# Lived experiences of people living with long-term neurological conditions and using telerehabilitation during the COVID-19 lockdown in Switzerland: Explorative interviews

## *Erfahrungen mit der Telerehabilitation während des COVID-19 Lockdowns in der Schweiz von Menschen die mit neurologischer Langzeiterkrankung leben: explorative Interviews*

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**Background** Therapy interventions were disrupted by the first lockdown caused by the COVID-19 pandemic. An instant change to telerehabilitation had to be implemented by physiotherapists.

**Objective** Exploration of lived experiences of individuals living with a long-term neurological condition receiving telerehabilitation physiotherapy intervention during the first lockdown.

**Method** Persons with a long-term neurological condition were recruited from the outpatient clinic of a local hospital in the Swiss German speaking part of Switzerland during February and March 2021. Semi-structured individual interviews with a phenomenological perspective were audio-recorded, transcribed verbatim and analysed using reflexive thematic analysis.

**Results** Four persons, two with Multiple Sclerosis and two with Stroke (aged 44-75), were interviewed. Three main themes were generated, of which two had three subthemes: 1) Living with a neurological condition during a pandemic (*daily life without and within a pandemic; symptoms; feelings and attitudes influenced by the pandemic);* 2) Therapy Experiences (*therapeutic relationship; remote therapy; therapy experiences after the first lockdown);* and 3) Family and Social Environment. Synchronous interventions such as live video sessions or live online groups were favoured when compared to telephone calls or asynchronous digital interventions. However, for participants, it was equally important to explain how the pandemic influenced them generally.

**Conclusion** Individuals interviewed appreciated having received therapy during the lockdown, favouring synchronous interventions. However, there are still many unanswered questions about how best to support these populations, and evidence-based recommendations are needed.

**Key Words** neurological disorders, stroke, multiple sclerosis, telehealth, COVID-19

**Einleitung** Der durch die COVID-19 Pandemie verursachte erste Lockdown führte zur Unterbrechung nicht dringend notwendiger Physiotherapiebehandlungen in der Schweiz. Ein unmittelbarer Wechsel zu Telerehabilitationsinterventionen durch Physiotherapeuten:innen war notwendig.

**Ziel** Eine explorative Untersuchung von Therapie- und Lebenserfahrungen während des ersten Lockdowns bei Personen die mit einer neurologischen Erkrankung leben.

**Methode** Menschen mit einer neurologischen Grunderkrankung wurden im Ambulatorium eines Regionalspitales rekrutiert. Es wurden semistrukturierte Interviews unter phänomenologischer Perspektive aufgezeichnet, transkribiert und mit Hilfe einer reflexiven thematischen Analyse ausgewertet.

**Ergebnisse** Insgesamt wurden vier Personen, zwei mit der Diagnose Multipler Sklerose und zwei mit Status nach Schlaganfall (im Alter zwischen 44-75), befragt. Bei der Datenanalyse wurden drei Hauptthemen herausgearbeitet, von denen zwei jeweils drei Unterthemen hatten: 1) Leben mit einer neurologischen Erkrankung während einer Pandemie (*tägliches Leben ohne und innerhalb einer Pandemie; Symptome; Gefühle und Einstellungen, die durch die Pandemie beeinflusst wurden*); 2) Therapieerfahrungen (*therapeutische Beziehung; Teletherapie; Therapieerfahrungen nach dem ersten Lockdown*); und 3) Familie und soziales Umfeld. Dabei wurden synchrone Interventionen wie Live-Videositzungen oder Live-Online-Gruppen im Vergleich zu Telefonanrufen oder aufgezeichneten digitalen Interventionen bevorzugt. Alle Teilnehmenden erlebten auch negative Folgen in Bezug auf die Symptome und das soziale Leben und erklärten wie die Pandemie sie allgemein beeinflusste.

**Schlussfolgerungen** Die Teilnehmer:innen schätzten es, während des Lockdowns eine Form von Therapie erhalten zu haben und bevorzugten dabei synchrone Interventionen. Es gibt noch viele unbeantwortete Fragen darüber, wie diese Bevölkerungsgruppe in solchen Situationen am besten unterstützt werden kann, und es werden evidenzbasierte Empfehlungen benötigt.

**Schlüsselwörter** Neurologische Erkrankungen, Schlaganfall, Multiple Sklerose, Telemedizin, Telerehabilitation, COVID-19

## Background

The new coronavirus called SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) that leads to coronavirus disease 19 (COVID-19), which caused a worldwide pandemic, has emerged as one of the biggest public health crises in a century [1]. In Switzerland, the Federal Council decided on the 16th of March 2020 that this was an "extraordinary situation" by the Epidemics Act and adopted the "lockdown" as an intervention for the pandemic's national containment. According to Ordinance 2 on actions to combat coronavirus, health care institutions were prohibited from carrying out non-urgent medical examinations, treatments and therapies [2]. Telemedicine/Telerehabilitation was one possible way, for physiotherapists to deliver their treatment to patients needing physiotherapy. The term telerehabilitation used in this paper refers to the definition provided by the task force of World Physiotherapy (WCPT) and the International Network of Physiotherapy Regulatory Authorities (INPTRA). 'Digital practice' in physiotherapy includes telerehabilitation which is "a term used to describe health care services, support, and information provided remotely via digital communication and devices" [3]

