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Body Awareness, Self-Identity, And Perception of Exercise Importance After Stroke Rehabilitation

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Abstract

A stroke is a serious life-threatening medical condition that happens when the blood supply to part of the brain is cut off. Although stroke presentation rate is decreasing, it still continues to be one of the main cause of mortality and morbidity in Portugal, its prevalence remains high. Stroke consequences, in most of the cases, results in some degree of dependence with direct implications for the daily life of the stroke survivor who goes through a long process of adaptation and acceptance of their new reality. The purpose of this study was to understand stroke survivor's self-perceptions regarding their body awareness, body image, self-identity, and the perception of exercise importance after the rehabilitation discharge.

Methods

We conducted 15 semi-structured interviews, via zoom platform, with stroke survivors from both sexes, aged between 20 and 52 years old which were integrated on the group "Grupo de Ajuda Mútua" from the national organization "Portugal AVC". Due to the national dimension of this organization, study participants were distributed all over the continental territory of Portugal, from north to south (including the districts of Viseu, Guarda, Lisboa, Faro, Porto e Aveiro). The data analysis was conducted using the Nvivo software.

Results

Stroke survivor's self-perceptions of their body and their Self change, independently of the motor sequelae. The way the survivor sees himself in the first phase after the stroke, causes a change in the perception of his own body, leading to the emergence of issues

related to his own identity and a reduction in self-esteem.

Discussion

Stroke survivor's self-perceptions about their body and their Self changes, independently of the motor sequelae. The way the survivor sees him/herself in the first phase after the stroke, causes a change in the perception of his/her own body, leading to the emergence of issues related to his/her own identity and a reduction in self-esteem. All these issues tend to dissipate as there is an understanding and gradual acceptance of the stroke. The way society sees the stroke survivor also negatively influences the survivor's self-perceptions. Exercise may have a relevant impact on such perceptions and on the way survivors perceive themselves after stroke.

Conclusions

The perception of the importance of physical exercise after stroke rehabilitation is unanimous among survivors, but there is an overlapping between physical exercise and therapeutic exercises, in most survivors, which still demonstrate some lack of confidence in sports professionals, suggesting the need for specific physical exercise programs for stroke survivors.

Keywords: Body Awareness; Physical Exercise; Self-Perceptions; Self-Identity; Stroke survivors

Introduction

Cerebrovascular diseases are the major cause of death in European Union. In diseases of the circulatory system, where cerebrovascular disease stands out, stroke is the one with the

most significant expression (Ferreira et al., 2017). Stroke is considered the most common neurological disorder among adults and the leading cause of mortality and morbidity. The physical and cognitive consequences can mostly sometimes, cover up the emotional changes that are assumed to be important in the rehabilitation and quality of life of stroke survivors.

According to (Mukherjee, Levin, & Heller, 2006), a stroke leads the survivor, the family and the health professionals involved, to some ethical dilemmas. After a stroke, it is common for the survivor to experience dysfunctions in the emotional, cognitive, physical and social domains, the rehabilitation of these survivors must extend beyond hospital or similar facilities, it is extremely important that there is an extension of some therapies to the family environment, the survivor must feel all the support and attention in order to minimize the impact of the sequelae left by the stroke, thus promoting an improvement in the quality of life and a milder adaptation in the emotional and social domains as well. Most of the time, the biggest difficulty that the stroke survivor has is acceptance and understanding of the stroke. The focus in stroke rehabilitation is the rehabilitation of physical capacity. Physical capacity is thus seen as the individual attribute that one must work with and adapt to neuromuscular changes resulting from stroke, although it is widely recognized that emotional and social changes are equally important in an individual's physical rehabilitation process, these aspects have not yet been adequately explored in the stroke rehabilitation programs (Ellis-Hill, Payne, & Ward, 2000). In this context, it is important to understand how the emotional issues resulting from the stroke, namely the issues related to its new "Self", influence survivors' perceptions in the domain of Body awareness, Self-Identity, and the perception of the importance of physical exercise after discharge from rehabilitation. The cause of emotional problems after stroke are complexes involving neurological, physical, and cognitive constraints and the restriction or loss of ability to perform activities. It is expected that these constrictions caused by stroke, profoundly affect survivors' perceptions of identity and self-esteem (Mukherjee et al., 2006). Survivors experience a separation from their "self" before the injury and associate rebuilding their identity as an important goal in their recovery (Levack et al., 2014). Identity change has been described as the "loss of myself" and the distancing of the new "Self" that is perceived as unknown or strange, and this perception can persist for up to 5 years (Murray & Harrison, 2004; Pallesen, 2014). Disabilities resulting from stroke negatively affect the "Self" by associating this negative view with high states of anxiety and depression (Ellis-Hill & Horn, 2000; Vickery, 2006). Identity changes affect both stroke survivors and family members, generating a sense of threat and an attempt to restore one's identity. When this attempt fails, an adjustment mechanism is triggered, and there may be a period of mourning for the lost identity and an effort to build a new "Self" (Levack, Kayes, & Fady, 2010). This attempt to build the "Self" is an effort that can influence the rehabilitation process. Negative change in identity, like identity itself, is associated with emotional problems: social isolation, pessimism about the future and loss of quality of life (Cantor et al., 2005; Cloute, Mitchell, & Yates, 2008). Also associated with

