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RESEARCH ARTICLE



"More than effort, it's dedicating time and perseverance." experiences of physical activity and physical exercise in stroke survivor with high functional capacity: a qualitative study

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ABSTRACT

Background: Stroke survivors exhibit sedentary behavior, and many do not engage in physical activity and exercise for a number of reasons. Secondary prevention through physical activity is a priority to avoid a new stroke or disease.

Objective: To describe the experience of stroke survivors with maintained walking ability living in Spain regarding physical activity and exercise.

Methods: A qualitative phenomenological study was conducted. Purposive sampling was carried out to include 35 stroke survivors who had stroke more than 6 months ago from 14 neurorehabilitation centers in 24 cities in Spain. Data were collected through semi-structured interviews and researchers' field notes. The Giorgi approach was used for the qualitative analysis of the data collected.

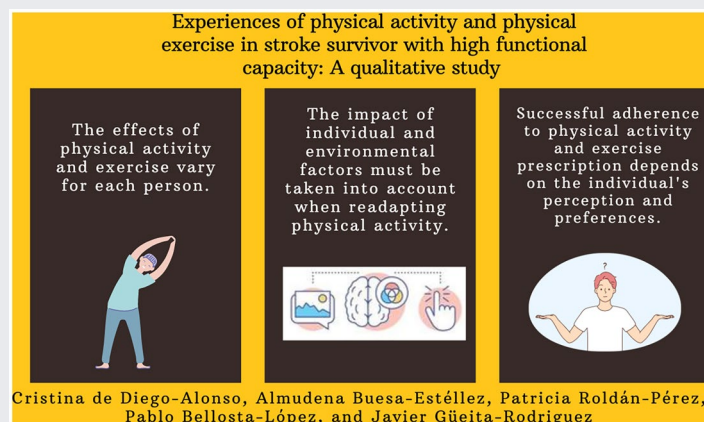
Results: Three themes emerged: a) Changes in the experience of physical activity and exercise adaptation; b) Reasons for and against the practice of physical activity and exercise; c) Experiencing tiredness and fatigue.

Conclusions: Our results show the individual post-stroke perception of each person, the reasons for and against the practice of physical activity and exercise, as well as the impact this has on their daily life and activity. These results will help health professionals to understand the needs of stroke survivors when prescribing physical activity and exercise included in intervention programs.

KEYWORDS

Exercise; physical activity; qualitative research; sedentary behavior; stroke

GRAPHICAL ABSTRACT



> IMPLICATIONS FOR REHABILITATION

- Previous experience and the current situation impact individually on the performance of physical activity and exercise in each stroke survivor.
- The influence of individual and environmental factors must be considered in the readaptation of physical activity after a stroke.
- Successful adherence to physical activity and exercise in stroke survivors, requires knowledge of the individual's perception and preferences.
- Physical activity needs to be adapted to the multifactorial background and progression of stroke survivors, ambulation being a suitable approach.

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Introduction

Physical activity (PA) is defined as any bodily movement produced by skeletal muscles that results in energy expenditure that can be measured in kilocalories and can be classified as occupational, sports, fitness, household or other. Likewise, Physical Exercise (PE) is a subset of planned, structured, repetitive PA with the ultimate or intermediate goal of improving or maintaining physical fitness [1].

Stroke survivors exhibit a poor level of PA and sedentary behavior [2], which implies not reaching the PA levels recommended by the World Health Organization (WHO) [3]. However, little is known about the conceptualization and categorization made by stroke survivors in relation to the PA involved during the performance of daily activities and the factors that may influence this perception and efforts to adapt. Previous research shows that some stroke survivors associate intense PA with PE, and just little associate it with the performance of daily life activities (e.g., self-care or housework) [4].

Qualitative studies among stroke survivors reveal diverse preferences in PE and daily activities chosen by patients [4], influenced by varying levels of capacity, opportunities, and motivation [5]. The complexity of the reasons related to this sedentary behavior are multifactorial [5]. Most qualitative studies on stroke survivors have focused on fatigue [6], physical disabilities [7], or the barriers and facilitators to PA participation particularly in those with a sedentary lifestyle [8,9]. However, little is known about the experiences of stroke survivors with mild sequelae who are able to ambulate and may lead a less sedentary lifestyle.

To date, no qualitative study has described the experience of how PA and PE characteristics are modified in stroke survivors in Spain and the adaptations this entails in their lives, especially those preserved functional walking ability and without impaired comprehension and communication after at least 6 months post-stroke. This subgroup, often overlooked in research, holds significant potential within the healthcare system to actively engage in adopting healthy lifestyles, thereby reducing the risk of stroke recurrence [10,11]. Research into their lived experiences is needed to inform the development of individualized intervention plans.

