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Experience with Activity Monitors of Patients with COPD, Sarcoidosis and Pulmonary Fibrosis in the Netherlands

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Abstract

Purpose: Physical activity (PA) offers great health benefits for a wide range of conditions. Critical factors for PA are motivation and encouragement. The aim of this study was to evaluate self-reported experiences with PA and activity monitors among Dutch patients suffering from chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, or sarcoidosis.

Study design: Patients' experiences with PA and various activity monitors were evaluated using an online survey addressing the use and possible benefits of activity monitors, conducted among Dutch patients with COPD, sarcoidosis or pulmonary fibrosis, in cooperation with Dutch patient societies.

Results: A total of 1160 patients completed the survey: 460 with COPD, 467 with sarcoidosis, and 233 with pulmonary fibrosis. The majority of patients (95%) emphasized that exercise and PA was beneficial to them. Professional supervision of PA was reported by 39.1% of the COPD patients, 28% of the sarcoidosis patients, and 40.9% of the patients with pulmonary fibrosis. Patients using activity monitors (n=267; 23%) reported having better insights into their daily performance and activity (80%) and feeling encouraged to accomplish more PA (76%).

Conclusion: This study showed that PA is beneficial to a majority of patients suffering from COPD, sarcoidosis or pulmonary fibrosis. Using activity monitors (almost one-quarter: 23%) stimulated patients to be more physically active and provided them with a better understanding of their disease, thereby improving their self-management and behavior. Further research is needed to explore the role of self-monitoring in improving patient empowerment and self-care.

Keywords: Activity Monitor, Behavior, COPD, Disability, Physical Activity, Pulmonary Fibrosis, Sarcoidosis, Self-Monitoring

Introduction

There is worldwide consensus about the health benefits of regular engagement in physical activity (PA) of at least moderate intensity [1]. Therefore, many countries have introduced initiatives to improve population PA levels [2]. Research in chronically ill patients has shown that exercise improves quality of life (QoL) and is beneficial to patients suffering from a wide range of chronic symptoms, such as fatigue, reduced exercise tolerance, muscle weakness and dyspnea [3,4]. Among these chronically ill patients are patients with chronic obstructive pulmonary disease (COPD), sarcoidosis and pulmonary fibrosis.

Exercise tolerance and daily PA proved to be predictors of QoL and survival in chronic pulmonary diseases such as COPD [5,6]. In line with this, research found that impaired exercise tolerance, fatigue and muscle weakness appeared to have a negative influence on the QoL of patients with sarcoidosis and pulmonary fibrosis [7-13].

Motivation is a critical factor in pursuing and continuing to pursue PA. Intrinsic participation motivates patients to continue PA or helps to achieve goals associated with PA, such as affiliation and social engagement, challenge and skills development. Increased perceived competence for PA also has positive predictive value for more adaptive exercise behavioral outcomes clearly associated with greater exercise participation [14]. Behavioral strategies to enhance PA self-monitoring, such as logging walking activity and using pedometers to track step counts, have been shown to improve health-related outcomes [15]. The use of wearable technologies, such as the Fitbit, is becoming increasingly common among the general public [1]. In addition, understanding one's own disease mechanism is important in self-management and patient empowerment. Self-management is important because people want an approach targeted to their own personal goals, situation and behavior.

The aim of this study was to evaluate self-reported experiences with physical activity and activity monitors among Dutch patients suffering from COPD, pulmonary fibrosis or sarcoidosis.

Methods

Study Design

In cooperation with the Lung Foundation Netherlands, the Dutch Sarcoidosis Society (Sarcoidose.nl), the Dutch Pulmonary Fibrosis Society and the ild care foundation, the authors designed a cross-sectional web-based anonymous questionnaire that broadly investigated experiences (if any) with self-initiated PA, such as exercising in a gym, walking, biking, playing golf, or gardening, as well as the use of activity monitors. Recruitment took place from October 2017 to April 2018 and was designed to engage large representative samples of all three patient populations.

