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## Experiences of the Redesigning Daily Occupation programme – a qualitative study among persons with neurological diseases

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### ABSTRACT

**Background:** The Redesigning Daily Occupations (ReDO) is a programme targeting persons who need to restructure activities and routines to achieve a healthier balance in everyday life. Issues that often is needed for persons with neurological diseases.

**Aims/Objectives:** To describe how persons with neurological disease experienced the ReDo-programme and to investigate how their occupational patterns and fatigue changed during the programme.

**Material and Methods:** A mixed method study with a convergent parallel design including ten participants. Questionnaires and individual semi-structured interviews have been used and data analysed by descriptive statistics and thematic analysis.

**Results:** The findings indicated an increased participation in everyday life after the intervention. Furthermore, the main theme showed that the intervention enabled reflections and new insight. Sub-themes included: feeling pressured to perform, being part of a group and changing occupational pattern.

**Conclusions:** Participants valued being a group; however, they experienced the intensity as being too high. The content of the intervention enabled reflections and new insights regarding their occupational pattern, which was experienced as a starting point towards behavioural changes and re-prioritisation of occupations in everyday life.

**Significance:** A modified version with lower intensity and careful goal setting might be valuable for persons with neurological diseases.

### ARTICLE HISTORY

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### KEYWORDS

Everyday life; neurological disease; rehabilitation

### Introduction

Neurological disorders are a common public health problem and the third most common cause of disability and premature death in the European Union [1]; furthermore, it is the second leading cause of death and the most common cause of long-term disability in the world [2]. In Sweden, approximately 2% of the population have an injury or disease in the nervous system, and common diagnoses are stroke, traumatic brain injury, multiple sclerosis or Parkinson's disease [3]. Common consequences due to neurological disorders include, for example, brain fatigue, cognitive, motor and psychosocial impact, which make it

difficult for the person to carry out and participate in daily activities, such as family life, activities at home, leisure and work [4–9]. Fatigue is an important consequence to consider in rehabilitation interventions due to its impact on quality of life [7]. Furthermore, the occupational balance could be changed after a neurological disorder, such as a stroke, and there is a need of support for persons with stroke to adopt activity-based strategies when reorientation to promote health [10]. There is a need for adaptation in everyday activities several years after a brain injury, as persons with an acquired brain injury have an increased number of occupational gaps and decreased participation in everyday activities after an injury

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[11]. It is important to focus on this since previous research have shown there is a strong relationship between occupational gaps and life satisfaction [12]. Thus, it is important to increase the knowledge on prevention, care and rehabilitation interventions for this group, as the prevalence and burden of disease is estimated to increase with the progressive ageing of the European population [1, 2].

Existing national guidelines in Sweden recommend individually tailored and multidisciplinary rehabilitation interventions for persons with stroke [13], multiple sclerosis and Parkinson's disease [14]. A systematic review and meta-analysis further support that interventions designed according to individual needs, delivered by a multidisciplinary team, and across settings and levels of care, may improve patient-reported health-related quality of life compared with standard care in persons with Parkinson's disease [15]. Due to the various symptoms and consequences following neurological disorders, the rehabilitation interventions need to be person-centred and individually tailored. Another systematic review of literature reviews found that active participation in goal setting, in which the individual context and preferences are considered, contributed to greater engagement in rehabilitation. The review also showed better outcomes of participation and occupational performance [16]. Neurological disorders and symptoms often entail long-term disabilities and thus a need for self-management and adaptations in everyday life in order to handle the consequences that might be present [17]. Persons with chronic diseases have to take their own responsibility for their self-management; it is a lifetime task, where healthcare providers have a role of being a teacher and a partner as well as a professional supervisor [18]. Self-management is, however, complex and individual. A qualitative study found several strategies used by persons with a neurological disorder or symptom. All strategies chosen were based on the specific condition and previous experiences of life situations. This entails that rehabilitation interventions focusing on strategies for self-management in everyday life need to consider individual preferences [19].

A common consequence after neurological disease is fatigue and a qualitative study highlighted the importance to receive support and education regarding fatigue in rehabilitation programs [8]. Fatigue Management is an intervention that is recommended. One six-week long intervention programme has, for example, shown positive results on sleep quality and depression up to nine months after completing the intervention [20]. This intervention has also been translated into Swedish and found to be feasible in

the Swedish context [21]. It also contains elements of self-management, which are deemed valuable in rehabilitation interventions due to neurological diseases. The Redesigning Daily Occupations (REDO) programme also contains self-management strategies. It is an occupational therapy programme targeting persons who need help with focusing on restructuring everyday activities and routines to achieve a healthier balance in everyday life [22]. Specifically, the REDO-programme constitutes three phases, where the first phase focuses on occupational self-analysis; the second phase targets goal setting and strategies for change, and the third phase targets return to work explicitly. The programme is delivered in group format and comprises two sessions per week for 10 weeks [22]. So far, it has mainly been used for persons with stress-related problems and long-term pain in Sweden, but it has also been used in an Irish context [23]. Previous research found that the REDO-programme contributed to increasing self-esteem [24], and it has been shown to be able to support women in changing how they carry out their daily occupations and routines by increasing awareness about their occupational patterns [25]. Furthermore, in another study by Karlsson et al. [26], it has been shown that the REDO-programme helped women to find balance in their everyday lives. Thus, the REDO-programme contains elements that might be valuable in rehabilitation interventions focusing on persons with neurological diseases and symptoms as well. This study aimed to describe how persons with neurological disease experienced the REDO-programme and to investigate how their occupational patterns and fatigue changed during the programme.