The aim of this study was to describe the experience of stroke survivors with high functional capacity in Spain concerning their PA and PE habits and preferences, exploring the influence of the environment and the individual to understand their reasons for undertaking and adhering to PA and PE.

Methods

This study presents the results of a qualitative research study, included as part of the multicenter Part&Sed-Stroke project [12] designed to examine the multifactorial interaction between PA and participation in everyday life of Spanish stroke survivors over 6 months ago, able to walk who live in their own home and presenting a high functional level when meeting the eligibility criteria described below.

A phenomenological study was carried out [13] based on Husserl's framework [14] to explore the essence of stroke survivors' lived experience using their first-person narratives regarding PA after stroke. In the field of qualitative studies, phenomenology seeks to gain an understanding of the lived experiences of other people in specific circumstances [13] such as therapeutic interventions or health habits [14]. The aim of phenomenology is to study the phenomena as they appear, in order to arrive at an essential understanding of human experience [15].

Research team and reflexivity

Five researchers (2 occupational therapist and physiotherapist and 3 physiotherapists) participated in this research, with an average of more than 10 years of experience working with people with neurologic pathology. All the investigators had experience in health sciences research. ABE, JGR, PRP, PBL were PhD and CDA was a PhD student. Specifically, ABE and JG had more than 10 years qualitative research experience and PBL had extensive experience on methodological research designs as well. CDA had received training in qualitative research and was supervised by ABE and JGR during the conduct of this study. None of them had a clinical relationship with the participants at the time of the study.

Regarding the reflexivity strategies, a bracketing process was carried out prior to the study. Continuously throughout the rest of the phases, the positioning of the research team was established through an intense collaboration among them with scheduled meetings to share the project development, as well as to triangulate during the different stages of the analysis and drafting of the results [16].

Participants and sampling strategies

Stroke survivors participating in this qualitative study were recruited from the Part&Sed-Stroke project [12] with a sample of 140 subjects. Participants were identified and recruited from 14 specialized stroke rehabilitation centers from 24 different cities throughout Spain. The participating centers were associations and private institutions where participants attended on an outpatient basis one or several times a week to receive individualized treatment sessions specialized in neurological rehabilitation (physiotherapy, occupational therapy, neuropsychology or speech therapy). According to the purposive sampling and applying the inclusion criteria described below, the sample participating in this qualitative study was recruited.

In phenomenological studies, it is common to include participants through purposive sampling [17], selecting individuals based on specific purposes associated with addressing the research question or objective of the study [13,17]. Participants who met the inclusion criteria were recruited consecutively from the initial sample of 140 subjects, and data collection ceased when the information obtained in the interviews became repetitive [17]. Of the 140, 54 were asked, 4 did not want to participate and 15 did not answer or could not be interviewed. The final sample size was 35 participants, as no new data were obtained.

The inclusion criteria consisted of: a) adults over 18 years of age, b) with a history of stroke (with a medical diagnosis) more than 6 months ago, regardless of etiology, c) residing at home, d) Functional Ambulation Categories ≥ 3 (able to ambulate). Exclusion criteria: a) patients with cognitive impairment Mini-Mental Cognitive Test score >24 and/or alterations in verbal communication (no aphasia), b) refusal to participate.

Data collection

Based on the phenomenological design, first-person data collection tools (unstructured and semi-structured interviews) and researcher's field notes were used simultaneously [17]. The first phase of data collection was carried out from September 2021 to April 2022 by means of unstructured interviews. In the second phase carried out from April 2022 to July 2022, a question guide was developed from the data obtained in the first phase

(participants P01 to P03) and through a triangulation process between the research team members (CDA, ABE, PRP) that served as the basis for the format of the semi-structured interviews (participants P04 to P35) (Table 1).

The first interview was conducted face-to-face by CDA and ABE, whereas the remaining interviews ($n=34$) took place *via* a private video chat room, due to the geographic distribution of the sample. All interviews were conducted and recorded with the written permission of the participants prior to the interview. Each participant received a personalized invitation to a videoconference by the Microsoft Teams platform (Microsoft Corp., Redmond, WA, USA; version 24256.2502.3123.1, 2023) as part of the institution's Microsoft 365 Education Subscription and under university security protocols. The interviews were transcribed verbatim, and a total of 1194min of recordings were obtained. In addition, 35 field notes were collected by the researchers during the interviews [17]. To ensure confidentiality, each participant was assigned an alphanumeric code and the interviews were stored and password-protected by the research team until analysis and then destroyed.

