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ORIGINAL ARTICLE



Determinants of physical activity in wheelchair users with spinal cord injury or lower limb amputation: perspectives of rehabilitation professionals and wheelchair users

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ABSTRACT

Purpose: To gain insight into determinants of physical activity in wheelchair users with spinal cord injury or lower limb amputation, from the perspective of both wheelchair users and rehabilitation professionals.

Methods: Seven focus groups were conducted: five with wheelchair users ($n=25$) and two with rehabilitation professionals ($n=11$). The transcripts were analysed using a sequential coding strategy, in which the reported determinants of physical activity were categorized using the Physical Activity for people with a Disability (PAD) model.

Results: Reported personal determinants of physical activity were age, general health status, stage of life, demotivation due to difficulty burning calories, available time and energy, balance in daily life, attitude, and history of a physically active lifestyle. Reported environmental determinants were professional guidance, inconvenient exercise times, accessibility of facilities, costs, transportation difficulties, equipment difficulties, and social support.

Conclusions: Important, changeable determinants of physical activity that might be influenced in future lifestyle interventions for wheelchair users are: balance in daily life leading to more time and energy to exercise, attitude towards physical activity, professional guidance, accessibility of facilities (providing information on how and where to find accessible facilities), and social support (learning how to get this).

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Amputation; focus group; determinants; exercise; physical activity; spinal cord injury; wheelchair

► IMPLICATIONS FOR REHABILITATION

- A physically active lifestyle improves everyday functioning, and decreases disability and the risk of secondary health problems in wheelchair users with spinal cord injury or lower limb amputation.
- After inpatient rehabilitation, it is difficult for wheelchair users to maintain or further enhance their physical activity, a lifestyle intervention can help them in this.
- To be effective, lifestyle interventions should address important, changeable determinants of physical activity.
- Important, changeable determinants of physical activity reported by wheelchair users and rehabilitation professionals are: balance in daily life leading to more time and energy to exercise, attitude towards physical activity, professional guidance, accessibility of facilities, and social support.

Introduction

During inpatient rehabilitation, wheelchair users are encouraged to adopt a physically active lifestyle by working towards an active and independent existence as much as possible [1,2]. However, in

the time following inpatient rehabilitation, it is difficult for wheelchair users to maintain or further enhance their physical activity [2]. In the first period after rehabilitation, people focus on regaining a "normal" day-to-day life, during which working on a

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physically active lifestyle has no or very limited priority. When this "normal" day-to-day life is established, it is hard for wheelchair users to adopt a physically active lifestyle. Moreover, it is no longer possible for rehabilitation professionals to keep providing the appropriate lifestyle guidance, since the rehabilitation period ends when wheelchair users return to their previous living situation [2–4].

It is well documented for the general population that a physically active lifestyle is beneficial for a person's health [5–7]. An active lifestyle is even more important for wheelchair users [8]. In wheelchair users with spinal cord injury (SCI) or lower limb amputation, physical inactivity, being overweight, lower life satisfaction and low vitality are frequently reported problems [4,8–14]. A cycle of deconditioning can arise, in which an inactive lifestyle leads to an increase in body weight, resulting in secondary problems as fatigue, distress, low vitality and sleeping disorders, which in turn lead to an even more inactive lifestyle [15,16]. A physically active lifestyle can break this cycle and could improve everyday functioning, reduce disability, and reduce the risk of secondary health problems in people with physical disabilities [8,17–21].

It is important to identify determinants of physical activity in order to understand the problem of physical inactivity thoroughly, and to be able to develop targeted behavioural change strategies [22,23]. In literature, demographics (e.g., age, gender), health-related factors, psychological factors, social factors and environmental factors are reported to be possible determinants of physical activity in wheelchair users [8,10,24–30].

Although several studies have been carried out in wheelchair users on perceived barriers and facilitators of physical activity, few studies contain the perspectives of both wheelchair users and rehabilitation professionals [31]. For the development of complex interventions, such as physical activity interventions for people with disabilities, a participatory research design is needed [22,23]. Asking both wheelchair users and rehabilitation professionals which determinants are related to physical activity, provides valuable insights on where interventions should focus on from both viewpoints. Moreover, involvement of both groups may promote the implementation and effectiveness of interventions [32].