psychological rehabilitation, the practice of physical exercise, after the period of hospitalization, assumes a very important role. Despite being known to be highly beneficial and recommended after stroke (Törnborn, Sunnerhagen, & Danielsson, 2017), stroke survivors do not achieve recommended exercise levels (Nicholson et al., 2014; Törnborn et al., 2017), creating the need to explore what are the survivors' perceptions of the importance of physical exercise and its relationship with the change in their perceptions of their new "Self".

The present study focuses on the emotional issues and perceptions of the stroke survivor. It was intended to explore the survivors' perceptions in relation to their new Self, the way survivors see themselves, the perceptions of Self-Identity and in the perceptions regarding the importance of the practice of Physical exercise.

Methods Participants

The participants described in this study (n=15) are involved with the group "Grupo de Ajuda Mútua" from the national organization "Portugal AVC", aged between 20 and 52 years old, with 7 male and 8 female participants. Due to the national dimension of this organization, study participants were distributed all over the continental territory of Portugal, from north to south (including the districts of Viseu, Guarda, Lisboa, Faro, Porto and Aveiro). The organization is a national association, constituted on the 23rd of September 2016, by and for stroke survivors, family members, caregivers, health professionals, associations, projects, and everyone who wants to participate in this cause. Due to the objectives of the present study, we decided to use a qualitative methodology that uses the interview method to collect detailed information about the feelings, perceptions, opinions, and ideas of each of the stroke survivor participants about:

- a. their body and their body image, as well as how these psychological constructs may influence their self-esteem and individual identity as stroke survivors.
- b. the expectations of stroke survivors regarding the role of physical exercise, as a therapeutic intervention instrument, used during the post-stroke rehabilitation process.

Interviews procedures

Initially, a semi-structured interview guide was prepared considering the objectives of the interview, the nature of the research questions formulated, allowing a reflective analysis and a closer look at changes in body awareness, body image, individual identity and perceptions about the importance of physical exercise in stroke survivors, shortly after being discharged from rehabilitation in order to develop a behaviour change intervention to help and encourage stroke survivors to return to regular exercise, always with goals related to improving health and wellbeing. In view of the contingencies

arising from the COVID-19 pandemic that affected the conditions for carrying out the study, we chose, together with the participants, to perform the same alternatively using the Zoom platform with the recording of the same. For reasons of comfort and convenience of the interviewee, interviewees who wished to do so were given the possibility to keep the video camera turned off, proceeding only to the recording of the audio recording with the voice of the interviewee and the interviewer.

For further analysis of the obtained results, and based on the experience lived by the researcher, herself a stroke survivor, the following categories of thematic analysis were pre-defined:

- Perceptions and changes in body awareness and body image.
- Perceptions about the way each one sees himself and the way others see them.
- Perceptions and changes of individual identity.
- Perceptions of the importance of post-rehabilitation physical exercise.

Data analysis

All interviews were transcribed in “Verbatim” and their content was subsequently analysed using specific software for content analysis, NVIVO software, content being analysed, organized and inserted into previously pre-defined categories and subcategories or into other new categories that may eventually arise during this same analysis. The validation of the obtained data was carried out based on the validation procedures proposed by Kvale (1996), using the triangulation of the obtained results.