Table 1. Interview procedure.

Unstructured interviews	
What is your experience of physical activity after stroke?	
Semi-structured interview guide	
Issue/Topic	Questions
Physical activity and physical exercise	Before the stroke, what did you consider physical activity and exercise to be like? What about now? What aspects influence whether you allocate more or less days/hours to the activities you can do? Among the activities you do now, which ones give you the most satisfaction? Why? Why and how do you do them? What information have you received about the physical activity you can do to "fight the after-effects of stroke?" What activities do you find most strenuous? Which activity is the easiest for you physically and/or mentally?

Prior to the interviews, sociodemographic data, including age, sex, place of residence, and the presence or not of a caregiver; as well as clinical data, including months since stroke, type of stroke, cerebral hemisphere affected, the Barthel Index (BI), and the International Physical Activity Questionnaire short version (IPAQ-SF), were collected in the participating centers through an encrypted data application [18]. The IPAQ-SF provided the minutes performing moderate-to-vigorous physical activity during the week [19], which allowed classifying participants complying with the WHO recommendations for adults living with disability (i.e., 150min of moderate-to-vigorous PA [3]).

Data analysis

The thematic framework method was used for data analysis, according to Giorgi's model [20]. This model presents five stages of data processing (Figure 1).

Subsequently, in both interview phases, a coding grid was created with the units of meaning, their groups, and the identified themes. Within this grid, narratives were identified that justified the results obtained [21]. This was followed by group sessions between the researchers. In these sessions, the themes obtained in both interview phases were analyzed and compared. Subsequently, in the triangulation, the final themes were obtained and decided by consensus among all the researchers involved. Finally, the synthesis of this information was transmitted to 30 participants to check that no relevant information had been forgotten. As a deviation from the published protocol [12], no qualitative software was used to analyze the data. For the analysis, the Excel program was used to organize and share the coding process (Figure 1).

Criteria for rigor and quality

To ensure the methodological quality of the study, the Standards for Reporting Qualitative Research were followed [22] together with the Consolidated Criteria for Reporting Qualitative Research