1. Does the participants' fatigue and occupational pattern change after participating in the REDO-programme?
2. Does the participants' self-rated satisfaction and performance of activities change after participating in the REDO-programme?
3. How do the participants experience participating in the REDO-programme?

## Materials and methods

### Design

This is a mixed method study with a convergent parallel design [27, 28]. Applying a convergent parallel design implies an equal handling and equal priority of the quantitative and qualitative data derived from the study. Furthermore, the data analyses are performed

separately. However, the results from each dataset contribute to an increased understanding of the aim and research question that is in focus.

The study is approved by the Swedish Ethical Review Authority (Reg. No. 2021-00102).

### Participants

Eligible participants for inclusion were persons who received team based rehabilitation due to neurological conditions at a specialised rehabilitation clinic in the middle of Sweden. The REDO-programme replaced other occupational therapy interventions; however, participants who had ongoing contact with a psychologist ( $n=3$ ) maintained that contact during the course of the programme. Furthermore, some participants had ongoing contacts with medical doctors and physiotherapists.

The criteria for inclusion were that the participants had: the ability to participate in a group intervention; sufficient capacity for the structure of the programme, and the ability to understand interview questions and share their experiences from the programme. Persons in an acute phase of their illness were excluded. Furthermore, those who met the criteria for participation in the project were assessed according to specific criteria included in the REDO-programme to ensure that they were motivated and in a phase of change that allowed them to assimilate into the programme. These specific criteria include; being on sick leave or in risk of sick leave, having a high visitor frequency to healthcare, or having symptoms/consequences of disease that may cause self-reported occupational imbalance.

The participants were selected by purposeful sampling in order to enable a variety of participants regarding diagnose, gender, age and sick leave [29, 30]. The occupational therapists at the clinic informed eligible participants about the aim and procedure of the study. The participants received written and verbal information regarding their participation and information that they could withdraw from the study at any time. Participating in the study meant in practice that the participants received the REDO-programme as a complement to their ordinary rehabilitation interventions. All of them had had or had an ongoing rehabilitation period at the clinic. The occupational therapist asked for participation, and all participants gave their written informed consent.

Ten women participated in the study. Their mean age was 47.1 years (range 31–59 years). Four persons had neurological disorders, and six had acquired brain injuries. The majority of the women ( $n=7$ ) were on full-time sick leave at the time for the intervention. Two persons were on part-time sick leave (25%), and

one participant was on part-time sick leave to various extents. Seven out of the ten participants were living together with a partner. They worked in the following occupations: teachers, administrative work, pre-school teachers and waitress. Further information about the participants' characteristics can be found in Table 1.

### The intervention

The intervention conducted in this study is a slight modified version of the Redesigning Daily Occupations (REDO) [22]. The basis for the programme is the same however some modifications were made in order to fit the target group. The REDO has an explicit focus on return to work and that has not been the outspoken focus in the intervention used in this study. The focus in this version of the REDO has targeted return to a well-functioning everyday life in a broader sense.

The intervention included two sessions per week, and the two first phases in the original REDO have been performed. The third phase in the REDO includes three follow-up sessions during the job training period. However, none of the participants were eligible to participate in job training, and the third phase was not performed according to the manual. However, two follow-up sessions have been conducted after the intensive programme in order to stay as close as possible to the REDO programme.

Two groups have been conducted. In the first group, there were three course leaders who shared the responsibility for the course, and all of them worked as occupational therapists at the clinic. However, they were only two course leaders at each session, and they alternated between each other. In the second group, there were two course leaders who joined every session. This change was made due to decreased occupational therapist resources at the clinic.

### Data collection

Data collection consisted of both questionnaires and semi-structured individual interviews, between March

**Table 1.** Demographic data regarding the participants.

Variable	Participants ( $n=10$ ) mean (range)
Age (years)	47.1 (31–59)
Sex (female/male)	10/0
Living conditions (living together/ living single)	7/3
Number of children	1.9 (0–4)
Diagnosis (neurological disorder/ acquired brain injury)	4/6
Sick leave at the time for REDO (full-time/part-time)	7/3

2021 and May 2022. The questionnaires were filled in by the participants on two occasions: before the start of the REDO-programme and after its completion. The questionnaires focused on execution, satisfaction and participation in everyday life activities as well as fatigue, which were measured using three questionnaires.

#### ***Canadian occupational performance measure (COPM)***

COPM is a person-centred instrument where the individual can identify and select activities that are prioritised for change [31]. The following activities are assessed: 1) personal daily activities (personal care, movement, coping in society), 2) productivity (paid/unpaid work, looking after the household, play/education), and 3) leisure time (quiet leisure time, active leisure time, social interaction). The person values the importance of the identified activities and provides an assessment of his or her performance and satisfaction with the activity. The instrument has good reliability for both performance and satisfaction, and has been validated and is sensitive to changes over time. A difference of 2 points in Performance and Satisfaction counts as a clinically significant difference [31].