Results

Body awareness and body image

After a stroke, every survivor seeks incessantly to understand their body and the way in which that event that came unexpectedly, that caused revolution, fear, and insecurity, had an impact on the body itself and the extent of this impact. The self-perception of the body changes considerably, so many of the interviewees consider that the “Achilles heel it's really the body image after a stroke”. Body perception, once known, gives way to the rediscovery of a new body, with new sensations and perceptions allowing “at a certain point my body seemed to be disconnected from me”. The initial impact of this change is always described as “a big impact on our life, of course it has because ... we are fine and from one minute to the next we can't talk”. The body, suddenly marked by a stroke, becomes the target of new feelings, new perceptions, new learning or relearning of skills and competences, the survivor's body awareness changes considerably, the perception of the body is influenced by new experiences, new abilities, however, the person remains the same, with their history, their biography, their desires, and their future expectations, which sometimes

must be changed and adapted to a new reality:

“It was like falling asleep in a turbulent and sudden way without knowing how... and waking up completely different...” (COIMADU10)

The sequelae left by a stroke are visible to everyone, especially if they are sequelae of a physical nature, such as hemiparesis, which is very common in stroke survivors. Such sequelae drastically alter the life of a stroke survivor, they are sudden, unexpected and in many cases devastating, causing very important changes in the daily lives of stroke survivors and their families:

“(...) my sequelae were in motor terms, that is, the side of the brain that was most affected was the right hemisphere, which is then reflected on the left side... and what does this translate into in practice... I have increased spasticity, for example fine hand movements, my hand has robotic movements, if I want to do a digital pinch grip, for example (...). Hemiparesis, ... it's not that I'm paralyzed, it's not ... but the muscles ... it's the response time, and then the muscles became, in my case, with an exacerbated force that I can't control, it's like I had always in tension, or is it always like this closed or it is always like this...aaah... is not functional. In terms of walk, I limp, my foot ... I do not move my foot, but in the meantime, after my daughter's birth I had an operation that is also very common among stroke survivors, which is an equinovarus foot operation, that is, the foot is like hanging foot ... those children who are born with clubfoot ... it is what happens at the feet of stroke survivors”. (COIMADU07)

The discovery of a new body, with new sensations and perceptions, is sometimes a slow and painful process that leads stroke survivors to experience feelings of rebellion and agony, “that moment in time, yes, when I felt lonely and different...”, until the state of acceptance and understanding of the neurological changes resulting from stroke is reached, and finally emerge “that feeling that everything will get better...”. When that moment in time is reached, feelings of rebellion give way to positive feelings of improvement and awareness of one's own body, of the new body, of the new body image:

“(...) it's a moment in time that makes us angry too because, we never expect it to happen to us and that's it [silence] (...) when our human dignity, so to speak, is shaken...it brings us a mixed feeling of emotions... that the situation is a shame... then with that feeling that everything will get better...” COIMADU008

“Unintentionally, I make an effort like this... in fact I have to make a conscious effort to free my arm and I don't know why... body awareness is a very affected issue in neurological terms.”.COIMADU003

When discussing about a multidimensional construct, as is the case of Body awareness, we also have to analyse another

related construct that is the Body Image, which in stroke survivors initially appears to be something distorted, *"The truth is that self-image changes a lot"*, knowledge of one's own body changes, the movement that we once knew undergoes adaptations due to neuromuscular sequelae, *"I don't feel the way I should feel, I feel anything but what I should"*. It is starting from the Body and its sensations, that we have the perception of ourselves (Cash, 2004; Damásio, 1999), sensations and perceptions that we have through the body allow us to have some knowledge about the external world (Damásio, 1999), reinforcing the link between proprioceptive and exteroceptive.

The way stroke survivors see themselves

The perceptions that stroke survivors have of their "Self" depend on the stage they are in. During the most acute phase of the stroke *"it is clear that there"* was that negative inherence", the survivors' reports express negative feelings of confusion in the relationship with their "Self", difficulties in accepting the stroke and the new condition they are in, victimization and uncertainty about the future:

"I did not even see myself as myself, I did not even think I was myself... it was like I was in another body... a feeling of fragility, revolt too, incomprehension... I cannot even explain it, I saw myself as a poor thing who needed help and was not even able to accept what had happened to me." (COIMADU009)

