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The meaning of exercise and physical activity in community dwelling people with multiple sclerosis

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ABSTRACT

Purpose: This study explored the meanings community dwelling people with multiple sclerosis ascribe to exercise and physical activity.

Method: Using a qualitative approach, 16 face-to-face, semi-structured interviews were conducted. Data were analysed using Framework Analysis and emerging themes developed.

Results: Five themes were identified: “A Type of Movement”, “The Impact of Exercise and Physical Activity”, “It Changes”, “Sense of Loss” and “Coping with Multiple Sclerosis”. The findings demonstrated that people with multiple sclerosis held a multidimensional and complex view about exercise and physical activity.

Conclusion: The meanings people with multiple sclerosis ascribe to exercise and physical activity extended beyond movement, reflecting how they lived with a variable neurological condition. Personal and contextual factors were dominant influences.

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Multiple sclerosis; physical activity; priorities; coping; qualitative

► IMPLICATIONS FOR REHABILITATION



- Health professionals should consider the impact personal and contextual factors have on influencing decisions around exercise and physical activity in community dwelling people with multiple sclerosis.
- Understanding the multidimensional and complex views people with multiple sclerosis ascribe to exercise and physical activity might help health professionals in their discussions around exercise and physical activity and create opportunities to increase physical activity levels in people with multiple sclerosis.
- Health professionals should recognise that people with multiple sclerosis not only engage in exercise and physical activity to manage MS symptoms, but also as a way to connect with others and cope with the variability of the condition.

Introduction

Multiple sclerosis (MS) is a complex variable neurological condition that can affect the motor, sensory and autonomic systems [1]. The clinical features and symptoms are diverse and are mostly responsible for the disability experienced by people with MS. The most reported symptoms include weakness, sensory symptoms and fatigue [2] and are often associated with barriers to engaging in exercise and physical activity [3,4]. Physical activity has been defined as “any bodily movement produced by skeletal muscles that results in energy expenditure” [5,p.126] and would include domestic, occupational and sports-related activities. Exercise on the other hand has been defined as “a subset of physical activity that is planned, structured and repetitive” [5,p.126] and aims to either improve or maintain physical fitness. Research to date has demonstrated that many people with MS report lower levels of physical activity [6,7] and lead sedentary lifestyles [8] which is unfortunate as exercise and physical activity have been shown to improve symptoms and quality of life in people with MS [9,10] and are recommended in clinical guidelines [11].

Attempts have been made to encourage more physical activity in people with MS and these generally demonstrate positive results [12,13]. Related studies have also explored the experiences of exercise and physical activity highlighting the perceived physical, psychological and social benefits [14–16]. However, the majority include people with MS who are predominantly ambulant and focus on experiences of structured, supervised programs [14,15]. As a result, the understanding and meaning of physical activity and exercise in everyday life remains underexplored. This is important as such an understanding may enhance attempts to create opportunities to increase physical activity.

A recent study identified the top 10 prioritised exercise and physical activity practices for community dwelling people with MS and reasons for engagement in exercise and physical activity. The findings suggest a complex interplay of prioritisation and reasoning that moved beyond physical symptoms and structured programs that warranted further enquiry [17]. Therefore, this study aims to explore the everyday meanings of exercise and physical activity in community dwelling people with MS.

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Methods

This study took a qualitative approach. Data collection involved in-depth, one-to-one semi-structured interviews undertaken in a location of the participants' choice. For the majority, this was at their home which had the added advantage of offering a relaxed environment as well as contextualising their responses. Other locations included a quiet room at the university or at MS Therapy Centres.

Semi-structured interviews were chosen because the flexible design accommodates unexpected topics raised by participants while offering the researcher some control over the interview process [18].