In daily practice, Dutch rehabilitation professionals face many wheelchair users with SCI or lower limb amputation who have become physically inactive after inpatient rehabilitation. To solve this problem, they asked for the development of an eHealth intervention aimed at promoting physical activity in these target groups. As a first step in the development of this intervention, the aim of this study is to gain insight into determinants of physical activity in wheelchair users with SCI or lower limb amputation from the perspectives of both wheelchair users and rehabilitation professionals. The findings should make an important contribution to the field of health promotion programs for wheelchair users [33].

Methods

Design

The study design was qualitative, using focus groups for data collection. The focus groups for wheelchair users and rehabilitation professionals were conducted separately. This research is part of the Wheelchair Exercise and Lifestyle Study (WHEELS) project. The main objective of the WHEELS-project is to develop a mobile application for wheelchair users with SCI or lower limb amputation to promote a healthy lifestyle in terms of physical activity behaviour, nutrition behaviour and relaxation behaviour. The study was approved by the Medical Ethics Committee (METC no

P1761) of the Slotervaart hospital and Reade, Amsterdam, The Netherlands.

Participants

A convenience sample of wheelchair users and rehabilitation professionals (i.e., exercise therapists, physical therapists, occupational therapists and dieticians) was recruited through two exercise therapists working in local rehabilitation centres in the Netherlands: Reade, centre for rehabilitation and rheumatology (Amsterdam, The Netherlands) and Heliomare (Wijk aan Zee, The Netherlands). The aim was to create heterogeneous focus groups, consisting of four to eight participants each, to ensure that all participants had enough time to share their thoughts and to have enough time for discussion [34–36]. Possible participants were approached by telephone, face-to-face or by e-mail. In case of interest in participation, an e-mail with information about the study was sent. The recruitment of participants ended when data saturation (no more new insights) was reached: in qualitative research sample size can never be pre-determined [34].

Setting

In June 2017, seven focus groups were performed. Three focus groups (two focus groups with wheelchair users and one with rehabilitation professionals) took place in the rehabilitation centre Reade and three (two focus groups with wheelchair users and one with rehabilitation professionals) took place in Heliomare. The final focus group took place in October 2017, during the annual meeting day of the Dutch Spinal Cord Injury Association in Ede, The Netherlands.

Procedures

All focus groups took place in a conference room and lasted a maximum of 90 min. Before each discussion, all participants were asked to sign an informed consent form, and to complete a short self-developed questionnaire that was used to describe the research population. For wheelchair users, this questionnaire included demographics (i.e., gender, date of birth, level of education, living situation, characteristics of SCI or lower limb amputation, time since SCI or amputation) and two questions in which participants were asked to grade themselves on a scale of 1 (not consciously engaged) to 7 (very consciously engaged) in terms of having sufficient physical activity and keeping a good balance between rest and activity. For rehabilitation professionals, this questionnaire included gender, profession, years of experience with wheelchair users with SCI or lower limb amputation, a 7-point scale for perceived importance of sufficient physical activity in wheelchair users, and a 7-point scale for perceived importance of a good balance between rest and activity in wheelchair users. During the focus groups a semi-structured interview was held, guided by a moderator. The focus groups were audio-recorded with permission of the participants. The assistant moderator took notes to identify the participants on the audio-recording transcription and to identify main themes. The general rules for focus group implementation were applied [34,37], i.e., each participant has the right to vocalize one's views and opinions, respect each other, and do not share information outside the group (confidentiality). Furthermore, it was emphasized that all opinions were valuable and that there were no right or wrong answers. The focus group started with an introduction to inform participants

Table 1. Interview guide for the focus groups.

Question type	Questions wheelchair users	Questions professionals
Opening Problem	Can you introduce yourself? What do you do to stay healthy? Are you satisfied with your current lifestyle?	Can you introduce yourself? Do wheelchair users in general have a healthy lifestyle? Do you feel that most wheelchair users are aware of the importance of a healthy lifestyle?
Key	Which barriers and enablers do you encounter in working on a healthy lifestyle? What needs to change to improve your current lifestyle?	What are the most important lifestyle problems in wheelchair users after inpatient rehabilitation? Which factors prevent the development of a healthy lifestyle in wheelchair users?
Ending	What do you need to adopt a healthy lifestyle? What keeps you motivated to maintain a healthy lifestyle? Do you have any questions, remarks, suggestions or additions?	What can be improved for wheelchair users to make it easier to adopt a healthy lifestyle? What do wheelchair users need to maintain a healthy lifestyle? Do you have any questions, remarks, suggestions or additions?

about the goal of the WHEELS-project and the rules of a focus group. Afterwards, participants received a reward (a power bank).