There is a growing body of literature that describes facilitators, barriers and issues which need to be considered when offering telerehabilitation, both from a therapist and a patient perspective. Most literature describes the positive effects - such as convenience and management of individualised exercise interventions - when using digital tools within well-structured interventions [4-8]. The tools include telephone apps or wearable technologies, and telephone- or video treatments. However, patients require certain skills to benefit from telerehabilitation interventions such as computer literacy (using computers and related technology efficiently), media literacy (using search engines) and information literacy (evaluation of information in a variety of sources) [9]. This is in addition to their general health literacy, which can be understood as the personal knowledge and competencies to access, understand and apply health information to make decisions concerning healthcare and disease prevention [10]. Such issues of literacy and the fact that the adoption and use of digital devices in healthcare or telehealth services had not been widespread in Switzerland before the pandemic [11-13] led to the possible assumption that telerehabilitation interventions should be well planned and based on current recommendations. This ensures that patients can fully understand interventions and benefit from them.

However, the COVID-19 pandemic forced Swiss physiotherapists to swiftly change to telehealth treatments despite a lack of previous experience of providing services in this way [14]. Subsequently, this created an opportunity to study teletherapy in different areas [15, 16] and investigate what kind of interventions produced within a short timeframe were best suited to patients. A recent report from the WCPT about physiotherapy responses to COVID-19 outlines how physiotherapy practise changed during the pandemic [3]. Before the pandemic, some musculoskeletal therapy was provided digitally, but the pandemic accelerated changes in all service areas including therapy for neurological conditions. However, there was no known literature exploring how people living with a long-term neurological condition experienced the change to digital practice and their general experiences during the pandemic.

Individuals' experiences are at the centre of understanding how distant therapy approaches supported their health [17]. This patient population often have a long history with a range of therapy interventions because they need continuous treatment to improve or maintain their functional level [18-20]. This background enables them to compare and contrast the change between face-to-face and digital therapy. A phenomenological approach holds the potential to expose discrepancies between actual lived experiences and what the experiences were thought to be [17]. It is often closely associated with hermeneutics (the science of interpretation and explanation) [21]. Since language is a medium by which we experience and give meaning to our world, the data collection involved individual interviews [21]. The role of the researcher in the interpretation of the phenomenon is acknowledged [22] and so the study can be situated in the context of an idealist ontology [17, 22]. This work will generate insights into the experiences and needs of patients living with a long-term neurological condition by examining the following research question:

> “What were the experiences of persons living with long-term neurological conditions when being treated with telerehabilitation by physiotherapists during the first lockdown of the COVID-19 pandemic compared to previous therapy settings?”

## Methods

A semi-structured interview guide was developed to elicit participants' stories about their lived experience of therapy delivered as telerehabilitation during the first COVID-19 lockdown in Switzerland. The interview guide was developed using phenomenological interviewing principles. Questions are constructed over contextualisation, capturing the phenomena and clarifying the phenomenon [23]. Open questions covered the following topics: 1) physiotherapy treatment before the Covid-19 lockdown, 2) general effects on COVID-19 measures 3) experiences of tele-physiotherapy interventions during the lockdown, and 4) experiences with physiotherapy after the lockdown. The initial guide was tested with a lay person in terms of understanding the questions and was refined through discussion with three other researchers with interest in this topic. In addition, the author kept a research diary to reflect on interviews and make adjustments throughout the study to improve clarity for the participants. All interviews were conducted by the lead author, in person, during February and March 2021 and lasted for between 40 to 60 minutes.

## Recruitment and Participants

A method of convenience and purposive sampling was used, within available resources [24]. The researcher contacted several local clinical outpatient practices and rehabilitation centres and an outpatient centre at a local hospital, all situated in rural areas and the German language part of Switzerland. The request was dependent on delivering some form of teletherapy intervention during the first lockdown, and asked for potential participants (see table 1) for an interview study.

Potential participants were initially approached by their therapists and any who showed an interest were then provided with full details of the research, including an informed consent form (IC). The therapists provided contact details to the lead author who communicated with interested participants to clarify aims and procedures. If there was agreement to participate, a written consent form was signed. Participants were offered the choice of an online or in person interview. Interviews were audio recorded and manually transcribed verbatim in Swiss German by the author, recognising that transcribing is an essential part of the analytical process [25]. Transcripts were then imported into the Data analysis program MAXQDA2020. The data is translated for reporting although this can have potential risks and dilemmas [26].