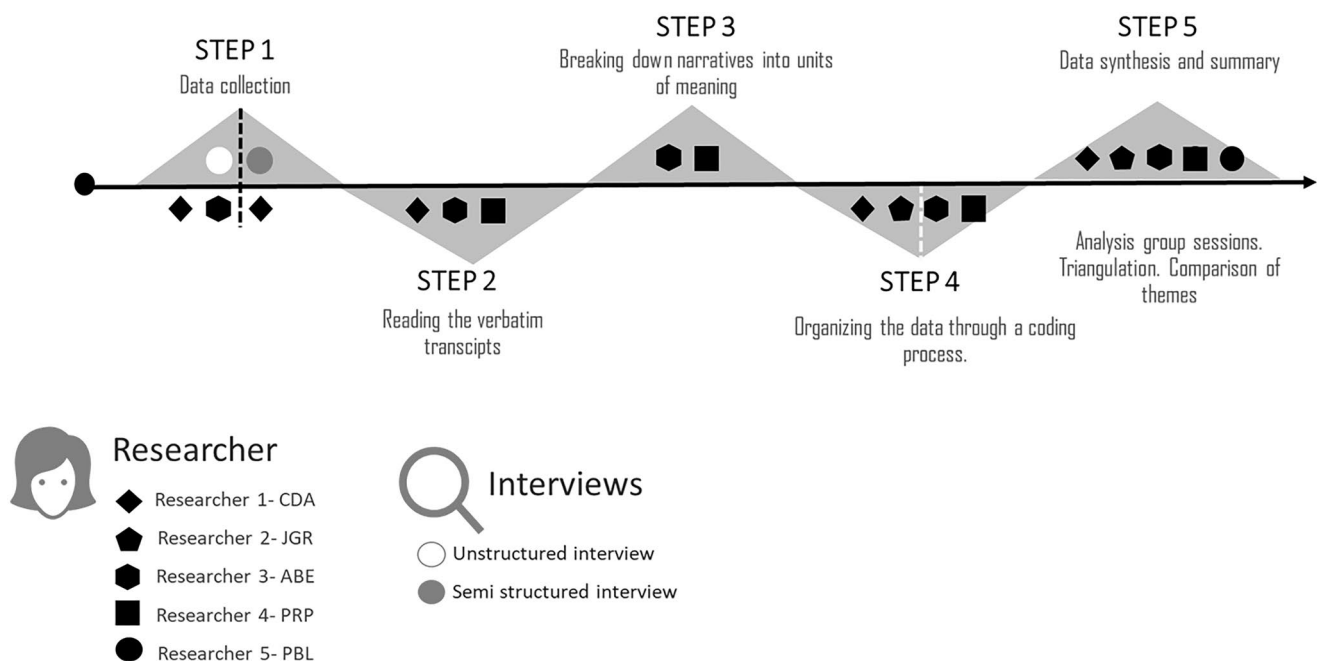


Figure 1. Description of the data analysis process.

Table 2. Trustworthiness criteria.

Criteria	Techniques Performed and Application Procedures
Credibility	Investigator triangulation: Team meetings were organized during the analysis of the situation, to design the questions for the semi-structured interviews, to compare the results and to identify the final results. Some of the participants read the preliminary results and agreed with them.
Transferability	In-depth description of the study, providing data and describing the study design and its different sections (context, research team, reflexivity process, sampling, inclusion criteria, data collection and analysis).
Dependability	Audit by an external investigator, responsible for the evaluation of the study protocol, with special attention to the method and implementation process during the study.
Confirmability	Researcher triangulation, triangulation of data collection. The reflexivity process was carried out by describing the positioning of the researchers; reflexive debriefing by the researchers during data collection and analysis. An interpersonal reflexivity process was carried out during the different stages of the study,

[23] (<https://www.equator-network.org/>) (Supplemental material). The techniques and application procedures used to check reliability are described in Table 2. Specifically, to achieve dependability, the researcher PBL supervised the implementation of the protocol. Also, the researcher JGR, given his extensive experience in qualitative research, guided the study, advising in the different phases which were the most valid strategies to maintain rigor.

Ethical considerations

This study was approved by the Research Ethics Committee of the Community of Aragón (internal registration number: PI21/333). Furthermore, this study was conducted in accordance with the principles of the Declaration of Helsinki. Permission to record audio and video was obtained from the participants by means of an informed consent form.

Results

A total of 35 participants (12 women, 23 men) with a mean age of 57.2years come from 24 cities of seven different regions of Spain participated in the study. They showed the experience of a section of people who had had a stroke more than 6months ago, and who live in their own home, walk independently and have no communication barriers. In particular, the present study explored these adaptations in a profile of stroke survivors able to walk, 40% of whom are independent (BI = 100) and 60% mildly dependent (BI ≥ 60) in activities of daily living. Twelve (34,3%) of the 35 participants needed help from a caregiver. The sociodemographic and clinical characteristics of the participants are shown in Table 3.

Three specific themes emerged from the data analyzed: a) Changes in the experience of physical activity and exercise adaptation; b) Reasons for and against the practice of physical activity and exercise; c) Experiencing tiredness and fatigue. Table 4 shows a summary of the coding tree, with meaning units identified from narratives with relevant information, clusters of common meanings and, finally, the main themes.

Five participants gave their opinion on the synthesis of the results, indicating that their experience of PA was reflected in the information showing the different experiences without forgetting any relevant aspect.

Changes in the experience of physical activity and exercise adaptation

The participants described the characteristics of the activities and exercises they were able to perform, comparing them with their situation prior to the stroke. Pre-stroke activities were defined as sports, since they gave them the nuance of greater perceived effort, energy consumption and duration, together with the pleasure they generated as hobbies that they previously enjoyed. After the stroke, all activity and exercise lost its playful nature, due to the greater difficulty, effort and energy consumption required, becoming instead an obligation or necessity, considering it indispensable due to its benefits.

Well, now, physical activity is a must and before the stroke it was a good hobby I had. (P33)

I exercise every day; for me this is my current job. I go to the gym every day, I work out for 3 hours, 2 and a half hours, 3... Whether it's raining, windy, hot, cold... That's my job. (P28)

The perception of post-stroke intensity increased, limiting their ability to reach the same levels of cardiovascular effort, even though they knew that the activities were the same. They even define PA as anything other than sitting, since even getting out of bed or doing household chores is perceived as an effort.