A topic guide was developed from related literature including the results of the previously conducted Delphi Study [17]. The Delphi study utilised a four round Delphi questionnaire process which scoped and determined consensus of priorities for the top 10 exercise and physical activity practices and the reasons people with MS engaged in exercise and physical activity [17]. Details of the Delphi Method has been described elsewhere [17]. Cue cards identifying the prioritised categories from the Delphi study were used as a tool to facilitate the discussion. Indicative topics included, *what does the term exercise and physical activity mean to you? What are your thoughts on the physical activities selected by people with MS? What are your thoughts on the reasons why these physical activities were selected?*

Recruitment

Potential participants were people with MS ($n=70$) living in the community who completed a prior Delphi study [17]. Interested participants were asked to return the signed consent form acknowledging their willingness to participate in the study ($n=37$). Potential participants were purposively selected on the basis of gender, perceived level of physical disability and availability ($n=16$). Interviewing 16 participants was deemed adequate to provide the depth and breadth required to explore the meaning of exercise and physical activity in people with MS and the strategy used ensured a broad range of responses was obtained from study participants [18].

The study was approved by the School of Health Sciences and Social Care Research Ethics Committee, Brunel University London.

Data management and analysis

All interviews were audio recorded and transcribed verbatim. Transcripts were anonymised by assigning a pseudonym and checked for accuracy against the audio recordings. The interview length varied between 45 to 60 min.

The data were analysed using Framework Analysis [19]. The technique involves 5 iterative stages of analysis namely, Familiarisation- reading the transcripts, making notes and listening to the interviews several times: initial codes and ideas were identified deductively based on the categories from the Delphi study which informed the frame of the topic guide and also inductively to locate other ideas or themes that did not fit the topics; Identifying a thematic conceptual framework-this phase was informed by the topic guide as well as the research questions and refined until no further themes were identified. The revised conceptual framework, which contained 8 key themes, was discussed with the co-researchers prior to the next phase of the analysis, Labelling- involved applying the conceptual thematic framework to all 16 transcripts. All transcripts were labeled with the 8 key themes identified using the thematic framework, Charting-this

phase further reduces the data by summarising the content of each labelled paragraph. A thematic matrix was created and organised to facilitate ease of analysing the data within themes or between cases in the study; Mapping and Interpretation- the matrix-based charts were read and re-read across the themes and also across all participants. Each chart was mapped separately to identify the key dimensions and associated major themes [20]. This data analysis method provided a structured approach to the sorting, organising and interpretation of data.

Processes to enhance rigor and credibility

The primary researcher (AS) has a background in physiotherapy and special interest in neurology and conducted the interviews and data analysis. Acknowledging that this could have influenced aspects of the study a number of checks were utilised. A reflexive journal was kept throughout the data collection and analysis processes. Issues highlighted were discussed with co-researchers in order to address potential presuppositions [21]. Also, transcripts from the interviews were shared with the co-researchers (LD and MN) who reviewed each stage of the analysis and critical discussions ensued which enhanced the methodological rigor and transparency of the process [22]. Both co-researchers have a background in physiotherapy and experience working with people with MS.

Findings

Sixteen (12 females and 4 males) people with MS living in the community participated in the study. The type of MS varied across the group and all participants reported that MS had an effect on their ability to engage in exercise and physical activity. Table 1 details the demographic profile of the participants.

Five (5) major themes were developed from the data namely, "A Type of Movement", "The Impact of Exercise and Physical Activity", "It Changes", "Sense of Loss" and "Coping with MS".

A type of movement

A common feature reported across all participants when describing their understanding of exercise and physical activity was that exercise and physical activity were about movement. But while movement was common to both, the nature of each was different. For example, exercise was seen as something separate and outside of ordinary every day activities or used different parts of the body.