Question guide

The discussions were held with the use of a semi structured interview guide (see Table 1), that was developed by the research team. This interview guide was based on the interview guide used by Deliens et al. to identify determinants of physical activity in Belgian university students [38]. The questions were carefully adjusted for the current research and extra questions were added using appropriate literature [36,37]. The research team decided to ask open questions regarding a healthy lifestyle, the questions in the interview guide were not specified towards activity behaviour, nutrition behaviour or relaxation behaviour. This was to ensure that all participants could express what they considered most important regarding lifestyle.

Data analysis

Descriptive statistics were used to illustrate the characteristics of the study population, using the questionnaire data gathered prior to the focus group discussions. After the focus groups, the moderator and assistant-moderator evaluated and discussed the most notable emotions, statements and themes. The audio recordings were transcribed verbatim, after which they were analysed using a thematic content analysis approach [39]. Three types of coding were used: open, axial and selective coding [40]. The focus groups of the wheelchair users and the rehabilitation professionals were coded separately. Initial codes were created by coding text segments (open coding). The open codes were then compared and subcategorized in superordinate codes (axial coding). The Physical Activity for people with a Disability (PAD) model [41] was used to classify areas of determinants related to a healthy physical activity pattern (selective coding). The PAD-model is a combination of the International Classification of Functioning, Disability and Health (ICF model), and the Attitude, Social influence and self-Efficacy (ASE) model. It is used as a theoretical framework for interventions and research on physical activity promotion for people with a disability. According to this model the determinants were coded as personal or environmental determinants. Personal determinants were further categorized into: attitude, intention, barrier, facilitator, self-efficacy and health condition. Environmental determinants were further categorized into: barrier, facilitator or social environment. To ensure reliability of coding and data interpretation, the analyses were carried out by two researchers (LEA and TD). Disagreements were discussed and in case of persisting disagreements, a third researcher was consulted (JFMH). A determinant can be a barrier and a facilitator at the same time (e.g.: accessible

sport locations are a facilitator, while inaccessible sport locations are a barrier), in the current study the determinants are categorized as they were mentioned: i.e., the determinants can be both described as a barrier and a facilitator. The data obtained from the questionnaire were analysed with SPSS Statistics version 24 (IBM, Armonk, United States). The transcripts were analysed with MAXQDA version 12 (VERBI GmbH, Berlin, Germany).

Results

Participants

The estimated point of saturation was observed after five focus group discussions with 25 wheelchair users in total. In this group of wheelchair users the age varied from 39 to 75 years, 13 participants were male, 17 participants had SCI and 8 participants had lower limb amputation(s). All wheelchair users graded themselves between 5 and 7 (very consciously engaged) on the 7-point scale for consciously engaging in sufficient physical activity. In addition, two focus groups were held with 11 rehabilitation professionals in total. The focus groups with rehabilitation professionals were not continued until saturation was reached. Intentionally, a focus group meeting was held with a multidisciplinary group in each of the two rehabilitation centres involved in the project. The group of rehabilitation professionals worked between 1 and 30 years with wheelchair users with SCI or lower limb amputation, and consisted of 10 female and 1 male, 4 exercise therapists, 3 physical therapists, 2 occupational therapists and 2 dieticians. The rehabilitation professionals scored the 7-point scale regarding the importance of sufficient physical activity for wheelchair users with a 6 or 7 (very important). More sample characteristics of the two groups are described in Table 2.

Themes

The main and sub-themes that emerged from the thematic content analysis fitted well into the PAD-model. The main themes identified were:

- Personal determinants; with the sub-themes of health condition, barriers, facilitators and attitude; and
- Environmental determinants; with the sub-themes of barriers, facilitators and social support.

Personal determinants

Health condition

Both wheelchair users and rehabilitation professionals frequently mentioned general health condition as an important determinant of physical activity. More specifically, physical overload of the

Table 2. Characteristics of the wheelchair users ($n=25$) and professionals ($n=11$) who participated in the focus groups.