#### ***Fatigue severity scale (FSS)***

The FSS is a frequently used instrument measuring fatigue. It is a self-assessment instrument with nine statements about fatigue and the severity of fatigue. The instrument is graded on a Likert scale from 1 (not at all true) to 7 (completely true). The statements concern the experience of everyday situations from the past week. There is no golden standard for the 'cut off' limit in the instrument; however, in most studies where the FSS has been used, the limit has been set at an average value higher than 4.0 to indicate fatigue [6].

#### ***Occupational gaps questionnaire (OGQ)***

OGQ measures participation in everyday activities, i.e. if there is a difference between what the person wants to do and actually does in everyday life. The instrument comprises 28 different activities within the domains: instrumental ADL, leisure interests, work and social activities. The average range for the number of occupational gaps is between 2 and 4 activities for people aged 30–64-years-old [32]. OGQ is suitable as a screening instrument and as a survey of people's perception of participation in everyday activities. The

instrument has acceptable validity and reliability for various diagnostic groups with functional and activity limitations and measures what is intended to be measured, i.e. participation in everyday activities. In a study of a Swedish reference group, one could see a pattern of younger people having more activity gaps than middle-aged and older people [32].

#### ***Semi-structured interviews***

Semi-structured interviews were conducted by an occupational therapist working at the rehabilitation clinic, but with another group of patients. She is familiar with the REDO-programme but was not involved in the participants' rehabilitation. The interviews were conducted, on average, four weeks (range 1–6 weeks) after the intervention and varied between about 40–60 min. Almost all interviews were performed face-to-face, but one of them was a digital interview due to the participant's long distance travel. All interviews were digitally recorded.

An interview guide was used to describe how persons with neurological disorders and acquired brain injuries experienced participating in the REDO-programme and to investigate how their occupational repertoire changed during the programme. The guide focused on how the participants experienced the content in the programme, how the programme was distributed over time, and in what ways the programme influenced their everyday lives.

#### ***Data analysis***

The results from the questionnaire are presented with descriptive statistics. The data were analysed using thematic analysis with an inductive approach [33]. The analysis has been conducted by the three authors, and the process for thematic analysis, including six steps, has been applied. In the first step, the interviews were transcribed, and the material was read several times. In a second step, initial codes were generated. The first interview was coded by all three authors and then discussed in order to reach an agreement on how to label the initial codes. The codes were labelled using words and phrases close to the transcript. After the first interview, the rest of the transcripts were divided between the authors, and each coded three interviews. The three authors discussed the initial coding regularly. In a third step, all codes from the interviews were analysed together to see common patterns of the individual codes, and to combine the codes into more general themes. This step was also done in close collaboration between all

the authors. In step four, the themes and codes were reviewed, going back and forth between the codes, themes, and transcripts. In the fifth step, the themes and sub-themes were discussed and named by the authors. In the final step of the analysis, the report was produced, and quotes were added to increase the credibility of the findings. All authors contributed to the analytic process through close collaboration with regular discussions and critical reviews.

## Results

### *Changes in level of fatigue and participation in everyday life*

The participants reported high values on FSS before and after the programme, with a small increase in fatigue after completing the programme. Participation in everyday life was reported as increasing after the programme, as the mean value of occupational gaps decreased after the programme. Two of the participants had increased the number of occupational gaps by two occupations after the end of the programme, two participants had reduced the number of occupational gaps by one activity compared to before the start of the programme, and the remaining six participants had reduced the number of occupational gaps with two to nine occupations (see Table 2).

The participants also used the Canadian Occupational Performance Measure (COPM) to set goals for the intervention. On average, four goals were formulated by the participants, and all of them had at least one goal formulated regarding physical activities and social activities. Six of the participants experienced a clinically significant improvement in their satisfaction with performing selected activities, and three participants experienced a clinically significant improvement in performing selected activities.

### *Experiences of the programme*

The qualitative findings identified that the programme 'Enabling reflections and new insight', which constitutes the main theme. The participants described how being part of a group sharing experiences enabled insight about not being alone having a certain life situation, how the homework enabled insights about how to take on assignments in everyday life and how the continuous discussions during the programme enabled reflections regarding their occupational patterns and desirable changes. This is further described with three themes and six sub-themes (see Table 3).

