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Benefits and challenges in everyday life for patients performing subcutaneous immunoglobulin treatment at home: a qualitative interview study

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ABSTRACT

Objective Across medicine, new therapies are shifting treatment from clinic to home settings. At-home subcutaneous immunoglobulin treatment for immunodeficiency is an example of one such therapy. In this qualitative interview study, we investigated experiences of patients living an everyday life with subcutaneous immunoglobulin at-home treatment.

Study design, setting and participants 24 Danish patients participated in semistructured interviews. Six patients were interviewed in individual home-visit interviews, while the remaining 18 participated in one of six subsequent group interviews using an online video format. Participants represented three patient groups: patients with primary immunodeficiency, patients with secondary immunodeficiency, and patients with chronic inflammatory demyelinating polyneuropathy or multifocal motor neuropathy.

Results According to the interviewed patients, at-home treatment provided a high degree of flexibility and freedom in everyday life. When transitioning to at-home treatment, a sense of security had been achieved through individualised training and access to healthcare professionals. Some patients experienced uncertainty or insecurity during the initial period of administering treatment at home; however, this typically receded over time. For the patients, at-home treatment had become embedded in everyday life either through incorporation into existing everyday routines or through the development of new routines. The time-related and place-related flexibility of the at-home treatment had benefits for several arenas of everyday life: work, family, and leisure. Patients associated at-home treatment with a sense of freedom, which they ascribed both to independence from the hospital and to not being confronted with medical conditions and other patients in the hospital setting. A small minority of the patients viewed the reduced contact with healthcare professionals as a disadvantage, describing feelings of being alone and responsible for their treatment.

Conclusions Patients who had established at-home treatment routines in their everyday lives found the benefits of at-home treatment to outweigh the challenges.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The qualitative study design enabled in-depth insights into patients' everyday lives with at-home subcutaneous immunoglobulin (SCIg) treatment.
- ⇒ Most participants had more than 5 years of experience with at-home SCIg treatment, thereby enabling insights into well-established treatment routines and everyday life experiences.
- ⇒ A larger sample of less experienced patients might have yielded more detailed insights into challenges arising during the initial phase of at-home SCIg treatment.
- ⇒ By focusing on patients in at-home treatment, the study lacks the perspective of patients who have tried but discontinued at-home SCIg treatment and thus insights into patient-experienced barriers.

INTRODUCTION

In the Danish healthcare system, as in others, treatment is increasingly being transferred from hospital outpatient clinics to patients' homes.[1] However, little is known about how patients experience performing treatment at home and how they perceive the benefits and challenges of at-home treatment in their everyday lives. This study examines patients' experiences of at-home treatment with subcutaneous immunoglobulin (SCIg), a treatment that does not require monitoring, digital communication with the hospital, or assistance by healthcare professionals (HCPs) in the home. In special instances, municipal homecare can assist patients in performing the subcutaneous at-home treatment. However, this was not the case for any of the patients in this study. Moreover, being able to perform the treatment at home is typically a criterion for offering this treatment modality to a patient.

Patients may need immunoglobulin treatment due to conditions such as primary immunodeficiency (PID), secondary immunodeficiency (SID) or neurological disorders,

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such as chronic inflammatory demyelinating polyneuropathy (CIDP) and multifocal motor neuropathy (MMN):

- The category PID covers more than 500 types of immune deficiency,[2] with common variable immunodeficiency being one of the most frequent B-cell disorders. Many of these conditions are congenital and require lifelong treatment and follow-up. A typical symptom is recurrent infections.[3]
- SID refers to immune deficiencies caused by other diseases or treatments, such as chemotherapy. SID can be either temporary or chronic depending on the underlying cause.[4] Patients with SID are typically in concurrent treatment regimes and therefore, compared with other patient groups, these patients may not gain the same degree of independence from the hospital when shifting to at-home SCIg treatment, at least not in terms of the number of hospital visits.
- CIDP and MMN are chronic autoimmune neurological disorders that can cause muscle weakness, impaired fine motor skills and loss of reflexes. Like PID and SID, immunoglobulin treatment is also commonly used for these conditions.[5 6]