Although, at an early stage of the stroke, all survivors admit the existence of negative feelings in the way they see themselves after the stroke, attitudes towards the disease also seem to influence perceptions, and as one enters the chronic phase, self-perceptions and the way they see themselves changes, restructures, consolidates itself, with the reconstruction of its "Self", although in a *"different way because we always change something, but I already felt like myself"*. Some of the interviewees even share feelings and opinions that describe more positive changes, as they advance in time, and better understand and accept the changes resulting from stroke:

"The way I look at myself was already worse at first... at first because, well, I was facing many barriers and, in the meantime, I managed to prove to myself, not to others because I have nothing to prove to others (laughs)... But for myself, there is nothing I can't do if I decide that I'm going to do it, I'm going to do it, I'm not going to do it like I used to but I'll do it another way so that can... guaranteed I'll do it, if I want to go somewhere I'm not going one way I'm going another there's nothing stopping me these days" (COIMADU005)

Stroke sequelae and resulting disabilities are not transversal to all survivors, they depend on several factors (Aminoff, M. J., Greenberg, D., & Simon, 2015), the consequences of the stroke can occur at the sensorimotor, language, cognitive and emotional levels, depending on the area of the brain injured (Oden, 2002). When stroke survivors are asked how stroke has influenced how they see themselves, the answers, although different, always seem to agree that

"undoubtedly that influence...it is a very delicate matter...". In this self-perception, the sequelae, and the impact that the stroke had on the person are also important elements, the reactions are similar among the respondents, highlighting the desire to *"go unnoticed in the crowd"*. Knowing that this self-perception changes over time, *"a large percentage of our recovery is in the positive attitude we have in the face of adversity"*.

However, after the stroke, as already mentioned, the negative feelings of "depression, anxiety and the feeling of psychological paralysis" are frequent and transport survivors to relieve the most critical phase of the stroke:

"(...) I was 31 years old and suddenly I find myself confined to a bed; I moved my right arm.... the right side of my body I moved; I did not move it was the left side...aaa...and in the background I was there in a diaper, a urinary catheter ... so that part of ... what shall I call it ... the dignity itself... the hygienic part... of a person having a urinary catheter and not knowing why... after the urinary catheters I moved to diapers, all this was a bit complicated... I was 31 years old... (silence)... it is different I do not know..." (COIMADU003)

However, and over time, the progressive achievements resulting from the rehabilitation process, the less positive feelings fade and change as the perception develops that it is possible to improve physical and psychological health.

"(...) but when I realized that I was getting better than I changed my attitude and started to accept and fight with all my strength..." (COIMADU009).

How others see stroke survivors

The way society looks at stroke survivors is greatly influenced by the greater or lesser occurrence of sequelae and the visible physical impact they leave on the survivor's body. We are all aware that, at times, the behaviours, and attitudes of different elements of society can be highly harmful and disturbing for the stroke survivor, in particular those who are loaded with stigma, segregating attitudes or compassion and pity, even more difficult to understand and accept for someone who, sometime before, had a life totally within the norm, in social terms.

"I had that look and those poor and pity words and all those things that make us very fragile or instead of helping us... of course I had that, and I felt it a lot". (COIMADU12)

In an initial phase after the stroke, and even when the survivor is in a process of acceptance and adjustment to his new reality, in the process of adapting to the disabilities resulting from the stroke, individual perceptions of how each one is seen by others, is very similar, with reports of a phase in which *"one has to learn to deal with others, or with others in relation to us"*, being this phase described as a phase in which there is a need to hide the sequelae, visible or not.

"There was a post-stroke period, and of which there is still a remnant, let us say..., in which I lived a period of... wanting to hide from... being ashamed... to people and such, in a miserable state". (COIMADU001)

In the period when the perceptions of their own body are gaining consistency and are still the focus of the survivor, the question of how they are observed by others, by the environment in which they are inserted, conditions their social integration, existing in many cases a need for isolation.

However, when the survivor accepts what happened to him and changes his attitude towards the stroke, the question of how he is observed by others changes radically, from a feeling of *"poor thing with which he was observed by others"* to positive feelings of respect, admiration, and support.