Table 1. Participant inclusion and exclusion criteria

| Inclusion | Exclusion |
|---|---|
| • >18years old<br>• Able to communicate vocally in German<br>• Longer than half a year in regular physiotherapy treatment for a neurological condition<br>• Some form of telerehabilitation during the lockdown | • Known severe fatigue symptoms (after/before 45minutes of interview)<br>• Patients receiving treatment from the interviewer |

## Ethical considerations and Participant safety

Ethical clearance was obtained from Ethics Committee Northwest and Central Switzerland (ref. number: Req-2020-01440) and by the Faculty Research Ethics Committee of the University of the West of England (UWE rec ref no: HAS.21.01.067).

A strict code of conduct was adopted to comply with current COVID-19 safety measures such as wearing face-covering masks, maintaining a distance of a minimum of two metres and ensuring regular room ventilation when interviews were conducted on-site.

## Data Analysis

The researcher conducted a reflexive thematic analysis to construct summative, phenomenological meanings from the data [27, 28].

The analysis followed the six-phase process recommended by Braun and Clarke: 1) familiarising yourself with your data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the report [29]. A complete coding using the software of MAXQDA2020 (person driven analysis software) was conducted, and semantic and latent derived codes were created [30]. Within the reflexive thematic analysis, the coding process was open and organic [27]. It required no use of a coding framework, but the quality of practice was addressed by reference to the 20-questions guide for thematic analyses, according to Braun and Clarke [27]. Furthermore, the codes and themes were discussed within the research team to enrich the analytical process.

## Results

Three women and one man, aged 44-75 years and all living in rural areas of Switzerland, took part (see table 2).

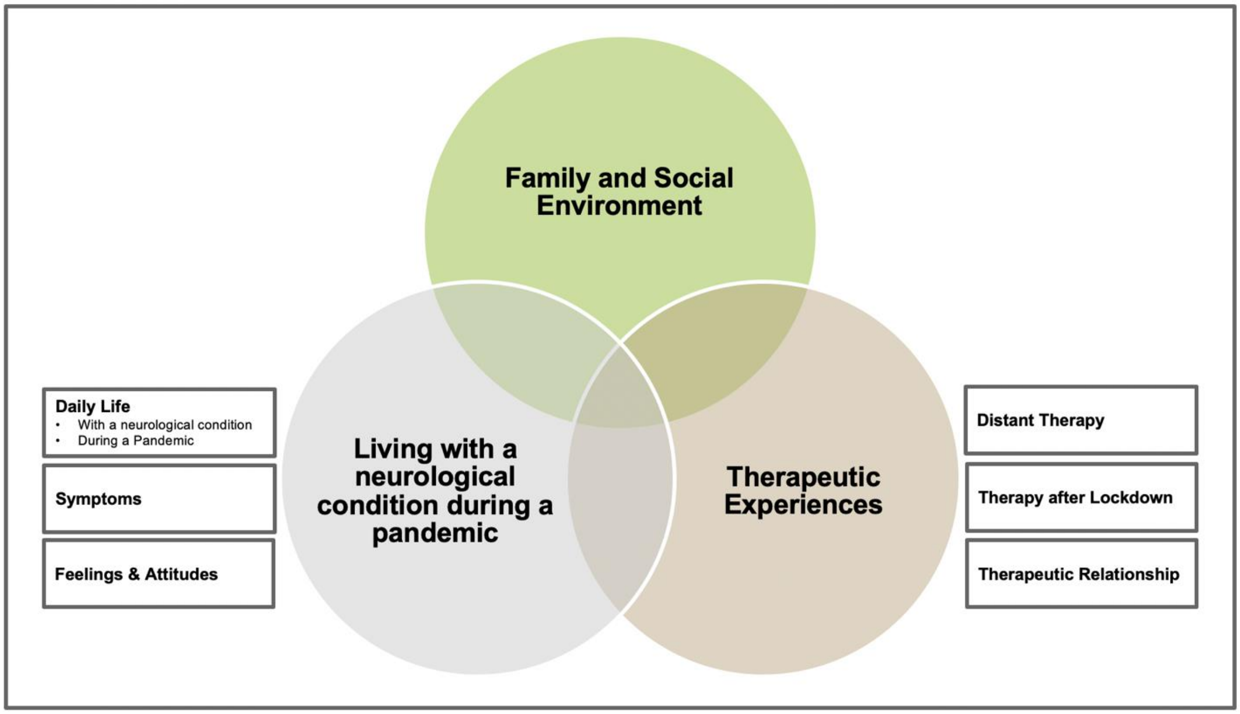
Table 2. Participant characteristics

| Characteristics of the participants (n = 4) | | | | |
|---|---|---|---|---|
| Pseudonym | Age | Highest level of education | Neurological Condition | Treatment start date |
| Johanna | 56 | EFZ* | Stroke | 2018 |
| Felix | 75 | Doctor | Stroke | 1989 |
| Sophie | 64 | EFZ* | MS** | 2016 |
| Anna | 44 | EFZ* | MS** | 2015 |
| * Federal certificate of proficiency (Eidgenössisches Fähigkeitszeugnis)<br>** Multiple Sclerosis | | | | |

In preparing the manuscript for publication, the original quotes were translated from Swiss German into English. The quotes were given to a fluent English and German language speaking person to double check translation. Three main themes were extracted during the analysis (illustrated in figure 1):

1) Living with a neurological condition during a pandemic
2) Therapeutic experiences
3) Family and Social Environment

Figure 1: Lived Experiences during the first lockdown



The themes developed are summarised below with illustrative quotations.