Exercise is something that, in a funny kind of way doesn't form part of one's, kind of routine... something that you make separate time for., it's so... slightly more in isolation, to all the things that you would do ... (Sue, 50 years, F, severely affected, line 91–94)

... I think with exercise you're using parts of your body that you don't normally use during the day. You know what I mean? During normal everyday sort of running of a place I don't think you use the same muscles as you do when you exercise. I think that's probably it – that you use different muscles. And you're strengthening those or you're trying to strengthen those muscles, which do actually come in normal every day ... you find that you can do things better (Linda, 71 years, F, moderately affected, line 482–493)

In contrast, physical activity was associated with daily routines and purposeful activities.

Physical activity around here, is lawn mowing, and you know, picking up rotten apples and sticking them in and dragging big sack stuff out the front... You know, like I was trying to get up a ladder today,

Table 1. Demographic profile of sixteen interview participants with multiple sclerosis.

Name	Age	Functional level	Impact of MS on exercise and physical activity	Occupation	F/M	Type of MS
Grace	47	I- mobility without aid	Severely affected	Retired	F	RR
Tom	70	I- mobility with aid	Severely affected	Retired	M	SP
Anne	63	I-mobility with aid	Mildly affected	Volunteer	F	U
James	53	I-mobility with aid	Moderately affected	Retired	M	PP
Jill	47	I- mobility without aid	Severely affected	Unemployed	F	SP
John	62	D- powered wheelchair	Severely affected	Retired	M	PP
Harry	71	I- mobility with aid	Severely affected	Retired	M	U
Sue	50	I- mobility without aid	Severely affected	Retired	F	RR
Pam	65	I- mobility without aid	Moderately affected	Unemployed	F	U
Lily	66	I-mobility with aid	Mildly affected	Employed	F	PP
Linda	71	I-mobility with aid	Moderately affected	Retired	F	U
Eileen	72	I- powered wheelchair	Severely affected	Retired	F	U
Mary	60	I- mobility with aid	Moderately affected	Retired	F	PP
Ivy	68	I-mobility with aid	Severely affected	Retired	F	PP
Bev	55	I-mobility with aid	Moderately affected	Retired	F	SP
Carol	61	I- mobility without aid	Moderately affected	Retired	F	SP

D: Dependent; F: Female; I: Independent; M: Male; PP: Primary Progressive; RR: Relapsing Remitting; SP: Secondary Progressive; U: Unknown.

unsuccessfully, you know fitting the...you know. (pointing at light bulb). so you know, its, sort of, the practical stuff. (Carol, 61 years, F, moderately affected, line 56–66).

Linda suggests that while exercises are separate they are linked to everyday life activities. Therefore, physical activity and exercise whilst considered different in definition based on usual and unusual types of movement, they were nevertheless on a spectrum.

While participants drew relatively clear distinctions between exercise and physical activity, some crossover was evident. For example, John stated:

if I was going to write it down I would put physical activity and socialising in, somehow overlapping in the same bracket. Because, I can't really do anything physically, but I can socialise, I can enjoy meeting people like you, chat and have a very fulfilled life, really. (John, 62 years, M, severely affected, line 124–128).

Therefore, the very basis of movement being physical was somewhat undermined. John's understanding of physical activity was extended to the social context thereby displaying a broader concept of physical activity.

The impact of exercise and physical activity

Exercise and physical activity were perceived to have a broad impact on participants' lives. For example, both were attributed to improving muscle strength and physical fitness as well as to preventing physical deterioration and loss of mobility.

I do them (exercise and physical activity) to keep mobile really, as much as possible. yeah. it is for mobility really and some of them helps to build up muscles. not big muscles (laughing). (Mary, 60 years, F, moderately affected, line 32–36)

The psychological impact of exercise and physical activity was also noted irrespective of the physical abilities of study participants. For example, participants felt both exercise and physical activity gave them a 'feel good factor' and sense of achievement.

feel good factor. ... I don't know what it is in your body that when you exercise it sort of seems to release all these bits and pieces and it makes you feel better (Linda, 71 years, F, moderately affected, line 142–158).