For both PID, SID, CIDP and MMN patients, immunoglobulin treatment can be administered either as intravenous immunoglobulin (IVIg) or SCIg. IVIg is typically administered at an outpatient clinic or during hospitalisation. Due to variations in patient needs both within and across diagnostic groups, the frequency of IVIg treatment ranges from once every 3–6 weeks for patients with PID or SID to 4–5 days of hospitalisation per month for patients with CIDP or MMN. However, subcutaneous alternatives have become available, allowing patients to administer treatment at home following training in the outpatient clinic.[3 7 8]

Switching from hospital-based IVIg treatment to self-administered SCIg treatment at home represents a radical shift for patients. This change reconfigures the patient's role in treatment administration, alters the impact of treatment on daily life and reshapes the pattern of contact with the healthcare system. Previous studies on patients' experiences with immunoglobulin treatment have mostly focused on treatment preferences regarding treatment modality/administration route[9–11] or medical equipment.[9 12–14] Others have investigated quality of life or treatment burden.[13 15–18] Only few studies have taken a broader perspective on patients' lived experiences with immunoglobulin treatment, such as the social, familial or work life aspects (for exceptions, see [19–21]). Taking on an everyday life perspective may thus contribute valuable insights into how patients integrate at-home treatment into their daily routines and the consequences this has for family life, social participation and work.

The aim of this study was thus to explore the experiences of patients living an everyday life with at-home SCIg treatment, including the perceived benefits and challenges associated with the treatment.

METHODS

Study design

The study was conducted as a qualitative interview study combining semistructured individual home-visit interviews and online group interviews. The combination of home-visit interviews with individual patients and online group interviews allowed us to gain both deep and broad insights. The individual home-visit interviews enabled in-depth insights into the mundane, material and practical aspects of at-home SCIg treatment, whereas the group interviews allowed us to assess these insights in a larger group of patients. The semistructured interview approach was chosen to leave room for interview participants to expand on aspects of at-home treatment not included in the interview guide.

Participants

Participants were recruited among patients suffering from either PID, SID, or CIDP/MMN. Eligibility criteria included prior experience with SCIg self-administration at home. Participants were also required to speak Danish and were selected to ensure recruitment from across different regions of Denmark. A total of 24 patients participated in the study: 9 with PID, 7 with SID and 8 with CIDP/MMN. At the time of the interviews, 17 participants had more than 5 years of experience with at-home SCIg treatment, 6 had between 1 and 5 years of experience and 1 had less than 1 year of experience. Participants included 10 female and 14 male patients. The vast majority of the participants were either 51–60 years old (N=10) or 61–70 years old (N=12), with only one being younger (31–40 years old) and one being older (71–80 years old). Geographical representation was balanced between Western Denmark (N=12) and Eastern Denmark (N=12).

Data collection

For the individual home-visit interviews, HCPs at six hospital departments (two departments from each disease area) assisted in recruiting six patients with experience of self-administering SCIg treatment at home. Patients who met the study's eligibility criteria (see Participants section) were informed about the study and received a written invitation to participate in a home-visit interview. The invitation letter described the study and detailed how personal data and interview material would be handled. Participants were informed that their participation was voluntary and did not have any connection to or influence on their treatment at the hospital. With the patients' consent, their contact information was shared with the researchers, who then followed up to provide additional oral and written information and confirm the patients' interest in participating. Interview appointments were made by the interviewers. In total, six home-visit interviews were conducted.

For the group interviews, 18 patients were recruited with the assistance of patient associations representing each of the three patient groups. Four patient

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associations, covering the patient groups, were contacted and all agreed to share information about the study, including a call for group interview participants. The call was issued through newsletters, social media platforms and/or the patient associations' websites. Interested patients contacted MBJ directly by phone or email. Due to the geographical dispersion of participants, the group interviews were conducted using an online video format. A total of six group interviews were conducted.