Study Subjects and Procedure

Patients were recruited from among the membership of the Lung Foundation Netherlands, the Dutch Sarcoidosis Society (Sarcoidose.nl) and the Dutch Pulmonary Fibrosis Society, using the societies' newsletters, and newsletters of the ILD Center of Excellence at Nieuwegein. No incentives were offered. To participate, patients had to be proficient in Dutch and have internet access. Patients were provided with a specific link to the survey by the online questionnaire tool Surveymonkey (www.surveymonkey.com). The survey queried experiences regarding PA, experiences with the use of various self-purchased activity monitors, and demographics (gender and age).

Statistical Analysis

Statistical analysis was performed using SPSS 20 (SPSS, Chicago, Illinois) software. Standard descriptive statistics were computed. ANOVA was used for comparison between the COPD, sarcoidosis and fibrosis patient samples. Outcomes of the questionnaires are presented as mean ±SD unless stated otherwise. Statistical significance was assumed at $p<0.05$.

Results

In total, 1160 patients completed the survey: 460 with COPD, 467 with sarcoidosis, and 233 with pulmonary fibrosis. Almost all (95%) reported exercise and PA to be beneficial to their health. Professional supervision of PA was reported by 39.1% of the COPD patients, 28% of the sarcoidosis patients and 40.9% of the patients with pulmonary fibrosis (Table 1), and 28% of the study participants were involved in a rehabilitation program or were supervised by a physical therapist. Twenty-three percent had experience with one or more activity monitors. Activity monitors offered patients information about their daily performance and activity levels (80%) and encouraged them to pursue more PA (76%; table 2). Seventy-six percent of the users reported that wearing an activity monitor offered benefits in addition to their medication (76%). As regards the type of activity monitor used, pedometers were reported to be less user-friendly and less reliable than the more advanced instruments such as Fitbit.

Table 1: Participation in physical activity programs by patients suffering from COPD, sarcoidosis, or pulmonary fibrosis, with or without self-purchased activity monitors.

	COPD n=460	Sarcoidosis n=467	Pulmonary Fibrosis n=233	*p*-value
age (years; ±SD)	59.9±11.9	55.5±10.8	67.7±9.4	<0.001
sex (% men)	35	48	68	<0.001
I have professional supervision, %	39.1	28.0	40.9	<0.001
Through physiotherapy, %	44.1	36.1	48.0	0.001
Through a rehabilitation program, %	6.1	6.6	6.0	NS
Through a fitness program, %	43.0	33.0	41.9	0.003
Through membership of a sports club, %	14.1	12.9	13.9	NS

COPD=chronic obstructive pulmonary disease; SD=standard deviation; NS=not significant

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Of the non-users (n=893), 58% indicated that they would consider using an activity monitoring device in the future if it was reimbursed by their health insurance, while 16.6% were not interested at all in using an activity monitor in the future. The use of activity monitoring stimulated patients' engagement in PA and improved their understanding of their disease across all three patient samples. Although the sarcoidosis patients reported the smallest benefits from the use of an activity monitor (with 45.8% reporting that it "makes me feel fitter" vs. 61.6 and 64.5% for COPD and pulmonary fibrosis patients, respectively), they were the most positive about using activity monitors (Table 2). A large majority of the users would recommend activity monitoring to other patients. Forty percent of the users would appreciate contacts with fellow patients to exchange experiences.

Table 2: Experiences of patients suffering from COPD, sarcoidosis, or pulmonary fibrosis with any kind of self-purchased activity monitor: Fitbit, smartphone (activity tracker), pedometer or smartwatch.

	COPD	Sarcoidosis	Pulmonary fibrosis	*p*-value
I have an activity monitor, %	25.2 (n=116)	22.7 (n=106)	19.3 (n=45)	0.01
age (years ± SD)	55.9 ± 12.2	51.8 ± 10.0	65.5 ± 10.6	<0.001
sex (% men)	36	56	73	<0.001
Use of my Activity Monitor				
Informs me of what I do during a day, %	78.6	85.1	76.1	0.01
Stimulates me to be more active, %	78.7	85.1	68.9	0.01
Makes me feel fitter, %	61.6	45.8	64.5	0.01
Gives me more disease awareness, %	68.7	87.1	68.9	0.05
Is a valuable addition to my treatment %	78.6	75.3	72.5	NS
Is a valuable addition to my activity program and/or activities during the day? %	78.6	80.2	72.2	0.04
Is something I would recommend to other patients, %	94.8	94.2	95.2	NS
Should be reimbursed by the health insurance, %	92.8	91.5	93.1	NS