Maybe when I didn't have the stroke, of course, for me going shopping, carrying bags and climbing the stairs was not a physical activity, but now it is, that's why, that aspect has changed. (P08)

Now, basically, getting out of bed and going to the bathroom is hard for me because of the effort. And there the effort is... it's unbelievable, but that's just the way it is. (P16)

Activities after stroke were described as "done differently", at a lower intensity, reducing speed and pulse rate due to the difficulty to include and maintain them. Tasks that they would never have thought of as costly, became demanding and energy demanding, and were avoided, adapted, or substituted as the main strategies.

To get the heart rate up... No, no. I can't do such a vigorous activity to get the... to get the heart rate up like it used to. (P33)

I used to do a lot of things in one hour and now maybe an hour is not enough time, now you move at a different speed. (P01)

The other day I went to a notary, I parked the car - I, I measured it, right? - 450 meters from the entrance of the house to the notary's office.... .. a quarter of an hour through Barcelona. This is my speed at the moment. (P18)

Walking was the activity that participants most compared before and after their stroke, due to its applicability and feasibility in their daily lives, describing its characteristics in terms of speed, distances, and effort. Walking is most often performed to get to places by choosing long paths or uphill slopes, or as a way to monitor their evolution by paying attention to the speeds and distances covered.

Now, besides going out for coffee, I usually go out for a long walk in the morning, of course, I go to more distant places, right? yes, I combine coffee with (laughs) moving around a bit. I go for a walk around the park, right?. (P11)

I normally walk every day, except if it's very windy or raining; I walk every day for half an hour or three quarters of an hour. If I can't walk for whatever reason, I get on my bicycle (...) at home, which for me is already a big effort. (P01)

The participants narrated that they delegate the burden of exercise to rehabilitation, not wanting to perform other demanding exercises outside of that environment, in order to prioritize

Table 3. Sociodemographic and clinical data of the participants..

Code	Age	Sex	Residence Place	Time since stroke (Months)	Caregiver	BI	WHO
							Recommendations (150 min of MVPA according to IPAQ-SF)
P01	58	Women	Zaragoza	139	No	70	No
P02	50	Women	A Coruña	114	No	90	Yes
P03	54	Women	Burgos	35	No	75	No
P04	62	Men	Huesca	30	No	100	Yes
P05	59	Women	Zaragoza	43	No	95	No
P06	61	Women	Ferrol	17	No	95	No
P07	50	Women	Ferrol	67	Yes	95	No
P08	50	Men	Canet del mar	24	Yes	100	No
P09	69	Men	Sabadell	148	Yes	100	Yes
P10	73	Men	Zaragoza	100	No	100	No
P11	73	Men	Huesca	42	No	100	No
P12	51	Men	Cornella de Llobregat	36	Yes	95	Yes
P13	72	Men	Valladolid	8	No	100	No
P14	64	Men	Torrelles de Llobregat	49	Yes	85	No
P15	65	Men	Burgos	10	No	85	No
P16	58	Men	Vitoria	30	Yes	80	Yes
P17	71	Men	Sanlúcar de Barrameda	46	No	95	Yes
P18	66	Men	Sant Cugat del Valles	68	No	100	No
P19	59	Men	Alpedrete	44	Yes	95	No
P20	58	Men	Bilbao	7	No	95	Yes
P21	61	Women	Madrid	148	No	100	Yes
P22	45	Women	Galapagar	130	No	100	Yes
P23	58	Men	Barboles	12	No	100	No
P24	24	Men	Barbastro	36	Yes	95	No
P25	62	Men	Zaragoza	65	No	95	No
P26	43	Men	Esplugues de Llobregat	79	No	100	Yes
P27	27	Women	Xove	103	No	100	No
P28	52	Men	La palma del Condado	55	No	95	Yes
P29	79	Women	Burgos	35	Yes	80	Yes
P30	60	Women	Oña	17	Yes	70	Yes
P31	50	Women	Ferrol	35	No	100	Yes
P32	60	Men	Zaragoza	40	No	90	No
P33	46	Men	Zaragoza	44	Yes	85	Yes
P34	43	Men	Marchena	46	No	100	No
P35	70	Men	Huesca	173	Yes	95	No

BI: Barthel Index; IPAQ-SF: International Physical Activity Questionnaire Short-Form; MVPA: equivalent combination of moderate and vigorous intensity PA; PA: physical activity; WHO: World Health Organization.

Table 4. Summary table with themes, groups of common meaning and meaning units.