The social impact of exercise and physical activity were referred to in two main ways. Firstly, by the social interaction usually brought about through exercise classes that provided space to engage in friendly banter and peer support. Secondly, through social connectivity, that is, connecting with others through the capacity to undertake leisure activities:

well, you know, you're getting out and about you're seeing people and meeting people, you're keeping up some social contacts at the same time ... (Tom, 70 years, M, severely affected, line 250–252)

The importance of the physical ability to partake in these socially connecting activities was also evident when participants described challenges they faced in doing so. For example, Mary described difficulties associated with navigating different modes of transportation resulting in her reducing her physical activity and doing more driving in order to sustain her important activities.

I drive. it's very rare that I don't because I can't get on a bus, can't get to the bus stop and climb on the bus. I did go on a train last week., there's certain things that you've got to look out for. like the gap between the platform and the train!. (laughing). they are atrocious aren't they? ... (Mary, 60 years, F, moderately affected, line 195–200)

Transportation was also represented in the data as facilitating the freedom of movement necessary to live a normal (John) and independent life (Pam):

so I think if you've got MS. people drive for different reasons and again that's about keeping independence. You know, people would say. do you want me to get your shopping or something if I am not very well but you know, I say no, it's ok, if I can drive. so you know I think it is important. (Pam, 65 years, F, moderately affected, line 350–353)

While exercise and physical activity were noted as having many benefits, it is apparent that these moved beyond the physical and the psychological to also include social connectivity. Indeed, when physical capacity was challenged it is the concept of physical activity as movement in social space, by whatever means, which was emphasised.

"It changes"

A feature of participants' narratives was that their interactions with and meaning of exercise and physical activity was not static. Collectively this theme "It Changes" illustrates that the meaning of exercise and physical activity was contextualised to the progressive nature of MS and personal life situations. Mary for example, described the gradual changes in her physical abilities, where activities once taken for granted prior to MS, now required considerable thought. These changes over time had an impact on her daily activities:

it has changed because... I could pop down the road to get something from the shops. but I can't now. so, I can't just walk down the road! Everything is a major planning, expedition really if I'm going

out! (laughing). Have I got my trolley, have I got my sticks. (Mary, 60 years, F, moderately affected, line 71–74)

Change was also associated with uncertainty. For example, the uncertainty about the type of MS and its implications for the future.

I don't know how mine is going to progress. I don't even know what type of MS I've got. urm. I was told it was benign but I don't even know what that means. (Mary, 60 years, F, moderately affected, line 308–310).

Participants described how the changes as a result of MS, age or as a result of their present circumstances collectively had an impact on their priorities. As such, priorities became overwhelmingly influenced by their personal choice as well as their energy demands.

every day with this illness, because you're aware that you've got this limited amount of energy if you like... I just plan one activity, if I've got to go to the shops, I just have one visit and the rest of the day I'll collapse in a heap and you do one thing each day... well that's how you have to organise your life now, everything in your brain, what you do when you wake up is all organised around fatigue. and the time you've got to do things in. even dressing. when you were fit you used to sort of get washed and dressed in about half an hour; in your greatness, but now you've got something that's holding you back all the time, you know it's going to take at least three quarters of an hour to an hour to get washed and dressed and up and out of bed ... which is ridiculous when you look back at it (Ivy, 68 years, F, severely affected, line 338–366)

Ivy's narrative demonstrates that movement demands require management, both as a finite resource but also with the time structure of the day. This sense of balancing demands of energy and priorities were a feature of the narratives and began to demonstrate clear differences between physical activity and exercise. For example, Jill expressed that her priorities were in order of family, home and everyday physical activity. After these activities were completed the remaining energy was attributed to exercise.

my focus is on getting all the stuff I have to get done, done for the family and then any extra energy I can use on physio. it's extremely urm frustrating to get to the end of the day and think, I just haven't got the energy (Jill, 47 years, F, severely affected, line 241–243)