<i>Wheelchair users (n=25)</i>	
Age in years, median (range)	58 (39–75)
Male/female, n	13/12
Educational level, n	
Primary school/secondary school/higher professional education or university	1/10/14
Spinal cord injury/amputation, n	17/8
Spinal cord injury, n	
Paraplegic/quadruplegic/unknown	12/3/2
Complete/incomplete lesion/unknown	9/6/2
Amputation, n	
Single leg above the knee	4
Single leg below the knee	2
Double leg above the knee	1
Double leg at the knee (knee disarticulation)	1
Time since (first) spinal cord injury or lower limb amputation, median (range)	9 (0–55)
Living situation, n	
Home/inpatient rehabilitation	23/2
Body-mass index, kg/m ² , median (range)	26 (17–39)
This grade (1 not consciously engaged; 7 very consciously engaged) applies to me for:	
engagement in sufficient physical activity, median (range)	6 (5–7)
engagement in keeping a good balance between rest and activity, median (range)	6 (4–7)
<i>Professionals (n=11)</i>	
Male/female, n	1/10
Profession, n	
Physical therapist	3
Exercise therapist	3
Exercise therapist and research assistant	1
Dietician	2
Occupational therapist	1
Occupational therapist and researcher rehabilitation medicine	1
Years of working experience with wheelchair users, median (range)	10 (1–30)
This grade (1 unimportant; 7 very important) is appropriate for the importance of:	
sufficient physical activity in wheelchair users, median (range)	7 (6–7)
a good balance between rest and activity in wheelchair users, median (range)	7 (5–7)

arms was mentioned by almost all participants. One wheelchair user mentioned:

Since I can only use my arms to get around, my arms and shoulders are quickly strained, which limits my physical activities. (Focus group 1, age ≥ 58 years, complete SCI for < 2 years)

Additionally, comorbidities were mentioned as a debilitating health condition. The wheelchair users mentioned for example diabetes, kidney failure, heart failure and pressure sores. One wheelchair user explained:

Working on the prevention of decubitus costs a lot of energy, as a wheelchair user you need to be constantly aware of decubitus. (Focus group 2, age ≥ 58 years, complete SCI for > 10 years)

Barriers

Both rehabilitation professionals and wheelchair users mentioned that it is more difficult to burn calories for wheelchair users, which demotivates them. Burning the same amount of calories as non-wheelchair users costs a lot more effort, since the larger leg muscles use most energy.

Other important personal barriers mentioned are time and energy. Wheelchair users and rehabilitation professionals both mentioned that self-care and the activities in daily life require a lot of time and energy, especially for wheelchair users with a SCI. After all the general daily tasks, they have no energy left to work on a physically active lifestyle. Furthermore, the rehabilitation professionals referred to the fact that the employment situation is important for wheelchair users who are able to work. Since self-care and work are given priority, there is little time left for physical training:

That work is so important. How do you then combine being physically active in daily life with care, work and family? (Focus group 6, professional, working experience with wheelchair users > 10 years)

Another barrier that affects the level of physical activity is older age. Older wheelchair users mentioned that getting older with a SCI is related to more physical problems, more frequent overload of the arms and shoulders and more fear of falling. Rehabilitation professionals also mentioned older age as a barrier of physical activity. Additionally, the rehabilitation professionals added that the stage of life is very important: i.e., age and living situation at the time the person became wheelchair-bound. One rehabilitation professional described it as follows:

Most people need to undergo a lower limb amputation as a consequence of diabetes when they are older. At that stage it is more difficult to guide them towards a healthier lifestyle. This is different from a relatively healthy person with spinal cord injury, who had a physically active lifestyle before ending up in a wheelchair. (Focus group 3, professional, working experience with wheelchair users > 10 years)

Facilitators

The most important facilitator of physical activity mentioned by wheelchair users is balance in daily life, more specifically, a balance between activity and relaxation. Rehabilitation professionals also mentioned living an active lifestyle before SCI or lower limb amputation as a facilitator. They remarked that it is easier to become physically active for wheelchair users who have already experienced the beneficial effects of physical activity on well-being, because this makes them more motivated.