All interviews were conducted between November 2022 and February 2023. Interviews were conducted either by MBJ (four home-visit interviews) or by MBJ and EDK jointly (two home-visit interviews and six group interviews). MBJ and EDK are both trained in qualitative methods (MBJ in Medical Anthropology and EDK in Social Sciences in Social Work) and MBJ has extensive prior qualitative research experience. The home-visit interviews included either a demonstration of the treatment routine during the interview or a thorough verbal walk-through of the treatment routine at the beginning of the interview. This approach enabled practical and mundane aspects of the treatment to emerge, including routines and details related to storage, preparation and treatment administration. During the home visits, field notes were taken to capture and remember aspects of informal and non-recorded conversations as well as practical details, for example, relating to the specific treatment routine and the storage of medication or equipment. The group interviews were organised according to participants' background diseases, with two group interviews being conducted among PID, SID, and CIDP/MMN patients, respectively.

The interviews followed a semistructured interview guide covering the following themes: introduction; background; transition to/initiation of at-home treatment; carrying out and managing the treatment at home; relatives; changes in treatment; contact with HCPs and other patients; closing remarks (for full interview guides, see online supplemental files A, B). Throughout the interviews, the interviewers also focused on allowing themes and experiences not covered in the interview guide to emerge. A high degree of data saturation[22] was experienced during the group interview process, that is, no new subthemes emerged in the last interviews performed.

The interviews lasted from 30 to 80 min (in most cases approximately 1 hour) and were audio-recorded. The interviews were subsequently transcribed verbatim by the second author.

Data analysis

Interview data were analysed using the NVivo software and a thematic analysis approach to identify patterns in the data.[23 24] Data from the individual interviews and group interviews were coded within the same coding process due to the overlapping interview themes. The transcripts were initially coded into overarching themes by the second author, after which subthemes were identified jointly by the first and second authors.

Patient and public involvement

Patients were not involved in the design of the study or in the research process.

Standards for Reporting Qualitative Research reporting

The Standards for Reporting Qualitative Research checklist[25] was used to guide our reporting of the study (see online supplemental file C).

RESULTS

Achieving a sense of security when transitioning to at-home treatment

Study participants reported different pathways to at-home treatment. Across disease categories, some reported at-home SCIg treatment having been presented as the standard option when initiating immunoglobulin treatment. Others initially received hospital-based IVIg before transitioning to SCIg at home.

Participants emphasised that feeling secure during the transition from hospital-based to at-home treatment (or when initiating at-home treatment if SCIg was the first modality encountered) required individualised training and easy access to HCPs. Many participants described how sufficient, personalised instruction from a nurse in the outpatient clinic had helped build their confidence in administering the treatment at home, as described by Flemming:

> Nurses showed the procedure and then you could do it yourself – unpack it all and feel one's way through it. I did it there 3-4 times [before performing the treatment on my own at home]. (Flemming, patient with PID)

Taking the time to address each patient's specific concerns during training was identified as a key factor in facilitating a secure transition to at-home treatment. Frequently mentioned concerns included an initial fear of needles, difficulty handling the infusion pump, and worries about performing the procedure correctly. Peter explained how a nurse helped him address such concerns:

> I was trained by a nurse who had told me in detail about the treatment before we started and we did the training the way I preferred. I asked her to place the first needle and then I tried it myself. (Peter, patient with CIPD)

Even though most participants felt rather confident after the training sessions, many still experienced some degree of uncertainty or insecurity during the initial period of administering the treatment at home, as was the case for Anita:

> The first couple of times I felt a bit uncertain about whether I did it right, but it was soon put to rest and I have been incredibly happy about being able to do it at home, it has made me able to continue working

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> and live a completely normal life. (Anita, patient with MMN)

For most patients, the initial insecurity was temporary and faded after a few treatments at home. A key factor contributing to the secure transition, as highlighted by the patients, was knowing they had easy access to HCPs in case of challenges during treatment. All interviewed patients reported having the option to contact HCPs at the hospital by phone if needed. While only a few had been in situations where they needed to contact the HCPs, the mere availability of support was consistently described as reassuring and therefore a central element of the at-home treatment setup.