**Table 2.** Fatigue and occupational gaps.

	Fatigue Severity Scale			Occupational Gaps		
	Before	After	Diff	Before	After	Diff
Participant 1	6.50	7.00	0.50	15	14	-1
Participant 2	6.11	7.00	0.89	11	4	-7
Participant 3	7.0	6.33	-0.67	22	14	-8
Participant 4	4.78	4.56	-0.22	7	1	-6
Participant 5	6.78	6.78	0	17	13	-4
Participant 6	5.22	5.78	0.56	12	10	-2
Participant 7	6.44	6.89	0.45	10	11	1
Participant 8	5.67	6.00	0.33	7	9	2
Participant 9	6.11	6.44	0.33	12	3	-9
Participant 10	6.11	6.00	-0.11	6	5	-1

**Table 3.** Themes and sub-themes regarding the experiences of the programme.

Themes	Sub-themes
Feeling pressured to perform	Setting goals Doing homework
Being part of a group	Listening to each other Being part of a heterogeneous group
Changing occupational pattern	Performing activities during the programme Getting strategies and tools for everyday life

### *Feeling pressured to perform*

The participants described the start of the programme as being quite demanding. The programme structure was experienced as being too intense, and the participants would have preferred less frequent meetings. They perceived the programme as too intense because of the difficulties they faced in incorporating it into their everyday lives at the same time as working. Furthermore, they lacked sufficient time to complete and reflect on the homework, and a lack of energy after completing the programme meetings. Not having sufficient time or not being able to do tasks related to the homework and goal setting meant that they felt as if they had to perform more than they could manage.

Initially, there was thus some scepticism about the programme as the participants had difficulties understanding the purpose and some of the information that was given. As the programme progressed, the understanding of the aim of the programme increased; thus, they came to think of the programme as a well-developed concept with a clear thread throughout the programme. They described that the tasks built on each other and that the structure with recurrent repetition provided in-depth insights and reflections. The participants experienced the programme contributed to a change process that takes a long time.

*Setting goals.* The participants described difficulties in setting realistic goals in an already demanding everyday life. They related, for example, that it was difficult to know how the development of the disease or the symptoms would affect their ability to meet the goal

and that the goal was sometimes dependent on other persons and conditions in the environment. They also felt it was difficult to focus on several goals at the same time, and there was a feeling of having to perform in connection with setting and achieving goals.

Then at the beginning, it felt a bit overwhelming, maybe, that there was a lot; then there were tasks and there were goals, and then there was a bit of your goal, and write goals there. And what are your goals for this? And it was very, very intense right away. (H1)

The participants described that the short-term goals made it easier to see that the long-term goals were attainable and facilitated the participants to take actions that were necessary to make changes in their everyday lives. Not achieving their goals was described as a difficult process, which made the participants feeling sad.

But it can be difficult to set a real goal when you don't really know what the future has to offer. (H4)

*Doing homework.* Initially, the homework generated some frustration, and the participants expressed that it took a while to understand the purpose of the homework. The introduction of homework was perceived as unclear, and doing the homework contributed to feelings of stress and anxiety. The participants thought that these feelings arose because there was too little time between the programme sessions to do the homework, and they initially felt ashamed for not having done what was expected of them. It was difficult to do written assignments, but to reflect on the homework was easier. The participants thought it would have been easier if there was time scheduled to do the homework.

There is a lot of homework.//It is impossible to do what they want us to do. But on the other hand, it does start a thinking process; it does, but I feel that it is far too intense and there is far too much homework. (N1)

The stress generated by the homework decreased after a few weeks, and the focus was no longer on performing to the same extent. When the participants understood that the homework had a clear purpose, provided an opportunity for reflection and an opportunity to start implementing the course in everyday life, it became easier to take on the homework. Several participants described that the initial frustration and the feeling of being required to perform could have

been avoided with more clear instructions regarding the homework.

Oh, God, now I have to do that too. But towards the end, I could still, sort of think, and see that, that I could calm down, that it was sort of a thing that I had to sort of think, think to myself, that it sort of felt good. (H5)

### *Being part of a group*

Participants stated that participating in a group intervention was valuable. It was beneficial that all participants were new acquaintances to each other, with a group of people who would never have met otherwise. This enabled participants to be focused on the present, and they appreciated that there was room for conversation and reflection together with the other programme participants.

*Listening to each other.* The participants described an open climate in the groups, and they felt safe with each other. The group became a 'safe zone' where it was allowed to say what you felt or if something was not working. They appreciated having the opportunity to ask questions and sharing experiences with others being in a similar situation. The participants had an in-depth understanding of each other's situation, an understanding that cannot be learned, and the tips and advice the groups gave each other were important. The programme participants also provided feedback on each other's behaviour, which was experienced as valuable. The participants described that the group made them feel less alone in their situation, and of being needed. The recognition and support from the group in various situations contributed to the group's importance.

But this particular thing, that you have others, because sometimes you feel so different. And then you're like, there are many others who are just as different. (H6)

Some participants did not appreciate the group to a high extent. Instead, they stated that listening to other people's problems rather increased their own worries.

*Being part of a heterogeneous group.* The course participants had different diagnoses and life situations, which were perceived in different ways. Some expressed that it was difficult to feel a sense of belonging due to the variations in age, diagnoses, social situation and phase in rehabilitation, and some

described this mix of age, interests, diagnoses and problems as beneficial.

During the programme, the participants realised that the same diagnosis may appear very differently in various individuals and despite different diagnoses, the participants also could have similar problems. These similarities and differences enabled the participants to learn from each other, as they had shared experiences and understandings, even with different diagnoses.