*Theme 1: Living with a neurological condition during a pandemic*

The theme of *Living with a neurological condition during a pandemic* was developed. Three subthemes spanning daily life without and within a pandemic, symptoms influenced by the pandemic and feelings influenced by the pandemic were identified.

*Subtheme: Daily Life with a neurological condition and during a pandemic*

Participants talked about how they experienced their everyday life with a neurological condition and how this life changed during the pandemic. While Johanna seemed to have a relatively calm daily life before (going to therapy, doing household chores), the others had more appointments to manage, such as social responsibilities in the community. Because of the different realities of life, the pandemic influenced them differently. Three of them had to completely withdraw from social interaction, fearing an infection. While Anna experienced the initial time of the first lockdown as “a state of calmness” and enjoyed the additional time for herself, Sophie describes this time as an “absolute isolation of everything”.

> Sophie *“Of course we talked more on the phone... but what I noticed... I always wrote to someone or asked "how are you"... and everyone was glad to hear from me... but then I realized that no one was asking about me. I thought then maybe they are all very busy with themselves and think Sophie is certainly well.*

> Anna *”At the very beginning, I had the feeling that I was in a state of calm, that I didn't have any more appointments [...] to concentrate on myself and to feel into it [...].*

*Subtheme: Symptoms*

Opinions also differed when talking about their symptoms and how the pandemic influenced them. All experienced a form of functional decline from when the lockdown started to the time of the interviews. While Sophie is sure that the lockdown worsened her symptoms, Anna doubts whether the worsening is due to the pandemic restrictions or the natural course of her disease. Felix and Johanna recognise that they had increased pain periodically  because of the absence of manual  therapy or due to recent falls. However, neither were  sure whether physiotherapy treatment would have made a difference .

> Felix “*I’m getting worse, I have too little mobility and torso control […] I declined too much.”*

> Sophie *(The symptoms) “have gotten worse, but it's hard to say if it is because I have the secondary progressive form or… I can't tell you how much… is it because I stopped doing things regularly."*

*Subtheme: Feelings and attitudes*

When talking about the time directly before lockdown (one week before therapy was discontinued ), Johanna and Felix describe that they felt anxious attending therapy. However, Felix emphasises, that despite initially being glad that he did not have to go to therapy, he  lost  all motivation during the time at home and Joanna describes the negative feeling of exercising alone at home and feeling insecure.

> Johanna *“The fear always breathed in my neck when I came” (to therapy before 16$^{th}$ March 2020).* However, at home, she didn’t feel safe all the time: *“I prefer to be here (in therapy) […] with the people around me, if something would happen, (there is) someone, you can trust.”*

> Felix: *"I'm a couch potato, and tv addicted […] I’m not doing a lot of home exercises […] nothing really helps to overcome my weaker self.”*

Sophie describes the process of living with a neurological condition and then getting thrown into a pandemic as a “Sisyphean process” where you start and start again but do not come to an end. Before the lockdown, she felt that her disease was stable with all the therapy and exercises (after recovery from a previous decline following a medication change). However, the pandemic made her feel as though she was starting from the beginning, experiencing a decline in the first two weeks of the lockdown.

> Sophie "*It's such a Sisyphean thing. You do and do, and yet you always start again… I have really had my emotional low point.”*

### *Theme 2: Therapeutic Experiences*

### *Subtheme: Therapeutic relationship*

The most pertinent subtheme was about the therapeutic relationship within the main theme of Therapy Experiences. All participants describe the nature of their connection with their therapist and how important it is to them. For all of them, this relationship was why they were willing to “try” the distant therapy approaches. All of them mentioned that they were sceptical about remote therapy but their trust in the therapist helped them to try it out.

> Anna *“it is so important to have a constant health care professional who really knows you and sees you regularly […] someone who gives me an objective outside view”.*

All participants described that they were happy to see the therapists again, on-site or online. Felix even describes his therapeutic relationship as a friendship *"that has lasted 30 years”.*

### *Subtheme: Remote Therapy*

Talking about their teletherapy experiences, the participants, on the whole, told different stories. For example, Felix was not able to remember details of the telephone calls where the therapist might have told him how he should continue with his exercise.

> Felix *“I just called to cancel the appointments and then talked a little bit to the therapist from time to time […] anyway if the phone rings and I’m on the couch, it always annoys me […] and it is also a security factor when I stress (to reach the phone), the possibility that I can fall rises.”*

The others were able to recall how they took part in different forms of remote therapy. Johanna started with telephone calls and changed them to video sessions. She describes this change as reasonable but also that she could not reach the therapy intensity compared to on-site therapy.