Patients also developed various strategies to help them feel more secure when starting treatment at home. Some turned to relatives or neighbours as a source of either practical or emotional assistance. Practical assistance included help in handling equipment (e.g., operating the pump or placing needles) whereas emotional assistance focused on alleviating insecurity (e.g., by offering company and by having someone to help remembering each step of the procedure). Steen, a patient with SID, explained such a strategy to alleviate feelings of insecurity:

> We plan the treatment so that it fits into everyday life. When my daughter is home from work, she comes by my place and we sit together in the living room and do the treatment. If there are problems we can call the department round the clock. (Steen, patient with SID)

Others did not involve relatives in their treatment but scheduled their treatment according to the opening hours of their hospital department or their local healthcare centre, thereby ensuring that HCPs would be available if problems emerged.

For some patients, such strategies were only used in the start-up phase of their at-home treatment, while others incorporated the strategies permanently into their at-home treatment routine.

Establishing at-home treatment routines in patients' everyday lives

Across interviews, patients described how at-home treatment had become embedded in everyday life, either through new routines or by being incorporated into existing ones.

While all interviewed patients highly valued the flexibility offered by at-home treatment in terms of time and place, the vast majority established consistent routines around the treatment. As such, treatment would typically be scheduled for a specific time of day and/or week, performed in a designated place within the home, and combined with a familiar activity, thereby facilitating a sense of comfort, structure and predictability in the treatment process. Anita explained her routine:

> It is always Friday evening, so it is. I do it after dinner, I place the needles, find something to watch on TV and I lie on the couch. I try to have some rituals around it, e.g. I can have a glass of wine (…) Because it [the treatment frequency] is once a week and connected to a certain weekday I have never forgotten it; it has become an ingrained habit. (Anita, patient with MMN)

Another patient described planning and performing the SCIg treatment early in the morning when his wife would still be asleep, thereby allowing them to maintain their shared and highly valued morning routines. Others embedded the treatment routine in the family's collective routines, for example, by administering it while watching a movie together on Saturday night. As such, the time-related and place-related flexibility of at-home treatment enabled patients to tailor the process to their personal preferences, including the degree of family involvement. Most patients reported that the treatment had over time become a stable routine, something that felt natural and faded into the background, much like other habitual elements of daily life. This was also the case for Erna and Palle:

> The treatment does not take up much space [either physically or mentally] at home. For me it is just a part of life. (Erna, patient with PID)
>
> When you have performed the treatment for as long a time as I have, I do not think more about it than I think about brushing my teeth or things like that—it belongs to that category. (Palle, patient with CIDP)

A few of the interviewed patients needed help from others when performing the treatment because of challenges and insecurity caused by factors such as vision impairment or fear of needles, which made it difficult to place needles themselves. A man with vision impairment explained his wife's role in the treatment:

> Her role is to help me find the spots where I can place the needles (…) she is very important, if I was alone, I would have to have a home carer to help me place the needles. (Jakob, patient with SID)

For patients who needed assistance and therefore had to coordinate with others to perform the treatment, the time-related and place-related flexibility of at-home treatment was reduced. Nevertheless, patients who relied on help from others still described a strong sense of freedom, appreciating the flexibility offered by at-home treatment in their daily lives by reducing their dependence on hospital visits and on being subject to hospital routines.

At-home treatment, work life, and leisure activities

Work life was one of the everyday life arenas in which many participants reported significant benefits from transitioning to at-home treatment. These benefits were especially evident among patients with CIDP or MMN who, prior to switching to at-home treatment, typically had to spend 4–5 days per month in hospital. For these patients, such as Palle below, the flexibility offered by at-home

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treatment was described as a key factor in maintaining a normal work life:

> Before [the shift to at-home treatment] I struggled to attend to my job while in treatment since I was hospitalised for a week every month. It was problematic since I hold a key position in the company (…) I then started to get treatment over the weekends but then my family life suffered, it was just a struggle with work life and family life. It got completely attuned when I started doing the treatment at home. (Palle, patient with CIDP)

Working patients with PID and SID also reported benefiting from the time-related and place-related flexibility of at-home treatment, even though they had not previously spent as much time in the hospital as CIDP/MMN patients. Henriette, a patient with PID, explained:

> To me it was a relief to do the treatment at home instead of having to go to the hospital every third week. I used an entire day, and at the time I worked full-time. (Henriette, patient with PID)

Participants described how at-home treatment saved time by avoiding transportation and waiting time and by taking less time per treatment than IVIg. Many patients highlighted the ability to schedule treatment outside working hours as essential to balancing their professional responsibilities. As a result of this time-related flexibility, some patients no longer needed a reimbursement arrangement with their employer (a 'Section 56 agreement' under the Danish Sickness Benefit Act) and reported feeling free to choose whether to involve their employer in their medical condition.