Absolutely, because somewhere it's about perspectives and, and life and strategies; and it doesn't really matter what your situation is really, because you can get some things out of this anyway. (N4)

However, some participants highlighted a wish that all participants had the same diagnosis. They described it as sometimes being difficult that the programme participants had different prognoses due to their various diagnoses. When the programme was finished, several participants stated that they missed meeting the group and they wanted to have continued support and contact. Some participants had continued contact after the end of the programme via phone, joint chat group or physical meetings. Others found it difficult to reconnect with the group.

So when the weeks were over, it was almost like it was: well? No, but what should I do now? And what, who should I talk to then? And like what? Yes, it was somehow lonely again. (H5)

### *Changing occupational pattern*

The participants described how they changed their activity pattern during the programme, with positive effects in everyday life. For example, they described how they tried to reduce disruptions at work and in their everyday lives, prioritised activities and started to say no, performed one task at a time, and started to add pleasurable activities in their everyday lives even if it also meant exerting extra energy. They were all aware of the benefits with such changes; however, they also reflected on the risk of falling back into old habits after completing the REDO-programme.

*Performing activities during the programme.* The participants found the activities carried out during the programme to be simple and easy to conduct. There was no prestige in the activities, and they were perceived as rewarding and restful. The activities often served as a starting point for new thoughts and enabled time for reflection.

*So, that was very difficult because sometimes I think that it was a bit low level, but at the same time, I understand why. Because it's also to, sort of, start a thinking process in us. (H2)*

The activities gave valuable insights about being in the present while performing as well as insights into one's own behaviour. Furthermore, performing the activities enabled the participants to realise what they wanted to change and strive for in their everyday lives. However, they sometimes experienced difficulties in understanding the purpose of the activities. When this was not clear, the simplest activities were not appreciated.

And I probably missed that in almost all aspects, like a background; why are we doing this? Because, because I understood... when we kind of discussed it or asked. But that, it was not something that was addressed from the beginning. (H3)

Mindfulness was experienced as valuable, and the participants described that several of the activities also contributed to showing different ways of being mindful.

*Getting strategies and tools for everyday life.* The participants appreciated content that focused on activities in everyday life, with concrete strategies on how to bring about a change; they described that they always got something to take home. The course started a process that provided tools for the future. It was experienced as valuable, but also difficult, to work with oneself and reflect on how you can influence your own everyday life.

Yes, but they have given something, and you have really understood why you have made them, because they have illustrated something. Like being mindful or about how to reflect over time or just doing something for the sheer joy of it; so, so they've been great. (N2)

The participants described the tools that were introduced during the programme and which the participants continued to work with after the end of the programme. They described changes in their everyday life, such as letting go of their own demands and being more permissive towards themselves, for example resting, prioritising differently and taking help from others.

But then, I kind of applied both, to do one thing at a time and I follow my daily plan. (H4)

The participants valued the parts of the programme, focusing on strategies and reflection on how

they used to act in their everyday lives. However, they described that it would have been even better if they had received more information about the content and what was expected of them before the programme started. Such information would have enabled them to be more prepared for what was required. It was hard for the participants to reflect and work on themselves, especially when they realised that they previously had removed valued activities from their everyday lives.

Yes, but it's like I said, but it's important to have fun too... That, it can't just be work and... at home; you have to invest a little, but, but you benefit from it. (N4)

The programme was described as a facilitator for starting a process on how to distribute and prioritise activities in one's everyday life and gave an increased awareness of how to structure time. The participants gained new insights and an increased understanding of their own needs during the programme. For example, the importance of including desirable activities that previously had not been prioritised in their everyday lives.

## Discussion

This study describes how persons with neurological disease experienced the REDO-programme and investigates how their occupational patterns and fatigue changed during the programme. The REDO-programme is mainly used for people with stress-related problems and long-term pain; to our knowledge, there is limited knowledge on the applicability of the intervention targeting persons with neurological diseases. Common consequences due to neurological diseases include, among others, fatigue and occupational imbalance [10]. Thus, the restructuring of everyday activities, which is in focus in the REDO-programme [22], might also be beneficial for persons with neurological diseases in order to achieve a healthier balance in everyday life. The findings showed that the number of occupational gaps decreased after the intervention, indicating an everyday life in which the participants are able to do what they want and need to do, to a higher extent than before the programme. Furthermore, the main theme in the qualitative findings showed that the programme enabled reflections and new insights, as well as a change in their occupational pattern.

The findings showed positive trends in OGQ and COPM, which are promising results, even though the study is small. Still, the findings did not identify any

changes regarding fatigue. However, this was not to be expected due to the intensive programme and the short-term follow-up. Thus, future research focusing on the long-term effects of the REDO-programme for persons with neurological disorders would be beneficial. Even though the fatigue was found to be unchanged, the participants felt that other aspects of their everyday lives had improved. For example, they started to engage in valuable activities again without an increase in fatigue. The participants also received strategies to handle fatigue in their everyday lives, and it probably takes time to implement and start using these strategies in everyday life. One might consider if it would be beneficial to have a programme that is ongoing for a longer period of time in order to support implementation. The Lifestyle Redesign is an intervention having a similar focus as the REDO-programme, namely enable a balance in everyday life [34]. This programme is typically delivered over a period of several months and a scoping review have found promising results regarding increased well-being and changed occupational patterns in several target groups [35]. Still, the findings from this study indicate that the participants received tools they could continue using in their everyday lives, which promotes self-management. Self-management is an important feature to strengthen for persons with neurological disorders, as they need a wide range of different strategies to manage their everyday lives [19]. Previous studies have found that the REDO-programme enables persons with stress-related problems to take control of their everyday lives and create a new structure of activities included in the occupational repertoire [24, 26]. This was also the case for persons with neurological diseases.

