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ORIGINAL ARTICLE

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"Experiences of the burden of treatment"—Patient reports of facilitated subcutaneous immunoglobulin treatment in adults with immunodeficiency

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Aims and objectives: To evaluate patient-reported experiences of facilitated subcutaneous immunoglobulin treatment in adults with primary or secondary immunodeficiency.

Background: Decreased levels of circulating antibodies (humoral immunodeficiency) are often associated with higher infection rates which cause problems in daily living, for example, symptoms of severe and recurrent bacterial infections that may cause chronic lung diseases. For some diagnoses, treatment with immunoglobulin becomes critical and lifelong. The acceptability of administration forms is important to achieve adherence to treatment and to increase quality of life for these patients.

Design: Convergent mixed-method approach.

Methods: A structured telephone interview with nine questions evaluated on a score scale about treatment experience, satisfaction and ancillary supplies was used, followed by open-ended questions for each item.

Results: Prohibiting factors were revealed, exemplified by problems due to technical issues and ancillary supply issues. Promoting factors were shown by high a satisfaction according to the score-scale when combining treatment with daily life as well as increased well-being. Facilitated subcutaneous immunoglobulin treatment led to fewer treatment sessions, with a time-saving aspect also described by high scores in the item concerning longer treatment interval.

Conclusions: The opportunity to be given the best possible treatment plan adjusted for each patient's situation is central. Healthcare professionals should discuss the different aspects that can promote and inhibit the outcomes of treatment.

Relevance to clinical practice: The results can help professionals to understand different factors that may impinge on the patients' everyday life when they are forced into a lifelong treatment regimen. This knowledge is also important for nurses who have a responsibility to promote health concerning patients with long-term conditions in general.

KEYWORDS
adherence, burden of treatment, convergent mixed-method, facilitated subcutaneous immunoglobulin, immunodeficiency, long-term conditions, patient preferences, self-management

1 | INTRODUCTION

Decreased levels of circulating antibodies (humoral immunodeficiency) are often associated with higher infection rates which cause problems in daily living, for example, symptoms of severe and recurrent bacterial infections that may cause chronic lung disease, autoimmune disorders and inflammatory diseases. For some illnesses, the treatment with immunoglobulin becomes critical and lifelong (Picard et al., 2018). Concurrently, the acceptability and administration forms are important to achieve adherence to treatment, but also to increase the quality of life for these patients (Espanol, Prevot, Drabwell, Sondhi, & Olding, 2014). Having a long-term illness affects the physical, emotional and social states depending on each patient's life situation (Ambrosio et al., 2015). Furthermore, patients with a long-term illness may have to undertake extra work and increased vigilance each day to avoid exacerbating their condition or prevent it from recurring. This work could be interpreted as a burden of treatment because patients experience additional—together with the pressures of everyday life—demands on their time and energy to coordinate and organise their self-care as well as complying with complex treatments and monitoring regimens (May et al., 2014). Because of this, treatment regimens should be adjusted to fit into the life of these patients and should be selected based on each patient's preferences and needs. Healthcare professionals and nurses in general have a responsibility to be aware of the myriad factors that impact on patients living with a life-long illness and to understand the management for each patient to better support individuals and families to effectively manage their long-term condition (Wilkinson & Whitehead, 2009).

What does this paper contribute to the wider global clinical community?

- Findings in this study illustrate that there are two sides of a coin; prohibiting and promoting factors concerning a lifelong treatment. This is important for healthcare professionals to be aware of when supporting patients with a long-term illness.
- Persons living with long-term illnesses also want to live an active life; therefore, all treatment plans should be adjusted for each person's unique situation.