Beyond work, patients also reported improved access to leisure activities and travel as a result of the place-related flexibility of self-administered SCIg treatment. However, some patients (particularly those needing to take large doses of immunoglobulin) described a continued need to plan activities carefully, since post-treatment physical discomfort, such as fluid build-up under the skin or seeping from needle sites, could limit physical activity immediately following treatment.

Freedom from the hospital setting and the medical condition

Even though treatment—and thus medication and medical equipment—had moved into their home sphere, the vast majority of the interviewed patients associated the shift from hospital-based to at-home treatment with a high degree of freedom from their medical condition. They described 'feeling less ill' in the sense that, due to less frequent visits to the hospital and due to less frequent encounters with other patients, they were less frequently reminded of their condition. Niels and Hanne described this as follows:

> You avoid going to the hospital and being reminded of being ill. (Niels, patient with PID)

> I could not bear being in the department together with the seriously ill cancer patients (…) I was younger and well and felt stigmatised when getting treatment at the hospital. (Hanne, patient with PID)

Most of the interviewed patients explained that they preferred social relations based on commonalities other than medical conditions, and some described that being confronted with other patients' serious medical conditions at the hospital could provoke anxiety. There was, however, also a small minority of participants who viewed the reduced contact with HCPs as a disadvantage. These participants reported feeling more alone and responsible for their treatment than they would ideally like to be.

One patient reported feeling negatively emotionally affected by having medical equipment and medication at home, as this served as a constant reminder of her medical condition. However, the vast majority of the interviewed patients found storing medical equipment and medication in their home unproblematic, as explained by Jørgen:

> It is not a problem at all, it is all stored in a cupboard. (Jørgen, patient with CIDP)

As such, patients generally perceived the presence of medical equipment at home as a practical matter to be managed in order to attain the flexibility and freedom associated with at-home treatment. They described practical solutions such as dedicating a drawer to the equipment and using a designated shelf in the refrigerator for storing the medication. Patients who needed large doses of immunoglobulin often chose to use an additional refrigerator to store the medication.

Disturbed routines due to changes in treatment

Some participants reported having experienced changes in immunoglobulin variant, medical equipment (eg, pump type), or treatment duration due to changed dosage, and described how such changes could temporarily disrupt the embedding of the treatment in their everyday lives. For some patients, altered dosages had led to the re-emergence of symptoms. Others described how changes in equipment or treatment frequency had required them to develop new routines. However, the interviewed patients explained that such disruptions tended to be temporary, similar to the uncertainty or insecurity associated with shifting from hospital-based to at-home treatment. Once the treatment had been properly adjusted or new routines had been established, the sense of normalcy typically returned, and their medical condition once again faded into the background of everyday life.

DISCUSSION

As more at-home treatment options become available, it becomes increasingly pertinent to examine how such treatments affect and are integrated in patients' everyday lives. In this qualitative interview study, we have examined

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the experiences of patients living with at-home SCIg treatment. Among the interviewed patients, we found the at-home treatment to have become an embedded part of daily life through incorporation into new or existing routines at home. Individualised and sufficient training was identified as a key factor in facilitating a sense of security when shifting from hospital-based to at-home treatment. Moreover, easy patient access to HCPs was highlighted as important for patients' feeling of security when administering the treatment at home. The freedom and flexibility, which the interviewed patients associated with at-home treatment, had benefits for several arenas of everyday life, including work, family and leisure. Moreover, the vast majority of the patients valued the fact that at-home treatment reduced their number of hospital visits. They experienced that at-home treatment reduced the mental space occupied by their medical condition, even though medication, medical equipment and treatment routines had moved into their home.