Sense of loss

Changes in balance and priorities was often associated with a sense of loss, particularly of physical activities that had been a source of joy in the past:

in the past I use to love walking and would walk for hours and this is a great loss to me. I realise I can't really do the walking I use to do. (Bev, 55 years, F, moderately affected, line 90–93)

The loss of meaningful physical activity was described as akin to the grieving process. This was most clearly articulated by Ivy who could no longer continue her art due to physical limitations imposed by her MS.

it's almost two years ... I've had to give up painting because I'm right handed but my right hand isn't steady enough. I'm not a loose painter of water colour. and I'm not going to start after all these years, trying to be a loose painter, I'd go mad,. as you get worse, you lose, urm. different abilities to do things. and you sort of, especially with my art, you sort of go through a temporary, what do they call it? A temporary sort of grieving time. it's a loss (Ivy, 68 years, F, severely affected, line, 577–695)

The loss of activity, also had a direct impact on employment. Anne was a teacher by background; her employers were aware of her diagnosis and provided adequate support. However, due to restructuring within her department, she was moved to another location. She found this new working environment challenging to

navigate, as her mobility got worse and eventually gave up her job.

the amount of walking I did was a lot worse. amm ... I blame the local authority for that! (laughing). Because we had this really big art room and I was getting so that I couldn't really walk around it! . That was when my MS affected what I was doing. (Anne, 63 years, F, mildly affected, line 649–655)

In summary, the ability to undertake certain physical activity was associated with significant aspects of life; hobbies, pleasurable activities or the capacity to work. Therefore, the sense of loss pertaining to any of these extended beyond the physical and impacted the emotional aspect of the individual.

Coping with MS

Although participants expressed a deep sense of loss, emerging from the transcripts was also a sense that despite this loss, exercise and physical activity were used as a way of coping with MS. These activities when utilised enabled a sense of normalcy and added structure to their lives:

classes do sort of, give a framework to my week. I would think oh its x day, so x day this time I will be going to Pilates class or there would be y day.. and, if I go to the Physio sort of session. I would go to that.. because I am not working now if I didn't have that structure to my day ... ammm ... I could see the whole thing sort of falling apart! (Bev, 55 years, F, moderately affected, line 142–149)

Support provided by family, friends and the MS Therapy Centre in engaging in exercise and physical activity were viewed as a way of coping with MS. For Anne, the formal support with exercise provided by the MS Therapy Centre was a way to adapt to the variability of MS, age and the need to be fit:

I didn't find out about the MS Therapy Centre for a long, long time. Yeah... so. I suppose it came about at a time when I could fit it in with my life as well. Cause I was thinking I'm getting older and I need to do something that keeps me fit. and I'd finish work so I suppose it just came at the right time.. (Anne, 63 years, F, mildly affected, line 544–551)

Support however was not one directional but rather reciprocal in nature. For example, James described how he used the physical activities he could complete to sustain a useful role within the family unit:

Uhm, housework I try to do some, I don't like to get down low. I can Hoover, I can Hoover for Britain if you want me to. I can clean a sink and uh, I don't mind bending over the loo and cleaning a loo so I try muck in and do something (James, 53 years, M, moderately affected, line 334–338)

There were several examples where this focus on maintaining roles and the physical activity associated with that was prioritised over exercises for the sake of their MS. For some participants this acted to preserve their identity: as a mother, grandmother, contributor to home, bread winner. The role as a mother was evident in Jill and Grace's interview:

(referring to self-care activities) because I have to get Tom to school I have to go out, I can't just slop about in my pyjamas I have to get up and out and force the rest of the family out the door in the morning, urm. and then I do the domestic stuff... and then the dinner and then the homework, and urm yeah, and in between I try and fit my exercise routine in, which is a bit ad hoc at times, but there you go (Jill, 47 years, F, severely affected, line 235–239)

...so earlier when they (children) were in school .I would like to visit the parents evening and things like that so then that would be prioritised. I would be prioritising those things. So exercise just keeps going down. (Grace, 47 years, F, severely affected, line 348–351)

In summary, exercise and physical activity was a way of coping with the condition. However, participants described the strategies used not only for coping with MS but also in maintaining their identity, which symbolised much more than having a diagnosis with MS. Participants desired to be known for their individuality; physical activity was therefore used as a way to shape and preserve their sense of self.