2 | BACKGROUND

Humoral immunodeficiency can be caused by a primary immune disorder (PID), for example, common variable immune deficiency (CVID) or the lack of IgG subclass. Another cause is a secondary deficiency (SID) due to lymphoma, myeloma or chronic lymphatic leukaemia (Agostini, Blau, Kimby, & Plesner, 2016). Over the last 40 years, the general understanding of the genetic basis and immunological mechanisms behind PID has expanded. However, the exact prevalence of PID is not known, but it has been estimated that about 1 in 1,200 people in the United States are diagnosed with PID (Boyle & Buckley, 2007). Without treatment, patients suffering from PID have higher rates of four or more severe respiratory infections per year (Vultaggio et al., 2015). It is also known that patients with SID are at higher risk of developing severe infections. For example, patients with myeloma have a sevenfold risk of developing bacterial infections and a 10-fold risk for viral infections compared to matched controls (Blimark et al., 2015). This indicates that, for this group of patients, replacement therapy with immunoglobulin is an important treatment. The effectiveness and safety of replacement therapy of immunoglobulin have been thoroughly investigated, showing that the treatment reduces the rate of serious infections (Jolles et al., 2015). Because patients with severe immunodeficiency require therapy indefinitely, the form of administration as well as setting in which the therapy takes place is an important factor that can affect patients' health-related quality of life (HRQOL). It has been found that patients with PID experience lower HRQOL scores, higher hospitalisation rates and increased limitations in their social activities, work and physical activity (Jiang, Torgerson, & Ayars, 2015; Routes et al., 2016). The goal of treatment was to individualise treatment regime to provide optimal medical outcomes and quality of life for all patients in need of treatment. This could be accomplished by adapting the frequency of treatments, dose adjustments, self-management by home therapy or administration at the clinic per each patient's needs. In a recent review, subcutaneous immunoglobulin replacement therapy (SCIg) is shown to be more cost-effective than intravenous treatments, mainly through the reduction in lost working hours and specifically showing that home therapy may increase the patients HRQOL (Lingman-Framme & Fasth, 2013). Espanol et al. (2014) have found that immunoglobulin treatment could offer patients with PID a relatively high degree of normality, as almost 70% of patients with replacement therapy have described missing fewer workdays due to ill health. Thus, the condition still impacts on HRQOL and patients' desire to have a greater independence (Espanol et al., 2014). Previous research has concluded that SCIg could be preferable,

as it reduces the incidence of systemic adverse events and is more flexible and easy to administer both at home or at the clinic (Jolles et al., 2015; Vultaggio et al., 2015). One problem with SCIg treatment is the administration of the small volume that can be infused in one site, resulting in several sites that need to be used simultaneously, which requires multiple needle sticks and an increased infusion frequency of 2–8 times each month. In recent time, hyaluronidase-facilitated subcutaneous immunoglobulin (fSCIg) with recombinant human hyaluronidase has become available as a treatment option. Hyaluronidase is the enzyme that specifically breaks down hyaluronan, the gel-like substance present in subcutaneous tissue, which allows for larger infused volumes as well as faster infusion (Blau, Conlon, Petermann, Nikolov, & Plesner, 2016). Treatment with hyaluronidase can be preadministrated subcutaneously and followed by the human immunoglobulin infused in the same needle. fSCIg provides an opportunity to administer an increased dose at once with the same infusion rate as with intravenous treatment. When patients administer their own treatment at home, it increases the flexibility in terms of fitting around their lifestyle and fewer adverse reaction result (Agostini et al., 2016). Still, few data are available about patients' self-reported experiences of fSCIg treatment and the tolerability described from patients themselves. To our knowledge, only Ponsford et al. (2015) have reported that patients describe higher levels of satisfaction regarding the treatment with fSCIg (Ponsford et al., 2015).

2.1 | Aim

The aim of this study was to evaluate patient-reported experiences of facilitated subcutaneous immunoglobulin treatment (fSCIg) in adults with primary or secondary immunodeficiency, and to describe the differences between primary and secondary immunodeficiency in both naïve patients—those that not have undergone treatment before—and patients with a history of previous immunoglobulin treatment.

3 | METHODS

3.1 | Design

A descriptive convergent mixed-method approach was used in which the results were based on both quantitative and qualitative data derived from a structured telephone interview (Creswell, 2014).

3.2 | Settings and participants

Two different departments of infectious diseases participated; one regional county hospital and one university hospital in the southeast region of Sweden. All eligible participants per the inclusion criterion were asked to participate, and all agreed to participate. Selection criterion was decided upon prior to data collection. The criterion was defined as ongoing treatment of at least 6 months and with a participant age of at least 18 years old. There were varied reasons cited by participants for changing to fSCIg treatment: adherence problems, fear of needles, a short interval between treatments at clinic or home or problem with infusion sites. The exclusion criterion was if the patient had ended the treatment before 6 months due to noneffect of treatment or side effects. In total, 35 participants were eligible due to our selection criterion. Three participants ended the treatment before 6 months due to suffering side effects and were therefore excluded from the cohort. Four different types of infusion pumps were used; three had an electronic peristaltic technique, and one had mechanical operation. During the study period, infusion pumps were changed if the patient described problems concerning the infusion site or other technical issues about the pump.