Our study is not the first to examine patients' experiences with SCIg treatment. Previous research has documented patient-reported benefits of SCIg treatment compared with IVIg[9 15 17 26] and some studies have examined treatment preferences related to treatment modality/administration route[9–11 27] or specific types of medical equipment.[9 12–14] However, only a limited number of studies have taken an everyday life perspective on patients' experiences with at-home SCIg treatment (for exceptions, see refs. 19–21). The broad everyday life perspective of the present study has enabled us to contribute novel insights into the establishment of routines and the integration of at-home SCIg treatment in patients' daily lives, including work, family life and social and leisure activities—arenas that are all important to consider for patients in lifelong treatment.

The home as a site for treatment is a central theme of this study. As such, the study contributes novel insights into how patients incorporate treatment at home and perceive challenges and benefits associated with material and practical aspects of at-home treatment. Our findings show that, despite treatment (including medication and medical equipment) taking up physical space at home, the vast majority of the interviewed patients expressed that the treatment occupied little mental space and did not remind them of being ill. On the contrary, most perceived at-home treatment as a means to achieving flexibility and freedom from their medical condition. As noted in the Results section, only one participant expressed feeling emotionally burdened by having medication and medical equipment in her home. Even though negative consequences of at-home treatment were rare among the participants in this study, such potentially negative concerns should, however, be taken into account when considering implementing at-home treatment for specific patients.

One previous study found that, for some patients, reduced contact with other patients due to a switch to at-home treatment could be experienced as a loss of social network with others in a similar situation.[21] Interestingly, this experience was not shared by any of the patients participating in our study. On the contrary, most of the interviewed patients expressed relief at being freed from the hospital context, where social relations centred on medical conditions. As such, they preferred social relations based on commonalities other than medical conditions and reported 'feeling less ill' due to the reduced need to spend time at the hospital. A small minority of the patients did find the reduced number of hospital visits to entail disadvantages. However, these disadvantages were related to the reduced contact with HCPs, which left them feeling more alone and responsible for their treatment than they would ideally like to be.

Our focus on patients with extensive experience with at-home SCIg treatment (cf. the Participants section) is both a strength and a limitation of this study. This focus enabled us to examine how at-home treatment had become a consolidated routine practice among the patients participating in the study. At the same time, however, the focus on such experienced patients did methodologically limit our ability to identify barriers to at-home treatment. We encourage future research on at-home treatment to include patients who have tried but discontinued at-home treatment, thereby allowing for insights into a broader range of patient-experienced barriers. Future research could also benefit from investigating relatives' perspectives on the benefits and challenges of at-home treatment. Such investigations would enhance our understanding of the broader benefits and challenges associated with at-home treatment and thereby better equip HCPs to choose treatment modality together with patients.

Implications for clinicians and policymakers

HCPs working with at-home SCIg treatment should be aware of the importance of ensuring individualised training for patients prior to the patients being transitioned to at-home treatment. Moreover, when planning transition to at-home treatment, patients should be assured that they will have easy access to HCPs (e.g., by phone) if something unexpected happens in relation to the treatment at home. This helps patients feel secure both in the transition phase and when treatment has become a routine part of everyday life.

CONCLUSIONS

In this study, we explored patients' experiences of benefits and challenges of at-home SCIg treatment. We found that at-home treatment had been embedded into existing everyday life routines and that new routines had sometimes been created around at-home treatment, thereby allowing it to become embedded in patients' everyday lives. The time-related and place-related flexibility gained through at-home treatment was highly valued by the interviewed patients. As such, the patients experienced that at-home treatment was a source of freedom from their

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medical condition in everyday life despite their—often lifelong—need for immunoglobulin treatment. Overall, patients who had established at-home treatment routines in their everyday lives found the benefits of at-home treatment to outweigh the challenges.

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Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval The study complied with ethical principles for medical research as described in the Declaration of Helsinki. The study was registered in the VIVE GDPR register in accordance with standard procedures. The participants were informed of the study verbally and in writing prior to the interview and oral consent to participate was obtained. The participants gave permission for the interviews to be audiorecorded and rules were followed to safeguard personal data. The participants are pseudonymised in the text. According to Danish legislation, ethics committee approval is not required under these circumstances.

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