COPD=chronic obstructive pulmonary disease; SD=standard deviation; NS=not significant

Discussion

The majority of patients in our survey (95%) reported pursuing physical activities and exercise as they assumed these to be beneficial to their health condition. They engaged in some type of leisure-time activity, such as walking, exercising in a gym, biking, playing golf, or gardening. Professional supervision of PA was reported by 39.1% of the COPD patients, 28% of the sarcoidosis patients and 40.9% of the patients with pulmonary fibrosis. Although benefits of physical training were reported by almost all (95%), only 28% reported that they were supervised by a physical therapist or took part in a rehabilitation program, and nearly one-quarter (23%) used an activity monitor. This latter group indicated that it stimulated them to be more physically active and provided them with greater insights into their disease. The success of using an activity monitor depended on whether it was user-friendly. An appropriate activity monitor was useful both to stimulate and improve self-management, and change the behavior of patients with COPD, sarcoidosis, or pulmonary fibrosis. Only about a quarter reported using an activity monitor, and it can be expected that even greater benefit could be achieved if more patients used such a device.

A sedentary lifestyle and lack of PA are well-established risk factors for chronic disease and adverse health outcomes. Even small increases in levels of PA can have a significant impact on chronic disease risk and premature death, especially for people with the lowest levels of physical fitness [16]. Studies exploring walking exercise have found that those who walked at least two hours a week had a 39% lower all-cause mortality rate than those walking less than two hours a week [17]. Activity monitors provide patients with information about their PA because of their ability to measure activity continuously under real-life conditions [13]. Activity monitors are currently widely used by the general public. Studies have shown several positive effects of activity trackers, such as increases in daily PA, improvement of self-efficacy and motivation, higher QoL levels (in COPD patients) [5,18,19] and less fatigue in ILD and sarcoidosis patients [13,20,21]. Studies of patients with obesity [22,23] and diabetes [24] showed similar promising results. Recently, Gill et al. [25] demonstrated that HealtheSteps™, a lifestyle prescription program for patients suffering from chronic diseases, was effective at increasing PA (in terms of step counts per day), decreasing weekday sitting time (min/day) and improving healthy eating behaviors [25].

The program comprised the use of eHealth technology devices (Healthesteps app, telephone coaching and a private HealtheSteps social network) as well as in-person lifestyle coaching. The results showed that patients who engaged in the program (n=59) had increased their daily PA by 3132 steps/day more than the comparator group at 6-months follow-up. Moreover, they reported improved self-rated health (on the EuroQol Visual Analog Scale, EQ-VAS). Their study showed that activity monitoring devices (such as activity tracking apps)

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together with personal lifestyle coaching can effectively increase PA levels and lead to positive health behavior changes in patients with chronic diseases [25].

Although many studies have reported short-term positive effects of PA interventions, including pedometer-based interventions [26-28], long-term health effects require sustained PA changes [18], and evidence for maintenance is scarce. Recently, Harris et al. [18] showed the long-term success of these interventions. They had previously reported increased PA-levels at 12 months following 12-week pedometer-based walking interventions for adults and older adults recruited through primary care and delivered either by post with minimal support or through nurse-led PA consultation. The follow-up study demonstrated that higher levels of objectively measured PA were still present at 3-4-years follow-up, including an increase in additional steps/day of between 400 and 600, depending on the program attended (postal vs. nurse) in the intervention group compared with the control group [18]. Gill et al. [25] also reported positive results concerning the maintenance of PA changes; activity level and self-rated health (EQ-VAS) were higher in the intervention groups compared to the control group at 12- and 18-months follow-up [25]. These studies corroborate the positive effects of PA intervention programs and PA-tracking devices on patients' health and well-being in the long term. In the present study we found that patients were more encouraged by the more advanced activity monitors compared with the simple pedometer. This is in line with an earlier study, showing that a Fitbit is better accepted and associated with increased PA compared to a standard pedometer [29].