3.3 | Data collection

Quantitative and qualitative data were collected in the same session and consistent with the study aim; each set of data was given equal focus. A structured study protocol was used based on diagnosis, dose mg/kg, body weight, treatment facilities and dose adjustments. When the participant had received the treatment for at least 6 months, a structured telephone interview was performed with nine questions as described in Table 1. First, each question was rated on a score scale with a response option between 1–10. These scores were categorised into three parts: A participant score of between 7–10 was described as "better than before", a score of between 4–6 was described as "neither good nor bad", and a score of between 1–3 was described as "worse than before" (Streiner, Norman, & Cairney, 2014). Then, each participant was asked to comment on their experience to each rated question. Each score question was followed by more probing questions such as "please explain" and "can you tell me more about…". Data were collected from May 2014–September 2016. Two study nurses performed the data collection and were responsible for performing the telephone interviews.

TABLE 1 Interview questions following initial participant scoring

Tell me about your treatment experience	
What do you think of the treatment interval?	
Treatment issues:	Dose of immunoglobulin?
	What do you think of the ancillary supplies (needles, tapes and tying) you are using?
	What is your experience of using the infusion pump?
What is your experience regarding the efficacy of the treatment against infections?	
What is your experience of combining this treatment with your everyday life?	
What do you think about your changes in quality of life?	
Overall, how would you describe your satisfaction with this treatment?	

3.4 | Analysis

3.4.1 | Quantitative analysis

Descriptive statistics (mean, *SD*, range and percentages) was used to characterise demographic data. The results are represented by numbers and percentage in the score scales. Inferential statistics were used to calculate differences between groups; naïve and previous treatments and between PID and SID by performing a chi-square test using Statistical Package for the Social Sciences (SPSS), version 21.

3.4.2 | Qualitative analysis

Answers to the open-ended questions were transcribed verbatim and resulted in 164 statements. The statements were coded into thematic categories using qualitative content analysis. The nature of these categories was determined by the content of the comments and was used as codes. The codes were then compared and discussed between all authors to collapse similar and dissimilar codes into higher order categories. Subcategories were either reduced or expanded to reach agreement. In the final stage, the four subcategories were described by two generic categories illustrating experiences from participants which emerged in the analysis (Elo & Kyngäs, 2008). To ensure methodological rigour, an audit trail of coding decisions was used, and coding scheme and findings were discussed with colleagues who were knowledgeable about the technique (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

3.4.3 | Merging the data sets

In the final analysis phase, results from the quantitative and qualitative data sets were integrated using an interactive approach by comparing each result and given them equal focus. This approach achieved complementarity and proved an essential explanation to the study findings (Creswell & Clark, 2011).

3.5 | Ethical considerations

The ethical principles of respect for autonomy, beneficence, justice and nonmaleficence as described in the declaration of Helsinki were considered (CIOMS, 2002). Verbal and written information about the study was given to each participant prior to data collection. Each participant gave their informed consent to take part in the study. This study was approved by the Regional Ethical Review Board, Linköping University, Sweden (dnr 2015/261-31).

4 | RESULTS

4.1 | Participants' characteristics

The characteristics of the participants are described in Table 2. The participants' mean age was 55 years, and 59% were female. Participants diagnosed with PID were most represented with 75% of all participants. There was a total of 78% of the participants that had previously tested subcutaneous treatment (SCIg) before starting treatment with fSCIg. In total, 56% (n = 18) of the participants performed home therapy and the rest received their treatment at the clinic. All participants used two needles 24G (12–14 mm) and two sites for infusions. The amount of infusion varied between 100–250 ml/site, and 39% of the participants adjusted their dose during the study period.

TABLE 2 Characteristics of participants, type, place and length of treatments

Variables	Total *n* (%)
Gender	
Female	19 (59)
Male	13 (41)
Age	Range 19–80 Mean 55, *SD* 16.4 Median 57
Diagnosis	
Primary immunodeficiency (PID) 24 (75%)	
CVID (common variable immunodeficiency)	11 (34)
22q11 deletion syndrome	1 (3)
XLA (X-linked agammaglobulinaemia)	1 (3)
IgG subclass	11 (34)
Secondary immunodeficiency (SID) 8 (25%)	
CLL (chronic lymphocytic leukaemia)	5 (16)
Lymphoma	3 (10)
Length of fSCIg treatment (months)	Range 6–21 Mean 14.7, *SD* 4.5
Type of treatment	
Naïve (first)	7 (22)
Previous SCIg	25 (78)
Place of treatment	
Home	18 (56)
Clinic	14 (44)