Discussion

The purpose of the study was to explore the meaning of exercise and physical activity in people with MS living in the community. The socio-demographic profile of participants in this study are similar to those of other published MS groups relating to female to male ratio [4,15,16,23–25], functional level [16,24–26], and the type of MS [14–16] albeit slight differences in proportions. However, the views expressed are those of older people with MS (Mean age 62) and those who predominantly rate the impact of MS on their ability to engage in exercise and physical activity as moderate to severe. These views are underrepresented in the literature.

Overall the findings highlight that living with a deteriorating condition such as MS, alongside everyday life results in a multidimensional view of exercise and physical activity. Collectively, participants expressed that exercise and physical activity were about movement. Movements, whether structured (exercise) or unstructured, (physical activity) were deemed meaningful and relevant for living life with MS. Also, it was the ability to integrate physical activity in everyday life activities that gave it prominence. In this study, the central focus on participating in daily life activities was interesting to note as some researchers have highlighted that completing activities of daily living is one of the challenges faced by people with MS irrespective of their level of disability [27–29]. However, participants provided added insight which pointed to the interrelation that exists between exercise and physical activity; where exercise not only supported participation but also provided the means necessary to maintain some level of independence in daily life and social activities.

Whilst the physical [9,16,23] and the psychological [16,26] benefits of exercise and physical activity have been widely reported in both quantitative and qualitative literature and supported by this study, novel insights have also been highlighted with respect to the social aspects of life. Participants spoke about the social benefits in two ways. Firstly, as with other studies, they described the benefits of participating in group based activities, such as, peer support, acceptance, and camaraderie [16,23,24,26]. However, in this study, participants' descriptions about the social benefits went beyond the remit of a group exercise session and included unstructured forms of activity (physical activity) more generally that involved connecting with others as well as the external environment. Indeed, this focus on social connectivity resulted in an extension of the concept of physical activity to incorporate any movement in space which facilitated socialisation. That is, sustained engagement in physical activities provided a sense of liberation from the physical restrictions imposed by the condition, reduced social isolation by connecting with others in the community and thereby provided greater control over life situations.

Through the themes "It Changes" and "Sense of Loss", participants portrayed cyclical changes overtime depicted by a constant balancing act. These changes were influenced by factors including personal choice, energy demands versus energy expenditure and the prioritisation of certain activities. The latter two factors, prioritisation and energy demands, resonated throughout participants'

accounts. The use of prioritisation has been demonstrated in the wider MS literature [30,31], but little is known about it with reference to exercise and physical activity, and hence, it has been specifically recommended as an area that requires further research in relation to exercise and physical activity [26]. It was apparent from the findings of this study that the use of prioritisation as a strategy to manage changes associated with MS was common. Knowledge of these prioritisation strategies used by people with MS suggests that their self-selected exercise and physical activity practices were the outcome of several levels of negotiations for example, self, family and energy tradeoffs.

With reference to energy demands, the study highlighted that changes in exercise and physical activity practices were driven by balancing energy demands and expenditure, in order to manage fatigue. As such, activities that required urgent attention or activities that were meaningful to the individual were prioritised. Exercise and physical activity were therefore planned and organised around the availability of energy, time and priorities. This is an important finding as fatigue is one of the most reported symptoms experienced by people with MS [2,32] and is considered to be a significant barrier to engaging in exercise and physical activity [3,4,25]. Therefore, understanding these strategies from the perspectives of people with MS might help practitioners support people with MS more effectively in their decision making about exercise and physical activity.