> Johanna: *“It was good to see the therapist […] and to see the exercise descriptions […] we just talked over the phone […] the videocalls felt closer […] but you again have to do it on your own, it is just less intensive.”*

> Anna *“I was called several times by (the physical therapist) but it was not the same […] I stopped doing exercises regularly even knowing them and (the physical therapist ) tried to motivate me […] the phone calls were just insufficient and also the recorded videos did not change this […] “I just didn't care because she couldn't see me [...], and then you fidget around a bit yourself, and you don't know if you're doing it right."*

> The interviewer wonders if Anna’s attitude changed toward distance therapy… Anna: *“Yes, really positive, two years ago, I would have said, "Oh, what's the point, what's the use?” And now I really have to say it's a great option."*

She mentions that regular appointments would have helped to increase the "social pressure" a bit. Instead, her therapist called her irregularly, which was difficult for her.

Sophie went through a whole different story; she declined rapidly functionally so that she got permission from the doctors, after two weeks, to revisit the physiotherapist on-site. During the first two weeks,  two calls from the therapist’ were *“never enough",* and she felt the need for regular on-site therapy. However, she was happy that her Qi Gong teacher provided pre-recorded videos for her to practice routines, which was better than a written description.

In addition, Sophie and Anna got the chance to switch their regular group training for Multiple Sclerosis (MS) patients to an online form. Being sceptical at the beginning, both are now excited about the new opportunity. Anna thinks that it is better to do it from home and exercises to a higher intensity since partner exercises or similar are not possible. Sophie describes similar effects but emphasises that she misses the contact with social peers (theme 3). She also describes the factor of distraction during balance exercises.

> Sophie *“sometimes I want to see how the others are doing but I just have to concentrate on the coach otherwise it doesn’t work.”*

*Subtheme: Therapy after lockdown*

The third subtheme identified was therapy experiences after the first lockdown. All participants returned to their previous setting and didn’t continue with distant therapy. Only Anna and Sophie are continuing the live online group training. Anna also continued using a pedometer app, and Felix and his therapist are thinking about starting some skype meetings as a supplement to his regular therapy. The actual safety measures (wearing face-covering masks and physical distancing of 1.5 meters) gave Johanna a “feeling of safety." In contrast, Anna had a sense of distance from her therapist. Anna describes how managing a long-term neurological condition is different for her after the lockdown. For example, she can’t check out rehabilitation centres for suitability, due to visitor restriction by the rehabilitation centres. She would like to go somewhere else, due to previous bad experiences, but is not able to make an alternative arrangement because of the restrictions on visiting health facilities.

> Felix *“Having at least one training partner even being physically distant in the same room is a benefit. We were a small group of two persons for a long time […] this possibility gives me an interaction again.”*

> Sophie *“We already did these protective steps from time to time in the group, but that was just too quick. But the physiotherapists trained me again after my falls; that was really good.”*

> Anna (There is more distance between her and the therapist) *"already due to wearing a mask, and that’s a bit weird considering that (going into therapy) is quite a personal situation"*

*Theme 3: Family and Social Environment*

All participants described the significant impact of the pandemic on their social life. In all cases, the interviewees reported that the pandemic made them lonelier. Their daily lives changed dramatically in terms of social life, making the family the most critical support. All describe that even during "normal" times, they are the ones who support them in “daily life activities” and they explain how family members help if special things, for example, technical devices, don’t work. Two participants made clear that if they didn’t have the support of their husbands and children, many things would not be possible and that they often wouldn’t cope with new devices.

> Johanna *“I have to ask my husband when something does not work […] we built a unit and we have become entrenched over time.”*

> Sophie *“My husband is doing a lot […] and If something technical is not working, I ask my children."*

However, three of the interviewees described the changed relationship with friends caused by the pandemic. Even staying in close contact over phone calls or text messages, their relationships were strongly influenced by physical distance. Sophie and Anna recognised that more people than before “were stuck in their situation” and had to look after themselves first, which was “kind of sad”. Sophie mentions that she was surprised that while her friends responded positively to calls or text messages, they mainly talked about themselves. She was initially sad about this situation until she recognised that many lives had become more complex and that their response had nothing to do with their relationship. It appears that it was mainly the family that gave the participants the support they most needed.

> Felix *“my grandchild is the biggest source of joy, and I really want to see her growing up […], so I have to do my exercises […] friends stayed but sometimes I experienced kind of lethargy and even didn’t answer all Mailings because of laziness […] but no one was pushing me either.”*

> Sophie *“And then I always wrote to someone and asked how it was going. Everyone was happy and also wrote to me or phoned me until I started to notice that no one was asking about me [...] and then I thought, maybe they're very busy with themselves […] if they don’t ask about me, it is like swallowing a bitter pill […].”*

> Anna *"After a while, I felt that now it would actually be nice if I could have a little closer contact with others who are important to me [...]"*

## Discussion

An initial objective of the project was to investigate how individuals living with a long-term neurological condition experienced the switch to telerehabilitation interventions during the lockdown in Switzerland. Through the interviews, it became apparent that unstructured change to distant therapy interventions only worked to a limited extent for the participants and that a synchronous approach seemed to be favoured in comparison to asynchronous digital interventions. In addition to answering questions about the use of telerehabilitation for therapeutic interventions, the participants talked about how the pandemic had influenced their state of health and daily life. The predominant themes emerging from the participant’s responses were their experiences of living with a neurological condition during a pandemic, therapeutic interventions and of the effect on family and social life.