Even though the participants experienced several benefits with the course, some challenges were identified. The findings revealed that the participants found it difficult and demanding to formulate and set goals. Setting goals in rehabilitation is important in order to increase engagement [16]; however, it is evident from previous research that difficulties might arise when goal achievement is dependent on other factors than the person's own ability [36] and when a person is dealing with a progressive disease. To manage goal setting, goals need to be individually customised and managed to improve one's life situation [16, 36]. It thus needs to be highlighted that goal setting in the course might need more gentle guidance and discussion with the course leaders in order to make this part individually tailored.

The findings identified that the participants valued the group format in this intervention. This is particularly interesting, given the variety of diagnoses within the groups. Even though some participants

found it difficult to share experiences with persons having other diagnoses, most of them valued this mix, as the focus was placed more on everyday life matters than on the diagnosis itself. They helped each other in taking steps forward in their behavioural change processes, which has also been found in a previous study focusing on the REDO-programme [26].

### **Methodological considerations**

This is a small study conducted at a particular rehabilitation clinic, which limits the possibilities for generalisation of the findings. Nonetheless, the study contributes with valuable insights into how the intervention might be used in the context of neurological rehabilitation. At the time of the study, the REDO-programme had not previously been used at the rehabilitation clinic. Moreover, the course leaders led this course for their first time; thus, they experienced some uncertainties, which might have been reflected in the participants' experiences of the course. However, all course leaders had participated in the compulsory course and discussed the course content with each other. They also had extensive clinical experience and have worked with the target group for several years.

In this study a purposeful sampling [29, 30] were used in order to reach a variation regarding for example diagnose, gender, age and sick leave. In this study we ended up with a variation in diagnoses, age and amount of sick leave, however all participants were women which is a possible limitation in the study. The inclusion of participants to the study was also based on the occupational therapist's clinical assessment of the participants' need for this programme. Patients who were assessed as having a need to reflect and change their structure in their everyday lives were asked to participate in the study. The fact that the clinical occupational therapists asked for participation might be a potential ethical dilemma since there was a power relation between the patient and their clinical occupational therapist. However, taking part in the study meant that the REDO-programme were added to their ordinary team rehabilitation interventions. Furthermore, three eligible participants declined participation because they felt the programme was too intense or had too much going on in their everyday lives. This indicates that the potential patients received the question of participating in the study in such a way that they felt that they had the opportunity to decline. Some patients at the clinic were deemed to not be eligible for the programme for the same reasons as those who declined. This made the total

sample ending up with 10 participants due to practical reasons and reasons related to available resources. This might influence the results, as only those who were positive towards the programme participated; however, the findings also revealed some negative aspects of the programme. Even though the findings indicated that this programme could be used with persons with neurological disorders, several of these individuals were not eligible for the study based on a clinical assessment, and one might consider whether the programme is too intense for this group of patients.

Triangulation have been used involving all three authors in the analysis procedure. This strengthened the credibility of the study. Furthermore, conformability have been ensured by using representative quotes from the participants in the qualitative part of the results [37].

### **Conclusion**

This study presents how persons with neurological diseases experience the REDO-programme and how their occupational patterns changed during the course of the programme. Our findings indicate that the REDO-programme might be beneficial for persons with neurological disease. The experiences that were described target the content and the format of the programme. Regarding the format, most of the participants valued being in a group; however, they experienced the intensity as being too high, with the consequence of feeling stressed. Still, the present study also points to a need to consider the progressive development when setting goals and the intensity of the programme. The programme needs to be less intense in order to enable all patients to participate even though having fatigue. One session per week would be more suitable for this target group.

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No potential competing interest was reported by the author(s).