Attitude

When participants were asked what they need to adopt a physically active lifestyle, they emphasized the need for internal motivation. Both wheelchair users and rehabilitation professionals mentioned that it motivates wheelchair users to reach personal goals. Rehabilitation professionals emphasized that physical activity needs to be fun, while wheelchair users also want to feel the benefits of an active lifestyle. As one wheelchair user mentioned:

Sometimes you just do not feel like it. However, when you are there and you are working with the weights, it feels advantageous. It has benefits. (Focus group 4, age < 58 years, single leg amputation above the knee for < 2 years)

Both rehabilitation professionals and wheelchair users mentioned the importance of realizing that wheelchair users need to work on their lifestyle for themselves and not to please others.

Environmental determinants

Barriers

During the focus groups the participants focused mainly on the barriers of being physically active. The most frequent mentioned barrier for wheelchair users is the inaccessibility of sports facilities. Wheelchair users experience that many sports facilities are not accessible and that they do not have customized fitness equipment. The ones that are accessible are often more expensive.

Besides, the appropriate sports facilities themselves, the transport to get to the (sports-) facilities is perceived to be expensive, unreliable and takes a lot of time:

Sometimes I travel two hours, for half an hour of physical therapy. (Focus group 2, age ≥ 58 years, complete SCI for 2–5 years)

Another problem related to sports facilities is that the time of day for group activities is inconvenient/impossible. As one wheelchair user puts it:

They decided to move the lesson from Thursday afternoon to Thursday morning, however, everyone with SCI needs a lot of time to get ready in the morning and we need more time to get to the sports location.... baffling... just baffling... . (Focus group 2, age ≥ 58 years, incomplete SCI for 2–5 years)

Furthermore, it is hard for wheelchair users to get the right equipment, for instance it takes a long time to request and receive an appropriate handbike. On top of that, they experience problems with the handbikes: batteries with short battery lives and incorrectly adjusted handbikes were mentioned most frequently.

Facilitators

Wheelchair users indicated that proper facilities are an important facilitator for being physically active. Furthermore, guidance by a professional was frequently mentioned as a facilitator:

It would be great if the rehabilitation centre would have its own club for ex-patients, where we can exercise with the guidance of a professional, for example three times a week for one hour. Personally, I would go there. (Focus group 2, age ≥ 58 years, complete SCI for 2–5 years)

Social support

A few wheelchair users mentioned the importance of their social environment. Especially wheelchair users with higher lesions need their family and friends to prevent them from overburdening, since they are not able to perceive and judge the level of fatigue in their body. As one wheelchair user mentioned:

I cannot feel it when my body gets tired. I need to trust my wife, she can tell... (Focus group 5, age < 58 years, incomplete SCI for 2–5 years)

Furthermore, the social aspect of physical activity is very important for wheelchair users, both rehabilitation professionals and wheelchair users emphasize the importance of being part of a group. The support of family can be twofold, as one rehabilitation professional recognizes:

When the wheelchair user is part of a very passive family, not aware of physical activity and a healthy lifestyle, it is really hard to lead the entire family towards a physically active lifestyle. That is almost impossible. (Focus group 6, professional, working experience with wheelchair users ≤ 10 years)

The positive role of a professional or coach was emphasized as well by wheelchair users:

Nowadays I am more motivated. I need to keep working on it, it is more fun to continue when someone is there to encourage me and tells me to go on. (Focus group 1, age ≥ 58 years, double leg amputation above the knee for > 10 years)

In addition to social support from people, some wheelchair users also mentioned having a dog as a facilitator to be more physically active, because dogs have to be let out.

Discussion

As a first step in the development of a lifestyle intervention aimed at improving physical activity levels in wheelchair users with SCI or lower limb amputation, the aim of the current qualitative study was to gain insight into determinants of physical activity. Various determinants were identified, of which some can be changed (e.g., balance in daily life leading to more time and energy to exercise, attitude towards physical activity, professional guidance, accessibility of facilities, social support) and might be targeted in the intervention. Other determinants are not changeable (e.g., general health status, age and stage of life, history of a physically active lifestyle), but might be used to personalize the intervention.