### *Theme: Living with a neurological condition during a pandemic*

In the first theme, “Living with a Neurological Condition during a pandemic”, the subthemes included activity and participation, impairments, and personal factors as in the International Classification of Functioning, Disability and Health (ICF) [31]. Considering that almost all areas of the ICF framework were addressed, it can be concluded that the participants were negatively affected by the pandemic in all areas of their daily lives. This theme shows that participants were, at the time of the interviews, at least equally concerned about their state of health and how the pandemic influenced their daily life, as by the therapy approaches themselves. One possible explanation could be that the interviews were conducted after the second wave of the pandemic in Switzerland. The first lockdown, one year previously, seemed emotionally more distant from their current state of health. In the second wave, on-site physiotherapy was allowed in Switzerland, while in the first wave only urgent treatments could be offered [2, 32]. Participants were already back to the previous provision of on-site therapy. They explained how their lives and symptoms changed during the pandemic; most of the participants could cope with the situation and were glad to participate in “some therapy” during this time. All interviewed individuals experienced some form of “functional decline” and intensified/different symptoms.

These findings are in line with previous studies that describe the influence of the COVID-19 pandemic on the physical activity of the “healthy population” [33]. However, in contrast, the participants living with a neurological disorder struggled to distinguish between their “normal deterioration” and the consequences of decreased physical activity. Furthermore, therapists should consider when interpreting such descriptions that the perception of physical activity can also be in contrast to objective data, such as accelerometery and the use of objective measurements which might assess true decline in status [34, 35].

### *Theme: Therapeutic Experiences*

In the second theme of “Therapeutic experiences”, participants described how important it is to them to stay in contact with their therapists, although it seemed in some cases to be insufficient. As already described in 2003 by Haggerty *et al.*, three core elements exist for continuity in health care: informational, management and relational continuity. Analysis of the interviews in this study is in line with their recommendations for management in the presence of chronic disease – the flexibility to adapt the therapy to their individual needs and circumstances. Consistency of an ongoing relationship with a therapist is required [36]. All participants emphasised how important it was to stay in regular contact with their therapists using any means during the lockdown, enabling a continuous connection to a health professional whom they trusted. Although all therapists tried to offer at least some form of therapy/contact possibilities, one participant felt the need to take the initiative to access treatment herself, going back to on-site therapy. This need to take action by service users has been described by Pindus *et al.* (2018) [37]. Most of the patients did not receive regular phone calls during the first phase of the lockdown due to the governmental and hospital restrictions as well as due to the time available and the knowledge resources of the therapists. [2]. Only towards the end of April 2020 (5 weeks after the lockdown came into force) did the Federal Office of Public Health create the legal basis for billing video consultations for high-risk patients. They allowed the tariff code 7340 to be billed, which provided for a therapy treatment of approximately 15 minutes [13].

The tension between legal basis for reimbursement and economic efficiency could be the reason why the service was more restrained than patients would have chosen. Therapists required time to adapt. In some cases, this was too long for the participants to wait, even after providing help for active self-management over the phone, which has been reported as a benefit elsewhere [37]. However, participants felt that the phone calls were insufficient in terms of providing motivation and self-management strategies as the thought that “someone is watching and correcting you” was missing. This phenomenon has been observed by Dennet *et al. (*2020) in the MS population, who received a web-based physiotherapeutic intervention [34].

One interesting finding is that online group therapy was generally better appreciated than individual distant therapies. One possible explanation emerges from the meta-synthesis of Allen *et al.* (2016) about online communities and self-management support. The connection between physical activity and social ties, possibly a basis for relevant self-management, might have been a significant factor of this therapy during the challenges of the pandemic [38]. As two participants of the current interviews described, the physiotherapist enabled the participants in the online group to talk with each other before and after the online session. Physiotherapists should consider the benefit of empowering patients to form social connections as additional facilitators to implement online group therapy. Nevertheless, the different opinions represented in this study about distant therapy intervention highlight the importance of acknowledging that a variety of models of service delivery may be required to meet differing needs.

*Theme: Family and Social Environment*

Important issues emerged regarding the theme of “Family and Social Environment”, emphasising the importance of the social environment for persons living with a neurological condition and how perceptions of relationships differed during this time. People worldwide experienced forms of isolation and loneliness [39], but for the studied population, it seemed even more crucial. They described that family and friends, who were normally important for their mental health, suffered from low mood themselves and could not look after the participants.