In general, a substantial number of COPD, sarcoidosis, and pulmonary fibrosis patients are disabled by functional impairments due to disease-associated symptoms, especially fatigue, reduced exercise capacity, muscle weakness and pain [9,30,31]. Sarcoidosis patients have indicated less improvement of their physical wellbeing compared to patients suffering from COPD or pulmonary fibrosis. This might be explained by the fact that sarcoidosis patients are more severely impaired by fatigue than the other two categories, even after all signs of disease activity have disappeared [32-34]. Functional impairments are defined as limitations in, or inability to perform, certain physical activities, such as walking and lifting, or mental activities such as concentrating, remembering tasks, and conflict handling. However, patient follow-up often fails to pay attention to these functional impairments and tends to concentrate on medical parameters as disease-severity indicators, such as the results of pulmonary function tests and imaging [10,35]. A multidisciplinary approach is recommended and should include gathering information about physical as well as psychological health, using muscle and exercise testing, performance tests, and validated questionnaires like the Fatigue Assessment Scale (FAS) and the subjective Cognitive Failure Questionnaire (CFQ) [10,32,36-41]. Data derived from PA-tracking devices could be very useful and help patients and physicians assess disease burden and activity levels over time. There is an urgent need for more information and guidelines to assess the physical and mental capacities of patients with COPD, sarcoidosis, and pulmonary fibrosis, to ensure that lung function is not the only aspect taken into account [35].

Physical inactivity leads to high health service costs and is the fourth leading risk factor for mortality worldwide [4,18]. People use activity monitors to estimate their PA, such as distance covered or calories burned, based on step counts and sleep monitoring, and these trackers have been found to be relatively accurate and beneficial for such purposes. Increased PA facilitated by these devices could lead to clinical paybacks at low cost [19]. Although the clinical effectiveness of PA in ILD and COPD is increasingly understood, explaining the cost-effectiveness of PA guided by activity monitors can motivate involved parties and policy makers to ensure that this device/intervention is widely available [37]. These devices, along with their close integration with Apple Health and Google Fit platforms, can significantly help improve the QoL of patients and help integrate mobile technology into efforts to reduce many health problems. In the present study more than half of the patients who did not have an activity monitor would consider using it if it was reimbursed by their health insurance. It would be very interesting to evaluate in a future study whether health care benefits can be achieved from the use of activity monitors, and whether this would reduce health care costs.

Limitation

A major limitation of this study is that the data were self-reported by the participants. Corresponding objective data on patients' illness severity would have been very helpful. However, the aim of this study was not to evaluate the severity of the diseases, but to find out whether the sample we studied used activity monitors in general. The importance of patient participation in healthcare has been increasingly acknowledged [39,42], so studies from a patient's perspective are important. There is nevertheless a clear need for future studies combining both aspects.

Conclusion

The majority of patients we studied (95%) reported pursuing physical activities and exercise, which they regarded as being beneficial to their health condition. There was no difference in this respect between the various disorders. Professional supervision of PA was reported by 39.1% of the COPD patients, 28% of the sarcoidosis patients and 40.9% of the patients with pulmonary fibrosis. Almost one quarter of the included patients had experience with an activity monitor. Patients using activity monitors (n=267; 23%) reported having greater insight into their daily performance and activity (80%) and feeling encouraged to accomplish more PA (76%). We should embrace the use of activity monitors to meet the challenge of motivating

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and encouraging people to get moving. An activity monitor is useful to stimulate and improve self-management. Further research is needed to explore the role of self-monitoring with activity monitors, in addition to regular check-ups, in improving patient empowerment and patient care.

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Author Contributions

All authors were involved in the design of the study and data collection. CH, DD, and MD analyzed the data and drafted the manuscript. ME, BS, PW, and JDV revised it critically for important intellectual content. All authors read and approved the final manuscript.

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Data Availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Compliance with Ethical Standards

Conflict of Interest

The authors declare that they have no competing interests.

In accordance with the Dutch Medical Research Involving Human Subjects Act, the Medical Ethics Committee of St. Antonius Hospital Nieuwegein waived formal approval by the Committee.

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