Meaning units	Groups of common meaning	Theme
Sport vs. obligation and necessity. Perceived intensity. Modifying the intensity (speed and heart rate). Adaptations. Choosing feasible exercises. Prioritizing rehabilitation. Challenges.	Comparing pre- and post-stroke activities and exercises. Factors that modify the characteristics of the activity or exercise. Impact of perceived exertion.	Changes in the experience of physical activity and exercise adaptation.
Satisfaction, affinity, and relevance. Excuses. Fear of falling or pain. Choosing modifiable exercises. Accessibility issues. Meteorological factors.	Personal goals. Decisions according to the type of activity to be performed. Decisions due to the environment.	Reasons for and against practicing physical activity and exercise.
Fatigue vs. tiredness. Overexertion and maladaptations. Anticipation and preparation. Strategies for recovering energy.	Perception of metabolic expenditure. Impact on participation.	Experiencing tiredness and fatigue.

their efforts for rehabilitation. However, some participants try to adapt, set themselves challenges, try new activities and maintain a higher level of exercise after stroke, choosing exercises and activity options that are feasible to do, even if they had not experienced them.

Now, after the stroke, I am trying, above all, to give priority to rehabilitation. To move, to see if I am getting stronger and that is what I am doing now, fighting, and struggling, yes. (P13)

What I do is, as a priority, in the mornings I go to the physio and in the afternoons, let's say, I go for a quiet walk. Of course, for me it's a physical activity. (P07)

Now I can't do what I did before. I would like to go for a bike ride, I can't, but I can do this in the water, and I would never have thought of it... Well, I'm going to do it. Why not?. (P02)

At the moment, I'm able to swim well underwater with one arm. I don't get very far, but I can do it. (P12)

I'm doing the elliptical, some TRX and abs... And then I'm doing squats on a trampoline I have. To improve my balance, because it's really bad; my balance is very damaged, very much. And well, that's the activity I'm starting to do now... with continuity. (P19)

When we do outings in the countryside, in the mountains, at the beginning I'm a little bit more apprehensive because of the unevenness of the roads... I like it a lot more, because in the city I get bored.... Then it's a matter of looking for something to get out of that routine; it's always good for you. (P15)

Reasons for and against the practice of physical activity and exercise

On a personal level, those who undertook PA described the satisfaction they felt from doing it, especially because of previous affinity, experiencing their progress, or relevance outside the clinical environment that drives them to do it. Regarding functioning, they also expressed the need to release energy and emotional tensions, which was a determining factor for their decision to do it on a continuous basis as an outlet.

Well, it's true that when... I didn't ride my bike for so long, the first time I rode it, I was scared. I remember that I got emotional and all when I was riding it. (P34)

Physical activity is good. For me it's like an outlet, right now I mean. Well, it's like... look, the body needs it a bit and... well, in the end you feel better. Even if you have to sit down and rest, but in the end you really feel better. (P07)

I put in less effort, but at least I am able to ride my bike, which gives me a lot of satisfaction. (P20)

My body needs to vent its energy in some way. So, with exercise, for me, doing sports, going to the gym helps me a lot. (P27)

... seeing this man what had happened to him and all, well, physical activity is of tremendous importance. (P33)

For those who admitted not engaging in PA, they made "excuses" for not leaving their comfortable routine and deciding not to do anything, because it generated insecurity. Moreover, laziness and sluggishness caused by inactivity create a vicious circle.

More than effort, it's the fact of dedicating... The time, that consistency. (P24)

It's a tremendous effort for me to get started. However, once I get started, it's a bit easier, but it's really hard for me to start, I feel really lazy. (P22)

So, in the confinement it has been great and in the confinement, I exercised strictly every day. Now, ugh... Well, when there's not one excuse, there's another. Then the laziness will get the better of you. (P26)

Because they have also told me which exercises, I can do... Then I adapt and do the ones I like the most and the ones I don't (laughs). The ones I like the most are the ones that, mmm... don't cause me pain (laughs)... I don't want to strain, I'm afraid that, by straining too much I'll stiffen up and then I'll be in pain all day long, right? (P11)

The type of activity to be performed was fundamental, since the difficulty in adapting the PE to be able to perform them with only one limb made them very fearful of hurting themselves or falling. For this reason, they usually chose exercises that they could modify with certain solvency and comfort, which would allow them to progress in their practice and development. The participants usually begin with static, controllable activities such as the adapted exercise bike, rather than walking on the treadmill.

They do not usually choose to start by swimming, as their ability to float is already too difficult.