Therefore, it is essential to highlight that individuals living with a neurological condition are mostly able to cope with new situations or technologies with the help of family members or direct contact with a trusted person. The interview findings are consistent with the literature, describing that more needs to be done for people with low digital literacy [40]. Health and digital literacy factors should always be considered in telehealth intervention projects, no matter in what context they are situated. As the literature shows, even countries with high rates of access to the internet, such as Switzerland, have broad problems in the subject of health literacy [9, 41]. In Switzerland, only 10% of the population have excellent health literacy and 36% have sufficient health literacy for assessing and understanding health information and disease prevention [41]. This is an important issue for further research in the context of telerehabilitation in Switzerland – investigating how supportive persons can help patients overcome low digital and health literacy. Additionally, health professionals should be able to identify the digital and health literacy levels of their patients to provide more tailored interventions.

This study provides additional insight into individuals’ experiences living with a long-term neurological condition during a pandemic rather than those with musculoskeletal conditions [42]. After a year with COVID-19, some guidelines for virtual consultations for musculoskeletal care already exist [43, 44]. Most of them can be applied to neurological patients, such as legal considerations (e.g. insurance covering), safeguarding (e.g. ensure that patients have access to assistance if necessary), safety (e.g. choice of exercise environment, assessments) and security (e.g. clear guidance for chosen technology platforms). However, as highlighted in the results, the provision of additional support for the use of new technologies should be considered in recommendations for the investigated population. The population under consideration showed that many are dependent on supporters to overcome barriers of digital or health literacy. Researchers and therapists should consider including online support groups to help individuals with their self-management [45]. The benefit of social support could be an additional explanation for why the online group sessions were regarded as superior compared to the one-to-one telephone calls.

## Limitations of the study

As for qualitative research in general, this study is highly context-specific regarding lived experiences of individuals suffering from long-term neurological conditions with a small sample size in only rural areas. Unfortunately, no persons from surrounding clinical practices were included, and only patients from the local hospital outpatient department were recruited. It is anticipated that individuals from other clinical practices and/or urban sites might have had different experiences. Most hospitals had additional COVID-19 measures for their localities to reduce the number of people in a hospital, avoiding unnecessary contacts and to protect staff resources for hospitalised patients. The experiences of the clinical practices could have provided a broader picture.

Furthermore, the data is translated for reporting and this can have potential risks and dilemmas [26]. Following recommendations, the translations and narratives were put into the research context [46]. Being a bilingual researcher (mother language Swiss German, fluent in English), the author was able to examine the experiences of an under-researched population in Switzerland.

## Implications for the Practice and Research

- Where telerehabilitation is indicated, therapists should consider making individual appointments with the people to ensure continuity.
- The connection between physical activity and social ties that could form a basis for performing appropriate self-management during online training groups should be considered as the most pertinent benefit for this population.

- Health professionals should consider evaluating the digital and health literacy of their patients, providing them with additional support if necessary. Further research is required on how health professionals can quickly assess the literacy level of their patients.
- More qualitative research with individuals living with long-term neurological conditions should be conducted especially in terms of their special needs. Tailored telerehabilitation interventions should be developed and evaluated for this population as this research indicates that participants benefited subjectively, even from "unstructured" interventions.

## Conclusion

The results provide new knowledge about how people living with a long-term neurological condition experienced the effects of the COVID-19 Pandemic in the context of their disrupted therapy settings. The interviews demonstrated that unstructured change to distant therapy interventions only worked in a limited way for the participants. Synchronous approaches, such as video calls and online group sessions, seemed to be favoured in comparison to telephone calls or asynchronous digital interventions. All participants experienced negative consequences in terms of symptoms as well as social life. There are still many unanswered questions about how one can support this population best, and evidence-based recommendations are needed.

## Ethical aspects

**Consent for publication:** the three authors give consent to publish

**Registration and Funding:** this clinical trial has not been registered with a study register and received no specific funding from public, commercial, or non-profit entities.

**Availability of data and materials:** the data generated and/or analyzed in this study can be obtained from the corresponding author upon reasonable request.

**Competing interests:** No potential conflict of interest to declare

**Authors' contributions:** D.M. developed the theoretical formalism, performed the analytic processes and drafted the manuscript. K.F supported D.M. in the analysis of the data, discussed the results and commented on the manuscript. S.L. supervised the whole project and provided feedback to all steps.

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40’564 characters (including blanks) (40’000 +/- 10%)

Remarks regarding referencing: A difference was found between the publisher (Thieme) and the journal (physioscience) guidelines. Considering the most recent publications in physioscience print version from June 2021, it was decided to use the publisher's guidelines. As a result, a numbering for example [9] of the references was applied instead of a (Name, Date) format.

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# Appendix No. 1 HAS 21.01.067 Final Approval Letter

UWE Bristol University of the West of England

Faculty of Health & Applied Sciences
Glenside Campus
Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

UWE REC REF No: HAS.21.01.067

23rd February 2021

Monique Dummermuth

Dear Monique

**Application title: Lived experiences of patients with long-term neurological conditions during the COVID lockdown in Switzerland using telerehabilitation: explorative interviews**

Thank you for responding to the conditions raised in my letter to you of 9th February 2021.

I can now confirm full ethics approval for your project, but please note the proviso below.