The results are in accordance with theory on physical activity promotion in people with disabilities. The results could all be organized according to the PAD-model in which personal factors – including barriers, facilitators, health status and attitude – and environmental factors – including barriers, facilitators and social support – are assumed to influence exercise behaviour [41]. The results are also in line with previous research in which general health status, demotivation due to a perceived low return of physical investment, accessibility of facilities, transportation and equipment difficulties, social support, and professional guidance were also identified as determinants of physical activity [24,25,27,28]. However, our results also show that rehabilitation professionals provide additional valuable insights into determinants of physical activity. Compared to what is known from earlier studies, the wheelchair users participating in our focus groups seemed to put more emphasis on the exhaustion that normal daily life brings. This exhaustion was mentioned to be a consequence of sitting, which is fatiguing for wheelchair users with SCI. In addition, self-care and usual daily activities, such as getting in and out of bed or dressing, were reported to take a lot of time and energy for wheelchair users. After all the general daily tasks, they have no time and energy left for health-enhancing physical activities.

Although the knowledge on barriers and facilitators of physical activity was already quite extensive from patient's perspectives [29], this study also adds the insights of rehabilitation

professionals. Rehabilitation professionals approach the experienced problems of wheelchair users from a different perspective. They combine their knowledge of experienced problems and available intervention strategies. Overall, we noticed that rehabilitation professionals had a broader scope in comparison to wheelchair users. Where the wheelchair users mainly discussed isolated determinants of physical activity, the rehabilitation professionals placed the determinants in a broader context in which they also discussed the relationship between different characteristics and behaviours. One example is that wheelchair users mentioned older age as a barrier, while rehabilitation professionals mentioned the stage of life a person is in as an important determinant of physical activity. In this discussion, one of the physical therapists described a stage of life in which one gets an amputation after diabetes. She explained the relationship with age, physical disorders, getting used to medication, smoking, alcohol use, and the motivation to change behaviour. These factors often interact with each other and affect physical activity together. These kinds of explanations provide valuable insights for tailoring of the future intervention. Now that the lifestyle programme to be developed can focus on determinants that are considered important by both wheelchair users and rehabilitation professionals, it is more likely that the intervention will target factors that do affect wheelchair users and may result in behavioural change. After all, the intended recipients and implementers of an intervention are best able to interpret the perspectives and needs of the groups to which they belong [23].

For the interpretation of the results, it is important to bear in mind that the focus groups with the rehabilitation professionals and wheelchair users were performed separately. This method was chosen, to make sure that every participant would feel free to share all their thoughts. However, it prevented interaction between the two groups, which could have been beneficial to gain more insights into determinants. Furthermore, it is important to keep in mind that recruitment bias might have occurred. Participants who are already interested in a healthy lifestyle are more likely to participate in research related to a healthy lifestyle (as indicated by the high scores in Table 2 for the importance of awareness regarding physical activity), even though the researchers aimed for a heterogeneous group. Except for the general interest in physical activity, the groups were quite heterogeneous. Wheelchair users differed in terms of time since rehabilitation, level of SCI or amputation, age, gender and educational level. This ensured that different patient groups were represented in the current research. Furthermore, different rehabilitation professionals participated, in terms of profession and years of experience working with wheelchair users. Heterogeneous groups are valuable for focus groups, since it stimulates the group discussion. The study population was not large enough for subgroup analyses. It might be interesting to unravel the differences in determinants for quadriplegia and paraplegia. However, this step is not essential for the future development of lifestyle interventions. Furthermore, we feel confident to state that data saturation was reached in the focus groups with wheelchair users. However, we cannot ensure data saturation was reached in the two focus groups with rehabilitation professionals, because the second focus group emerged additional insights. However, the focus groups with rehabilitation professionals did provide valuable insights from different types of rehabilitation professionals working with wheelchair users.

This research provides valuable insights for the development of physical activity interventions for wheelchair users with SCI or

lower limb amputation. Determinants that might be influenced in future lifestyle interventions for wheelchair users are: balance in daily life leading to more time and energy to exercise, attitude towards physical activity, professional guidance, exercise times, accessibility of facilities (providing information on how and where to find accessible facilities), and social support (learning how to get this). Determinants that cannot be altered but are also important according to wheelchair users and rehabilitation professionals are: general health status, age, stage of life, and previous experiences with a physically active lifestyle. These determinants might be valuable when considering personalising of future lifestyle interventions.

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