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## References

- [1] Deuschl G, Beghi E, Fazekas F, et al. The burden of neurological diseases in Europe: an analysis for the global burden of disease study 2017. *Lancet Public Health*. 2020;5(10):1–12. Oct doi: [10.1016/S2468-2667\(20\)30190-0](https://doi.org/10.1016/S2468-2667(20)30190-0).
- [2] Dumurgier J, Tzourio C. Epidemiology of neurological diseases in older adults. *Rev Neurol (Paris)*. 2020; Nov176(9):642–648. doi: [10.1016/j.neurol.2020.01.356](https://doi.org/10.1016/j.neurol.2020.01.356).
- [3] Borg J, Borg K, Gerdle B, et al. Rehabiliteringsmedicin [In eng: rehabilitation medicine]. Lund: studentlitteratur AB; 2015.
- [4] Barone P, Antonini A, Colosimo C, et al. The PRIAMO study: a multicenter assessment of nonmotor symptoms and their impact on quality of life in parkinson's disease. *Mov Disord*. 2009;24(11):1641–1649. Aug 15 doi: [10.1002/mds.22643](https://doi.org/10.1002/mds.22643).
- [5] Gallagher DA, Lees AJ, Schrag A. What are the most important nonmotor symptoms in patients with parkinson's disease and are we missing them? *Mov Disord*. 2010; Nov 1525(15):2493–2500. doi: [10.1002/mds.23394](https://doi.org/10.1002/mds.23394).
- [6] Lerdal A, Bakken LN, Kouwenhoven SE, et al. Poststroke fatigue – A review. *J Pain Symptom Manage*. 2009;38(6):928–949. doi: [10.1016/j.jpainsym-man.2009.04.028](https://doi.org/10.1016/j.jpainsym-man.2009.04.028).
- [7] Naess H, Lunde L, Brogger J. The effects of fatigue, pain, and depression on quality of life in ischemic stroke patients: the bergen stroke study. *Vasc Health Risk Manag*. 2012;8:407–413. PubMed PMID: 22910531; PubMed Central PMCID: PMC3402053. doi: [10.2147/VHRM.S32780](https://doi.org/10.2147/VHRM.S32780).
- [8] White JH, Gray KR, Magin P, et al. Exploring the experience of post-stroke fatigue in community dwelling stroke survivors: a prospective qualitative study. *Disabil Rehabil*. 2012;34(16):1376–1384. doi: [10.3109/09638288.2011.645111](https://doi.org/10.3109/09638288.2011.645111).
- [9] Wu S, Kutlubaev MA, Chun HY, et al. Interventions for post-stroke fatigue. *Cochrane Database Syst Rev*. 2015;2015(7):CD007030. Jul 2 PubMed PMID: 26133313; PubMed Central PMCID: PMC37387276 doi: [10.1002/14651858.CD007030.pub3](https://doi.org/10.1002/14651858.CD007030.pub3).
- [10] Kassberg AC, Nyman A, Larsson Lund M. Perceived occupational balance in people with stroke. *Disabil Rehabil*. 2021; Feb43(4):553–558. doi: [10.1080/09638288.2019.1632940](https://doi.org/10.1080/09638288.2019.1632940).
- [11] Eriksson G, Tham K, Borg J. Occupational gaps in everyday life 1-4 years after acquired brain injury. *J Rehabil Med*. 2006; May38(3):159–165. doi: [10.1080/16501970500415322](https://doi.org/10.1080/16501970500415322).
- [12] Eriksson G, Kottorp A, Borg J, et al. Relationship between occupational gaps in everyday life, depressive mood and life satisfaction after acquired brain injury. *J Rehabil Med*. 2009;41(3):187–194. Feb doi: [10.2340/16501977-0307](https://doi.org/10.2340/16501977-0307).
- [13] Socialstyrelsen. Nationella riktlinjer för vård vid stroke. Sammanfattning av översyn 2020. [In English: National guidelines of stroke care. Summary of review 2020] [www.socialstyrelsen.se](http://www.socialstyrelsen.se). 2020 [cited 2023 September 20th]. Available from: [www.socialstyrelsen.se](http://www.socialstyrelsen.se).
- [14] Socialstyrelsen. Nationella riktlinjer för vård vid multipel skleros och Parkinsons sjukdom. Uppdaterade riktlinjer i korthet 2022. [In English: National guidelines of multiple sclerosis and Parkinson disease care. Updated guidelines in short 2022]. [www.Socialstyrelsen.se](http://www.Socialstyrelsen.se). Socialstyrelsen; 2022 [cited 2023 September 20th]. Available from: [www.socialstyrelsen.se](http://www.socialstyrelsen.se).
- [15] Rajan R, Brennan L, Bloem BR, et al. Integrated care in parkinson's disease: a systematic review and Meta-Analysis. *Mov Disord*. 2020;35(9):1509–1531. Sep doi: [10.1002/mds.28097](https://doi.org/10.1002/mds.28097).
- [16] Knutti K, Björklund Carlstedt A, Clasen R, et al. Impacts of goal setting on engagement and rehabilitation outcomes following acquired brain injury: a systematic review of reviews. *Disabil Rehabil*. 2022;44(12):2581–2590. Jun doi: [10.1080/09638288.2020.1846796](https://doi.org/10.1080/09638288.2020.1846796).
- [17] Kulnik ST, Hollinshead L, Jones F. "I'm still me - I'm still here!" understanding the person's sense of self in the provision of self-management support for people with progressive neurological long-term conditions. *Disabil Rehabil*. 2019; Jun41(11):1296–1306. doi: [10.1080/09638288.2018.1424953](https://doi.org/10.1080/09638288.2018.1424953).
- [18] Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*. 2003; Aug26(1):1–7. doi: [10.1207/S15324796ABM2601\\_01](https://doi.org/10.1207/S15324796ABM2601_01).
- [19] Auduly A, Hutchinson S, Warner G, et al. Managing everyday life: self-management strategies people use to live well with neurological conditions. *Patient Educ Couns*. 2021;104(2):413–421. Feb doi: [10.1016/j.pec.2020.07.025](https://doi.org/10.1016/j.pec.2020.07.025).
- [20] Sauter C, Zebeholzer K, Hisakawa J, et al. A longitudinal study on effects of a six-week course for energy conservation for multiple sclerosis patients. *Mult Scler*. 2008;14(4):500–505. May doi: [10.1177/1352458507084649](https://doi.org/10.1177/1352458507084649).
- [21] Månsson Lexell E, Haglund L, Packer T. The "managing fatigue" programme for people with multiple sclerosis - acceptance and feasibility with swedish occupational therapists. *Scand J Occup Ther*. 2020; Oct27(7):536–549. doi: [10.1080/11038128.2019.1634149](https://doi.org/10.1080/11038128.2019.1634149).
- [22] Erlandsson L. The redesigning daily occupations – REDO program: supporting woman with stress-related disorders to return to work – knowledge base, structure, and content. *Occup Ther Mental Health*. 2013;29(1):85–101.
- [23] Fox J, Erlandsson LK, Shiel A. A feasibility study of the redesigning daily occupations (ReDO(TM)-10) programme in an irish context. *Scand J Occup Ther*. 2022; Jul29(5):415–429. doi: [10.1080/11038128.2021.1882561](https://doi.org/10.1080/11038128.2021.1882561).
- [24] Eklund M, Erlandsson LK. Return to work outcomes of the redesigning daily occupations (ReDO) program for women with stress-related disorders—a comparative study. *Women Health*. 2011; Nov51(7):676–692. doi: [10.1080/03630242.2011.618215](https://doi.org/10.1080/03630242.2011.618215).
- [25] Wästberg BA, Erlandsson L-K, Eklund M. Client perceptions of a work rehabilitation programme for wom-