4.2 | Quantitative results

The chi-square analysis was performed to compare differences between the participants with PID and SID, but there was no significant difference statistically between the two groups according to the analysis (χ^2 = 2,116; df = 1; p = 0.145). Comparisons were made between participants with naïve treatment and those that had previous SCIg treatments, but no statistically significant difference occurred between those groups according to the chi-square analysis (χ^2 = 1,872; df = 1; p = 0.171). In Table 3, the results from the score scale from all participants are described with the number and percentage of participants' estimation. The results show ceiling effects across the entire score scale with 95% of all scores within the interval 7–10. Only 3.5% of the participants scored between 4–6, and 1.5% of the participants scored between 1–3. In total, 58% of the participants estimated the highest score (10) on all items. The item with the largest variance was "Technical issues" with only 34% estimating the highest score. Concurrently, the item with the smallest variance was

TABLE 3 Scores described in number and percentage (brackets) in each dimension of the score scale from all participants: PID, SID and participants with previous treatment

Total *n* (%) score scale 1–10	Total *n*	1–3	4–6	7–10
Treatment experience (All)	32	0 (0)	1 (3)	31 (97)
Treatment experience (PID)	24	0 (0)	1 (4)	23 (96)
Treatment experience (SID)	8	0 (0)	0 (0)	8 (100)
Treatment experience (Previous treatment)	25	0 (0)	1 (4)	24 (96)
Longer interval (All)	32	0 (0)	0 (0)	32 (100)
Longer interval(PID)	24	0 (0)	0 (0)	24 (100)
Longer interval (SID)	8	0 (0)	0 (0)	8 (100)
Longer interval (Previous treatment)	25	0 (0)	0 (0)	25 (100)
Amount of immunoglobulin/treatment (All)	32	0 (0)	1 (3)	31 (97)
Amount of immunoglobulin/treatment (PID)	24	0 (0)	0 (0)	24 (100)
Amount of immunoglobulin/treatment (SID)	8	0 (0)	1 (13)	7 (88)
Amount of immunoglobulin/treatment (Previous treatment)	25	0 (0)	1 (4)	24 (96)
Ancillary supply issues (All)	32	1 (3)	2 (6)	29 (91)
Ancillary supply issues (PID)	24	1 (4)	1 (4)	22 (92)
Ancillary supply issues (SID)	8	0 (0)	1 (13)	7 (88)
Ancillary supply issues (Previous treatment)	25	1 (4)	1 (4)	23 (92)
Technical issues (All)	32	1 (3)	4 (13)	27 (84)
Technical issues (PID)	24	1 (4)	4 (17)	19 (79)
Technical issues (SID)	8	0 (0)	0 (0)	8 (100)
Technical issues (Previous treatment)	25	1 (4)	4 (16)	20 (80)
Efficacy against infections (All)	32	1 (3)	1 (3)	30 (94)
Efficacy against infections (PID)	24	0 (0)	0 (0)	24 (100)
Efficacy against infections (SID)	8	1 (13)	1 (13)	6 (75)
Efficacy against infections (Previous treatment)	25	1 (4)	1 (4)	23 (92)
Combining treatment with daily life (All)	32	0 (0)	0 (0)	32 (100)
Combining treatment with daily life (PID)	24	0 (0)	0 (0)	24 (100)
Combining treatment with daily life (SID)	8	0 (0)	0 (0)	8 (100)
Combining treatment with daily life (Previous treatment)	25	0 (0)	0 (0)	25 (100)
Change of quality of life (All)	32	1 (3)	1 (3)	30 (94)
Change of quality of life (PID)	24	0 (0)	1 (4)	23 (96)
Change of quality of life (SID)	8	1 (13)	0 (0)	7 (88)
Change of quality of life (Previous treatment)	25	1 (4)	0 (0)	24 (96)
Satisfaction (All)	32	0 (0)	1 (3)	31 (97)
Satisfaction (PID)	24	0 (0)	0 (0)	24 (100)
Satisfaction (SID)	8	0 (0)	1 (13)	7 (88)
Satisfaction (Previous treatment)	25	0 (0)	1 (4)	24 (96)

Note. The scores are categorised as follows: 1–3 described as "worse than before," 4–6 described as "neither better nor worse," and 7–10 is described as "better than before".

"Longer treatment interval" with 81% of the participants estimating the highest score.

4.2.1 | Differences between primary and secondary immunodeficiency

A total number of 24 patients had PID, and eight patients had SID (Table 3). According to the results, more than half of each group achieved the highest score; 57% for PID and 63% for SID, respectively. The largest variance is illustrated in the item about "Ancillary supply issues" with 63% of patients with PID scored the highest score and 88% of patients with SID estimating the highest score. In addition, the item regarding "Technical issues" showing that patients with PID experience more problems (38%) related to ancillary supplies and technical issues compared to patients with SID (33%). Within this item, 21% of patients with PID scored worse than

before or better than before (1–6), compared to patients with SID that all scored between 7–10 (Table 3).