You know? But now... Man, I could do it with the right side, but I'm also very scared because I think: "Oh my, if I screw up my right side, what will I do?". (P19)

It's not that I get tired; it scares me a lot and also, hmmm (clicks tongue) I have to be more aware of, of buoyancy. Before it was a more natural thing, now it's... well, I have to be aware not... not that I'm going to drown, because I'm sure I won't drown, because I swim or used to swim quite well, but... it makes me a little nervous. (P19)

For example, running. I run badly....I run like a... a duck, come on. And... I'm very afraid there to trip and fall. Very scared...when I didn't have a stroke, you always put your hands down or something to soften the blow, and I'm afraid of falling. (P19)

The lack of accessibility of the environment was described as a sufficient reason to avoid PA. Regarding accessibility, going out into the street was perceived as a challenge due to the obstacles and slope of the pavement. Other environmental aspects such as meteorological factors that often lead to inactivity, and more specifically, the temperature of the sports facilities, which generate changes in their perception of energy expenditure.

Within the advances available to us, I use the stationary bicycle. (P10)

Going out to the center is very difficult for me, because ... when there are a lot of people, I am afraid that someone will push me or something and I will go to the ground. So, I limit myself to this, to being at home and so on. (P13)

Look, my street has a 21% slope: ... Just think of that alone, and in order to leave the house and walk to the car - which is parked, I have to climb up stairs. (P18)

The thing is that now it's been a week that I: "I don't go out now". If I go out now, I, I just melt, and you go out to the street and (laughs) you come back with third degree burns... I can't bear 35 degrees out there in the sun. (P14)

Swimming, which I liked very much. Now I don't go swimming for one reason, because at the indoor pools the water is not warm enough for what I need, because I have spasticity. So, I come out of the water stiff, like totally stiff, stiff, stiff.... So, I've stopped doing that. (P22)

Walking is easy. I mean, walking, most days, I can do 4km or more without noticing, so, fine. The bicycle ugh... The bicycle makes me very lazy because in winter it's cold, in summer it's hot. (P26)

Experiencing tiredness and fatigue

Participants were unable to differentiate between tiredness and fatigue, whether physical or mental, as they often referred to the subjective effort involved in exercising. They described the factors related to the perception of fatigue, as well as the fatigue caused by the performance of light daily activities that leave them depleted of energy, and the influence that both situations have on resuming participation in the form of overexertion.

Let's see, I don't do any intense activity because I can't. Not my head or anything physical, I can't do it. All the activities I do are moderate. (P07)

I feel tired with anything... Well, yes, cleaning the windows, the kitchen. I mean, what I notice is that I get tired, I get fatigued... so mmm doing anything makes me tired. (P05)

In addition, they recounted the anticipation and preparation for exercise and the impact of exercising. Moreover, muscle fatigue

generated maladaptations in the performance of the activity, which gave them an additional reason to stop. Also, they were particularly fatigued on the less affected side of the body, which had to make a greater effort to compensate for the movement of the more affected hemibody.

I want to start running and, and I have told... these guys that, that they should prepare an intensive program for me. (P19)

Quite a lot of effort, because of course, I have half of my body which has to move the whole body. (P25)

They are additional fatigues, I mean, when I'm walking a lot... if I have to stop sometimes it's because my shoulder hurts a lot, because I'm pulling my shoulder a lot. (P15)

They also shared the strategies employed to regain energy, such as taking breaks. Sleep is a vital choice that they value in their daily lives, as well as knowing their limits and the effects of breaching them.

To do more I personally just need to do a little bit and I can rest, a little bit more and rest. In other words, something that allows you to do it and rest. (P07)

Discussion

A sample of 35 stroke survivors living at home in several locations in Spain described their experiences concerning PA and PE, most of the time by comparing activities they remembered practicing before the stroke with their current activities. This aligns with previous studies [4] showing the difficulty in returning to active participation [24] against those who often resume the types of PA they did before the stroke [25]. Similarly to studies carried out in other countries [5, 8,9,26], our findings also reflected a change in the perception of PA and PE after the stroke, transforming it from being an idle activity carried out in leisure time to an obligation. This change may be key in understanding the development of sedentary behaviors and the non-acquisition of active routines [27], highlighting that self-efficacy and the previous experience can improve adherence to PA and PE [28].

The participants shared their proposals for adapting the performance of PA and PE to their current capacity, as noted in a study by Fallahpour et al. [29]. All these adaptations seemed to influence the perceived effort, in line with previous authors [30]. However, our findings delve deeper into the strategies adopted by participants to cope with this increase in their perceived exertion, describing how they avoid, modify or substitute activities. These findings will help to promote preferences adjusted to PA intensity tolerance of stroke survivors [31]. Notably, the present study provided valuable information about stroke survivors with good functional status, able to walk, preserved cognitive capacities, and no levels of moderate or severe dependence in their daily lives.