- en: the redesigning daily occupations (ReDO) project. *Scand J Occup Ther.* 2013; Mar20(2):118–126. doi: [10.3109/11038128.2012.737367](https://doi.org/10.3109/11038128.2012.737367).
- [26] Karlsson L, Erlandsson L-K, Cregård A, et al. Taking control of one's everyday life - a qualitative study of experiences described by participants in an occupational intervention. *BMC Public Health.* 2023;23(1):605. Mar 30 PubMed PMID: 36997894; PubMed Central PMCID: PMC10064529. doi: [10.1186/s12889-023-15515-z](https://doi.org/10.1186/s12889-023-15515-z).
- [27] Creswell J, Plano Clark V. *Designing and conducting mixed methods research.* (2nd ed). Thousand Oaks: SAGE; 2010.
- [28] Hadi MA, Alldred DP, Closs SJ, et al. Mixed-methods research in pharmacy practice: basics and beyond (part 1). *Int J Pharm Pract.* 2013;21(5):341–345. Oct doi: [10.1111/ijpp.12010](https://doi.org/10.1111/ijpp.12010).
- [29] Palinkas LA, Horwitz SM, Green CA, et al. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health.* 2015;42(5):533–544. Sep PubMed PMID: 24193818; PubMed Central PMCID: PMC10064529. doi: [10.1007/s10488-013-0528-y](https://doi.org/10.1007/s10488-013-0528-y).
- [30] Suri H. Purposeful sampling in qualitative research synthesis. *Qualitative Research Journal.* 2011;11(2):63–75. doi: [10.3316/QRJ1102063](https://doi.org/10.3316/QRJ1102063).
- [31] Law M, Baptiste S, Carswell A, et al. *Canadian occupational performance measure.* Third ed. Ottawa: CAOT Publications ACE; 1998.
- [32] Eriksson G. GAP i vardagens aktiviteter-instrument som mäter delaktighet genom att fånga skillnaden mellan vad klienten vill göra och faktiskt gör. [In Eng: occupational gaps - an instrument that measures participation by capturing the difference between what the client wants to do and actually does.]. Nacka: förbundet Sveriges Arbetsterapeuter; 2012.
- [33] Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology.* 2006;3(2):77–101. doi: [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa).
- [34] Clark FA. *Lifestyle redesign. The intervention tested in the USC well elderly studies.* 2015. USA: AOTA Press.
- [35] Pyatak EA, Carandang K, Rice Collins C, et al. Optimizing occupations, habits, and routines for health and well-being with lifestyle redesign®: A synthesis and scoping review. *The American Journal of Occupational Therapy.* 2022;76(5):7605205050. doi: [10.5014/ajot.2022.049269](https://doi.org/10.5014/ajot.2022.049269).
- [36] Goudman L, De Smedt A, Linderoth B, et al. Identifying goals in patients with chronic pain: a european survey. *Eur J Pain.* 2021;25(9):1959–1970. doi: [10.1002/ejp.1814](https://doi.org/10.1002/ejp.1814).
- [37] Elo S, Kääriäinen M, Kanste O, et al. *Qualitative content analysis: a focus of trustworthiness.* SAGE Open. 2014;4(1):215824401452263. doi: [10.1177/2158244014522633](https://doi.org/10.1177/2158244014522633).