"Initially I felt that everyone saw me as the poor guy who had that unhappiness in life... he got sick... the disabled person... etc... However, and I continue to say that this was when I changed my attitude and thinking, people... family, friends and people who worked with me... started to see me with admiration and much more affection for the way I am and how I face this situation..." (COIMADU009)

This change in attitude, this different view of things, looking at them in a much more positive way, contributes a lot to change the way others see us, developing more positive feelings, respect and esteem that help to consolidate our personality, the way we see ourselves, and the opinion that others have of us and our social value:

"I think that others now see me as someone determined and with a lot to teach and live still...what was a look of pity and sadness is now a look of admiration and pride...without a doubt...an example...that makes me very happy" (COIMADU10).

How stroke survivors perceive the self-identity

Self-identity is seen as the set of own and exclusive characteristics with which people can be differentiated from one another. Individual identity is something intrinsic, unique, personal, and authors such as Mannheim (1929), elaborate a concept of identity in which the individual creates his personality, but also receives it from the environment where he performs his social interactions.

"I'm the same person and I'm not, it's strange and hard to explain..." (COIMADU008)

Concerns related to self-identity are often referred to as pertinent in stroke survivors. The changes resulting from the stroke leave the survivor in an identity limbo, *"that duality of mine, I did not know if I could go back to the work...I did not feel myself"*, having a process of reconstruction of its "Self" after the Stroke, and we can even speak of the construction of a new

Self-identity because of an adjustment to the new reality.

According to (Ellis-Hill & Horn, 2000; Ellis-Hill et al., 2000), after a stroke, the survivor enters a completely different world from what he was used to, experiencing challenges at a physical and psychological level, the body seems separated from the "Self", *"There were times when I didn't really know who I was anymore"*.

These questions and confusions are described by survivors as relevant at an early stage, as the rehabilitation process progresses and the "stroke grief" takes place, and they are progressively clarified and contributing to the construction of a new identity "[...] it can be named that the remaining sequels generate the grief of the "lost body", or the lost independence" (Delboni, Malengo, & Schmidt, 2010).

"In the middle of that whole situation and the difficulties and adaptations and re-learning, I got to the point where I wondered who I was...(silence) would I be able to go back to doing what I used to do...how will it be later, anyway...this was also at a more complex stage when I was discharged from the hospital and started physical therapy and all these processes of reacquiring skills and competences..." (COIMADU008)

Survivors' reports at an early stage of the rehabilitation process express the confusion of feelings and perceptions they have about themselves, and there are also reports of important changes in self-esteem. The feeling of individual Identity is strongly linked to feelings of self-confidence and self-esteem (Rafael, 2017). As can be seen, such changes can be lighter or more profound, with different impacts for the stroke survivors:

"Of course... I stopped taking care of my appearance a little bit because I was also frustrated and angry, and then the condition of the wheelchair initially... and walking a bit "dizzy" when I left the chair... seeing myself in that condition It messed with my self-esteem a lot. Only when I really changed my attitude towards the problem did my personal issues also change." (COIMADU009)

Or yet:

"Of course, my self-esteem took a big hit with this...I was always a person with high self-esteem, sure of myself and what I do and suddenly everything changed...I also stopped taking care of myself more, the less feminine clothes to be more comfortable in the rehabilitation of cognitive difficulties...(silence)". (COIMADU008)

In this way, and according to (Ferreira, Macedo, Pinto, Neves, Andrade, 2017), Self-perceptions play an important role in establishing different psychological states and are responsible for the feelings that each one has about their own abilities, appearance, and the way each one of us thinks others see us as active members of society. Therefore, self-perceptions provide important information about individuals' self-identity, behaviour patterns and

their personality, and are now seen as important indicators of mental health and social adaptability.

Importance of Physical Exercise after Rehabilitation

When asked about the importance of physical exercise after rehabilitation, all survivors identify as *“important and fundamental”* the practice of physical exercise after rehabilitation. However, some limitations to their practice were pointed out, and they are related to the fact that most of the interviewees do not feel confident in the monitoring provided during physical exercise, ending up limiting themselves only to walking. Physical exercise is seen as a *“medicine for many things”*, however most survivors do not feel confident to practice physical exercise outside the clinical context, which may also be a cause for the low levels of physical activity in this population (Nicholson et al., 2014).