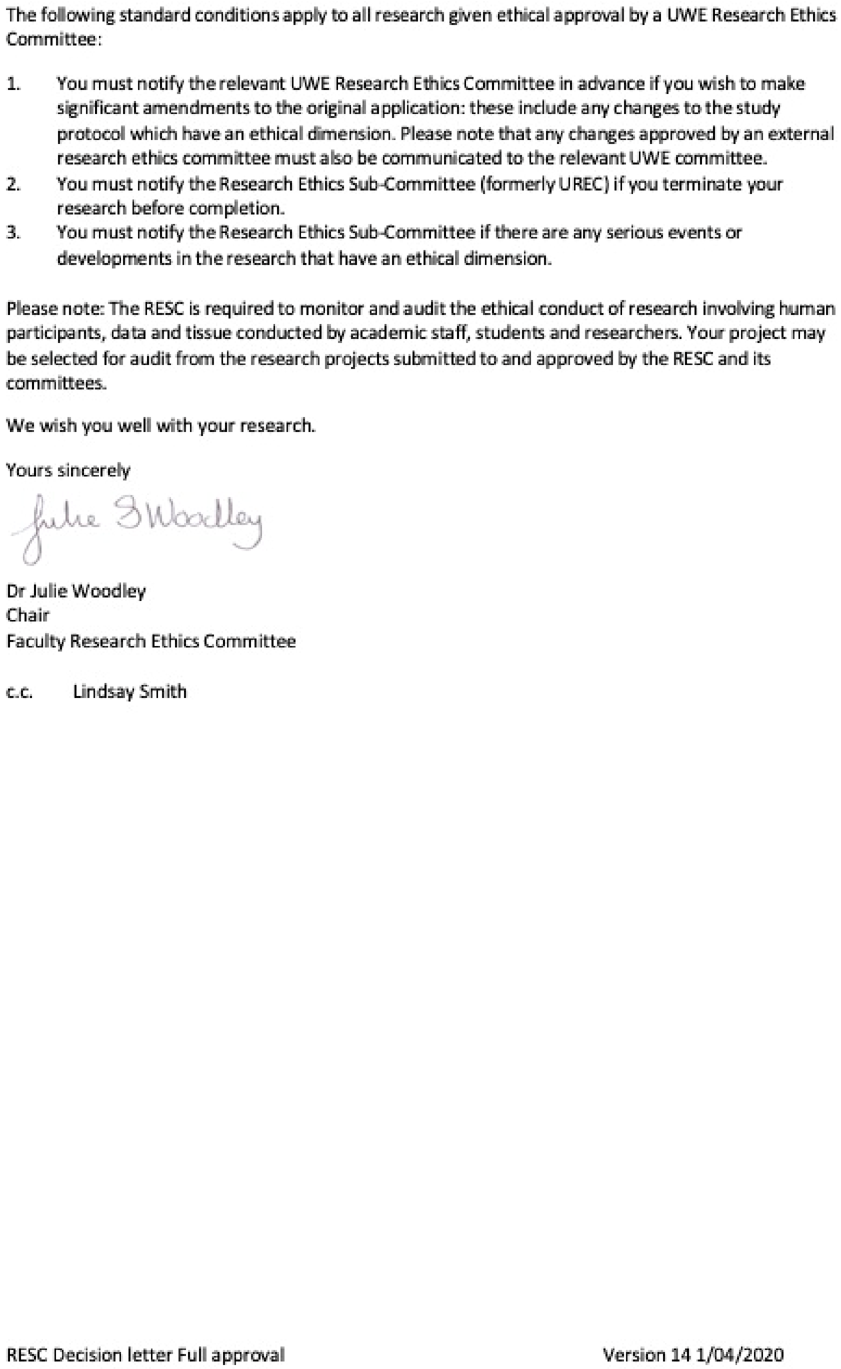
**Please note:** In light of the current situation regarding COVID-19, we can only authorise an immediate start for activities that do not breach either national laws or University policies. In these uncertain times, law and policy may change swiftly and frequently.

We are, however, continuing to scrutinise and grant ethical approval for activities that cannot take place at present, to ensure that once the situation changes and activities can go ahead, the research is not unnecessarily delayed.

What this means for your application:

1. If your application DOES NOT involve activities affected by the current crisis (e.g. online surveys or telephone interviews etc.) then you may start your research as soon as you receive this formal notification of your ethical approval;
2. If your application DOES involve activities affected by the current crisis then you must not start your research until you are lawfully and safely able to do so, and when it does not breach the University's policies. This will affect the dates you have supplied on your application form in relation to start and finish. When you have new dates, please can you write to us in order that we can add this information to your file?

If you are a doctoral student and this will affect your research timetable, please speak to your Director of Studies and the Graduate School for advice on how time delays will be supported by the University.



The following standard conditions apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.
2. You must notify the Research Ethics Sub-Committee (formerly UREC) if you terminate your research before completion.
3. You must notify the Research Ethics Sub-Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The RESC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the RESC and its committees.

We wish you well with your research.

Yours sincerely

Julie S Woodley

Dr Julie Woodley
Chair
Faculty Research Ethics Committee

c.c. Lindsay Smith