Among the PA and PE proposals made by the participants after the stroke, walking stands out as the activity they are best able to perform, which is useful and necessary for carrying out social activities. According to Lord & Wesselhoff [32], 70% of stroke survivors regain ambulation, but only 37-60% of stroke survivors achieve mobility in the community even four years post-stroke [24]. Our participants, walking independent, presented an average of more than four years of evolution since the stroke. Despite these PA facilitating factors, most of the participants failed to comply with the WHO recommendations of PA [2,33]. Therefore, it is essential to understand other limiting factors of PA influencing their sedentary behavior. These included factors such as architectural barriers in the city and meteorological and environmental

factors such as rain or temperature [24], which was reflected in the narratives of the participants from 24 cities in different regions of Spain with widely diverse climates. Therefore, despite ambulation is the most useful and effective activity for the performance of community activities. Our participants, able to walk, showed limited community transfer or performance of daily activities. In fact, only 15 (43%) of the 35 participants met the WHO weekly PA recommendations. This situation could show the lack of awareness of perceived exertion in everyday activities and the need for health education [34,35].

The participants described that they prioritize and reserve their efforts for their rehabilitation sessions. They also reported a desire to face new challenges. In light of our findings, it seems necessary to continue promoting a paradigm shift in which individualized guidelines are promoted for PA to be performed outside the health care setting, in a normalized environment [36-38].

Our findings highlighted the multifactorial nature of decision-making regarding PA and PE in stroke survivors, describing the ambivalence of personal aspects in incorporating PE in their lives. As noted by previous authors [5,39], the promotion PA after a stroke requires assessing the synergies between motivation and capacity and integrating these synergies into interventions. Participants in our study identified factors that they considered to be related to performance of PA and PE (person, environment and behavior), consistent with previous findings [40].

The participants reported the need for physical and mental preparation prior to the performance of PA and PE, which was also reflected by other authors previously as a self-regulation strategy, by anticipating and overcoming barriers [40]. Our results showed that maladaptations, in some cases, occurred when the strategies failed. Furthermore, the participants indicated the factors influencing the selected activity, showing that few people were able to make this leap to the incorporation of moderate or intense PA in a normalized social environment once the initial rehabilitation phase was completed.

The participants described the ways in which they have adapted the performance of PA, demonstrating a process of resilience and problem solving, which is considered a personal capacity for adaptation beyond the after-effects of the stroke [40]. To date, most research has focused on developing intervention plans to increase the level of PA but neglecting aspects such as self-efficacy and self-concept, or expectations of results [4,5]. Therefore, a change is needed in the rehabilitation model to consider the multifactorial relationships that condition adherence to PA and PE and the various adaptation options, considering the individual's perception.

Our findings showed the different experiences of physical and mental tiredness and fatigue based on the perception of energy expenditure. Almost 50% of people who have suffered a stroke experience post-stroke fatigue regardless of the degree of recovery. Our results show the need for daytime and nighttime rest times and awareness of limits as coping strategies in those with an adequate level of PA to tolerate perceived exertion and balance exercise levels, in line with previous studies [41]. It also reveals the lack of health education, awareness, or accessibility of useful tools for self-perceived effort or records of activity that can help people to plan the amount and/or intensity of PA to be performed per week, as well as possibilities to graduate it, adapt it and combine it with rest times.

Need for further research

Future studies should analyze the experience of physical activity and physical exercise in this high functional capacity group of stroke survivors during the first 6 months post-stroke. In addition

to observing the segment of more dependent stroke survivors, both during the first 6 months and thereafter.

Strengths and limitations

Regarding the strengths of this study, this is the first qualitative research carried out in Spain in which information was collected on the experience of these people residing in their own home and their natural environment regarding the performance of PA and PE, with little updated qualitative [42] and quantitative research [25] in other countries. In contrast, the limitation of this study is related to that these results cannot be extrapolated to all stroke survivors, due to the nature of the research question, the qualitative design selected and sample characteristics (i.e., cover only people with walking without aphasia or cognitive impairment).

In conclusion, the results show the individual perspective on readaptation to PA and PE after stroke without severe sequelae in Spain, considering the sequelae that limit activity, together with the preferences of individuals and the previous history of active lifestyle, along with the multiple influences of the environment on this behavior when the stroke sequelae do not limit ambulation and therefore the possibility of movement.

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