“I go for some walks... I tried to join a gym but it's like this... even if I go to do those cardio fitness machines, we have to be careful... people who are in the gym can have training but it's not normal... and we have one neurological problem ... that is, I cannot be doing things with a lot of load because otherwise the spasticity will increase even more and instead of keeping my arm like this, I keep my arm like this... and I get all shrunk... it can't be, and there are no gyms without being physiotherapy clinics for people with neurological problems ... it would be good if they existed ... (silence)”. (COIMADU006)

In addition to walking, activities such as cycling, and water aerobics were also mentioned as activities practiced. The self-perception that the survivor has of himself after the rehabilitation process and the way he experienced the stroke also influences the adherence or not to the practice of physical exercise with the guidance of a professional. Most survivors understand and look for *“something more specific in terms of rehabilitation, with people who have some knowledge of the more specific health area”*, suggesting that there is some uncertainty in the qualifications of professionals in the field of sport, but also that there is a perception and association of physical exercise with therapeutic exercises.

For most stroke survivors, the practice of physical exercise is understood as the repetition of therapeutic exercises, the reduced adherence to physical exercise programs is due to has already been mentioned, the lack of confidence in the training of sports science professionals, who through their training can provide an adequate response to the needs of survivors, however there is also a need for a specialized offer of physical exercise programs for people with stroke. This offer is very limited and not very specialized, generating feelings of uncertainty in target clients/patients:

“(...) this should be more specific and worked in the gyms, because... just because a person had a stroke, it does not mean that they will stay doing that rehabilitation gymnastics and physiotherapy all his life... at least if he wants to go forward and be again a more independent person and do other things... I do

not know, I say... because I am like that too...” (COIMADU009).

Conclusion

In this study, we explored the impact on the psychological level of the stroke survivor. This is a subject that is often ignored in rehabilitation as it is mostly focused on physical rehabilitation.

The survivors' self-perceptions about their body and their new “Self” highlight the impact of stroke at an emotional level, which supports the need for holistic programs, developed by inter and multidisciplinary professionals where the survivor's psychological rehabilitation is also attended.

The self-perception of the body, feelings and influence on self-esteem and identity, makes us conclude that in a first phase there is a change in the perception of the body itself. Despite the consequences of the sequelae at the motor level, there were reports of a reduction in self-esteem and the emergence of issues related to their personal identity.

All issues and changes tend to decrease as the survivor goes through the different stages of rehabilitation and adapts and gains awareness of their body, therefore rebuilding their self-identity. The process of rebuilding the “Self” depends mostly on, acceptance and understanding of the sequelae left by the stroke, when the survivor adopts positive behaviours and thoughts in relation to himself.

Physical exercise is unanimously recognized as important after stroke rehabilitation, however, there is also an association between physical exercise and therapeutic exercise, with no recognition by sports professionals for the prescription of exercise in stroke survivors, making it pertinent to create and specialize specific physical exercise programs for stroke survivors.

As a professional in the field of sports and with personal experience in the rehabilitation of a severe traumatic brain injury, according to my neurosurgeon equal in terms of sequelae and rehabilitation of a hemorrhagic stroke, I can identify and review myself in the reports of the survivors that participated in this study. In fact, the self-perception of the body changes, all the knowledge and awareness of our body in an instant is changed, what once worked in a certain way, now has a different or unknown mobility in the immediate, with the need to adapt to all levels to this new reality. The rediscovery of the body leads us to other questions related to the “Self”. A great confusion of feelings arises, initially feelings of revolt, and the sensation of waking up in a body with a unknown (in)capacity where there is a need to readapt and modify behaviours and forms of performance that leads to low self-esteem. This is a stage where the “Self” and self-identity issues are more evident, requiring psychological help so that depressive feelings are not linked. In my opinion, I do believe that physical rehabilitation is important and essential, but it should also be complemented by psychological support. Changing attitudes towards the new reality helps make the entire physical rehabilitation process less painful and depressing. Physical exercise as a therapeutic intervention

instrument is undoubtedly fundamental and widely recognized, however, after discharge from rehabilitation, I felt a gap in monitoring and in the provision of adjusted exercise programs, this feeling of insecurity in sports professionals and the lack of offer of specialized programs is shared by most stroke survivors, which translates into low levels of physical activity. Survivors associate physical exercise with exercise therapeutic rehabilitation, this fact can also be related to the fact that they do not feel capable of adhering to the offers of existing exercise programs, however many demonstrate willingness to adhere to appropriate and adjusted programs for stroke survivors.

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