is noteworthy for this study is that the individuals’ beliefs about what others *may* think of them inhibited their levels of physical activity, rather than their physical capability alone. Meanwhile, participants considered lower self-monitors were able to

minimise the ways in which they felt different to others and consider themselves as similar by taking part in physical activity. This drew their focus away from their CF symptoms.

Strategies to remain physically active – ‘just make sure that no one’s around in case I start coughing or if I’m sick or anything like that’

The themes discussed above illustrate that an awareness of CF (be it actual or imagined) has the potential to constrain the levels and type of physical activity engaged in. However, as noted in the participants section, all interviewees did engage in physical activity (all be it to varying degrees). Even the high self-monitors evidenced strategies to remain active, for example Kirsty notes:

I don’t like the idea of a gym at all and I don’t like the idea of being in a gym with other people so unless I have my own gym which I haven’t. So, I just prefer walking the common. So, I just walk as fast as I can... Because we obviously have to push ourselves, to the point we are coughing a lot and I don’t want to cough it up in front people...they’ll think she’s going to keel over or something. So nah, I’d rather keep myself to myself with exercise.

The notion of keeping ‘myself to myself, and avoiding the gaze of others allows Kirsty the opportunity to exert herself without having to consider the possibility of social disapproval. Four of the high self-monitoring participants described adapting the forms of physical activity they would do or exercising alone to allow them to feel more comfortable and less self-conscious.

As would be expected, the low self-monitors did not avoid exercising in social environments. They explained how they would discreetly overcome physical symptoms rather than adapt the activities they take part in due to being surrounded by others. For example, they might go into the changing room in the gym or public toilets to cough up sputum. Others made sure they always carried tissues and their inhaler. Ricky explains:

if you're in the gym, if you aren't feeling too well and you start coughing, you get a bit (.) it can be a bit embarrassing, but (.) just go to the changing room, (.) cough it out there, and then come back in and carry on. And, you know, the gym's pretty all right...everyone is there to be exercising; don't really take much notice of anybody else, to be honest.

It seems that most participants developed strategies to continue engaging in physical activity at some level without feeling embarrassed or different. This is encouraging. However some in the high self-monitoring group also described themselves as having low levels of physical activity. The findings outlined above suggest that it could be due to the ways in which they interpret social and interpersonal cues (even if the cues are imagined) which leads to disengagement with some physical activity.

DISCUSSION

This study explored the subjective accounts of physical activity for 12 participants with CF. Extensive research has been carried out describing the benefits of physical activity in CF, yet minimal research has focused on the experience of this for the individual.

The findings of this study emphasise the significance of the social context in which the participants engaged in physical activity. Moreover, it highlights a contrast in the way participants made sense of their ability to engage in such activity, interpreted via a central theme of self-monitoring. Those individuals who were very responsive to social and interpersonal cues appeared to have more difficulties to overcome in order to remain physically active and this group of participants seemed to be less active. It was interesting to note that the cues they were sensitive to were at times imagined rather than actual experiences they had encountered. In contrast, individuals who were less concerned about their social appropriateness appeared able to maintain their physical activity levels more easily.

For low self-monitors, regular engagement in physical activity could act as a normaliser and protect participants from an unhealthy identity. Similarly to chronically ill people studied by Charmaz (2006), some participants appeared to have established their own concepts of health and measures of their efforts to regain it. Accepting that '*everybody's got different fitnesses*' seemed to facilitate their adherence to physical activity regimes and permitted individuals to view their efforts more positively. Although all participants engaged in some degree of self-monitoring, for some, the emphasis on this was minimal and they appeared to make fewer adjustments to the environment within which they undertook physical activities. Those who were regularly active tended to show the characteristics of a low self-monitor, they adapted more easily if exercising in a public place and appeared more accepting of CF's accompanying symptoms. These individuals commonly disclosed that '*I know my pace*' and acknowledged they might not be able to sustain the same intensity of activity as healthy others, indicating that their perceptions of health had adjusted. The theory of response shift argues that in

order to 'normalise' individuals recalibrate and reconceptualise their health and well-being in order to accommodate the progressive nature of their illness (McClish et al., 2005). A response shift may have enabled these individuals to maintain their self-efficacy through reducing expectations of their physical performance and allowing them to view themselves in a more positive light. Conversely, those who were high self-monitors appeared less able to re-calibrate and continued to feel incapable if they were unable to participate at the same level as healthy others or at the same level as they have done in the past. Helping patients re-calibrate their physical activity goals and accept a lower fitness level may be key in exercise adherence. It is possible that changing an individual's mind-set about their physical health may be crucial to the encouragement of regular physical activity and therefore calls for deeper exploration.

Engaging in social comparisons was a common occurrence, but in the context of physical activity, some individuals identified the similarities between themselves and healthy individuals whereas others paid particular attention to the discrepancies this highlighted in relation to their CF. Social comparisons, therefore, can potentially have a constraining effect on activity levels, leading some to avoid physical activity in certain situations for fear that they will '*stand out*'. However, for others social comparisons bring positive outcomes and facilitate an engagement with physical activity. The ability to identify oneself as similar to healthy others through physical activity participation appears to protect these individuals from an ill person identity.

Many participants explained how they have developed strategies to remain active, although sometimes the high self-monitors felt too self-conscious and embarrassed to be physically active in social environments. Several high self-monitors described how

they removed themselves completely from the social situation and would exercise alone. The low self-monitors adopted discreet techniques to overcome physical symptoms, for example going into the changing room in the gym or public toilets to cough up sputum. Research with healthy individuals has suggested that the psychological benefits of physical activity are greater when carried out in socially enriched environments (Turner, Rejeski & Brawley, 1997), moreover CF patients have been found to benefit from exercising in a supportive environment (Blau *et al.*, 2002). So although some high self-monitors have found exercising in isolation an effective strategy for avoiding adverse social comparisons they are potentially missing out on some of the benefits to be gained from being physically active in social groups, and perhaps not maximizing the advantages of being physically active. Although, it must be noted that many physical benefits, such as preservation of lung volumes and functions, have been observed in CF patients who took part in an unsupervised individualised home exercise programme (Moorcroft *et al.*, 2004). For those who felt too embarrassed to participate in social settings, exercising alone seemed a viable alternative. However, acting like any other healthy person and participating in activities in a 'normal' environment may provide greater benefits, this calls for greater exploration. Working on building confidence in exercising in social situations may be key in building self-efficacy and reaching acceptance. In addition it may enhance exercise adherence by increasing the benefits of socially enriched environments.

In conclusion, this study highlights the diversity of experiences relating to physical activity amongst CF patients. Perceptions of the social environment appeared to be important to aiding participation for some whilst having detrimental effects on the activity levels for others. For some, physical activity performed an important role in

their sense of self, acting as a normaliser, enabling them to identify with healthy individuals and *'fit-in'*. Their positive outlook seemed central to their embodied experience of having CF and their adherence to such activity. For others, physical activity emphasised differences and left them *'exposed'* and feeling vulnerable as they focussed more attention on the CF. It would be useful to compare these findings with research on other pathologies where exercise self-efficacy and adherence to physical activity may be low (e.g. obesity). In this study self-monitoring was central to all physical activity behaviours. Those perceived as low self-monitors participated in more physical activity than those who were high self-monitors. Further exploration of exercise self-efficacy and physical activity within the social environment is needed to help develop and establish new methods to aid the engagement of inactive CF patients in regular physical activity.

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