Participants' narratives also highlighted the spiraling nature of loss, which started with physical deterioration but gradually encroached on other areas of life such as independence and employment. This sense of loss has been highlighted in the literature but is often centred on physical loss specifically related to mobility losses [31]. However, the narratives demonstrate the interconnected nature of physical and emotional loss whereby threats to engaging in meaningful physical activities resulted in complex emotional responses which could disrupt the balancing act utilised by people with MS as a way to manage the changes experienced as a result of MS.

Exercise and physical activity were seen as a way of coping with the dynamic changes associated with MS. People with MS have developed different methods of coping with the condition, which have been cited in the wider MS literature, for example humor and seeking information [15,30,33]. Also, coping with MS was the highest ranked priority for self-help in community dwelling people with MS [34]. In this study, an example of the use of exercise and physical activity as a method of coping was expressed through having established routines over the course of the week. For people with MS having an established routine reclaimed some control over MS, provided a way to offset MS symptoms and created a sense of normalcy. These findings have added to the existing evidence to suggest that exercise and physical activity was not only used to manage the symptoms associated with or as a consequence of MS but also as a way to cope with life.

Another way in which participants described ways of coping with MS was through their support networks. This level of support was either through formal services (e.g., organisations) or informal support provided by family. This finding is consistent with other studies which identified that people with MS have a variety of support systems ranging from physical, emotional and financial assistance which they have gained from individuals including, family, friends, employers and strangers [35,36]. While this level of support is meaningful and necessary for people with MS, this study also highlighted that physical activity was a form of reciprocity.

Participants revealed a complex view of exercise and physical activity. Exercise and more specifically physical activities were used as coping strategies to maintain their identity. For example, role within the home as a parent and or partner superseded having an identity framed by MS, even in the presence of severe disability. Roles within the home, especially looking after children are not often reported in exercise and physical activity studies as a form of activity. However, for participants in this study, engaging in physical activities around the home or outdoors helped to shape and preserve their identity.

Insights from this study support the call for taking a comprehensive approach to the management of people living with a chronic condition [37,38]. This knowledge from the perspective of people with MS can contribute to the way in which health professionals approach exercise and physical activity in the community. It highlights that people with MS weigh up activities based on whether or not they fit into their daily lives.

Strengths and limitations of the study

This study was grounded in a qualitative approach. It used semi-structured interviews to elicit views and opinions from the perspectives of people with MS about the meaning of exercise and physical activity; an area that is under researched in this population. The number of participants in this study is consistent with qualitative methods [18]. It should also be acknowledged that the researcher with a background in physiotherapy conducted all the interviews as well as analysed the data. However, the analysis was discussed and checked by the coauthors who have a background in physiotherapy and experience working with people with MS. In addition, participants were aware of the researcher's professional background and as such, might have adjusted their views accordingly. It is acknowledged that the majority of study participants were older, mainly retired people with MS. However, some participants for example, James aged 53 is retired but not of retirement age; so could be retired on health grounds and this is not unusual for people with MS who have disabilities and activity limitations. Nevertheless, their views and opinions might not be reflective of those who are younger and in employment. Also, some participants were actively involved in their local MS Therapy Centres and so were likely to be more aware of exercise and physical activity than the general population of people with MS living in the community. As such, the results may not be reflective of the views and opinions of other people with MS.

Conclusion

This study provided a deeper understanding of the meaning of exercise and physical activity in people with MS living in the community. It supports, as well as extends, the existing evidence base about the meanings of exercise and physical activity and highlight that people with MS held a multidimensional and complex view of exercise and physical activity. These views assert that exercise and physical activity were more than movement and not simply confined to the remit of engaging in exercise and physical activity in and of itself. These movements whether structured (exercise) or unstructured (physical activity) extended beyond the confines of body structure, function and disability. They were contextualised and embedded into everyday life as strategies for coping and living life in the community with a progressive neurological condition.

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