4.2.2 | Results from previous treatment before fSCIg

There were 25 patients with previous experience of subcutaneous IgG replacement therapy. In this group, 40% scored 10 in the item about "Technical issues", which also shows a variance with 20% of the participants estimating their experience of this dimension worse than before or better than before (scoring 1–6). The "Technical issues" item is about problems with the infusion pump (Table 3).

4.3 | Qualitative results

Two generic categories and four subcategories were revealed in the analysis, describing the experiences of fSCIg treatment. This was interpreted as "difficulties associated with treatment" and "decreasing burden of treatment". Each subcategory is described in italics and is illustrated with authentic quotations.

4.3.1 | Difficulties associated with treatment

The participants were experiencing *affecting symptoms* that influenced them after the administration of the drug. This was described as feelings of fatigue, fever, headache or sometimes an increased number of infections a few days following the completion of their treatment: "After having my infusions, I often got very tired". But there were also participants describing that they experienced fewer symptoms, compared to their experience of earlier treatments prior to testing fSCIg.

During treatment, there were several *disturbing external components* which were exemplified by leakage from the infusion site where the needle had punctured the skin. Some participants described that it felt like a tension from the site after the infusion. When it came to handle the infusion pump and all the material required for fSCIg treatment, participants experienced some problems, for example, about alarms from the infusion pump. Another disturbing component associated with treatment was to switch bottles if it was necessary, which was perceived as prohibitive: "My experience is that the alarms from the infusion pump is very frequent and you need to figure out by yourself why this is happening". Participants needed to follow a stepwise procedure to manage their fSCIg treatment. The multiple types of steps in the procedure demanded time and effort from the participants, and sometimes this was experienced as difficult to handle. If a mistake were made during this procedure, it was difficult to start over again and the procedure had to be started from the beginning. These interruptions were experienced as losing track of where they were in the procedure, which bothered them during the treatment: "It is hard with all the things that you need to do before having the infusion up and running… especially when you miss some step and need to go all over everything again".

4.3.2 | Decreasing burden of treatment

Participants described that one of the benefits of having fSCIg treatment was the *time-saving* aspect. Those who performed their treatment at home expressed the benefit of avoiding visits at the hospital each time they needed their treatment. Another time-saving aspect was that fSCIg treatment gave them opportunities to have sparse time intervals between treatment occasions: "I think that this kind of treatment is saving me time because I don't need to fit it around my life whenever I need to take my shots". This saved time in a stressful life situation if participants had to travel in their work or had young children that needed attention. Having control over treatment occasions by themselves at home provided an opportunity to avoid hospital schedules.

The second benefit was *increasing well-being* in everyday life due to having fSCIg treatment. Due to needing fewer needle sticks and being able to enter their own routine of treatment fitting into their life, it seemed that participants could forget about having a long-term condition that affected their life: "I'm not thinking about me having this illness anymore…kind of interesting…you know…". To be able to decide for themselves which day treatment should be administrated was another aspect that helped to increase their well-being. Participants also described a feeling of being healthier and being able to cope with their everyday life when they had fewer treatment events. It was also expressed as a feeling of freedom and that they took better care of their condition when having fSCIg treatment, since earlier they had sometimes been careless about taking their infusions: "This feels like heaven to me…now I decide in my life, not the disease…". Although having fSCIg treatment was not experienced without troubles, a strong wish was described by participants to continue as the positive aspects were considered more important than the negative aspects.

4.4 | Integration of quantitative and qualitative data (mixed analyses)

Two main factors emerged when integrating the results from each data analysis: prohibiting factors and promoting factors.

Prohibiting factors that were exemplified by problems due to technical issues and ancillary supply issues were observed in the quantitative results. In addition, prohibiting factors were also described by the difficulties in the subcategory "disturbing external components" and revealed by the qualitative analysis. At last, other prohibiting factors were described by patients who experienced (for example) physical symptoms due to treatment.

The second factor that emerged was promoting factors, which was illustrated in the score scale from patients experiencing a positive benefit with longer treatment intervals, revealed in the quantitative results. In combination with the time-saving aspect that occurred in the qualitative analysis, these are interpreted as important promoting factors concerning fSCIg treatment. Another illustrative promoting factor is the increased well-being that was described in the narratives. This was also confirmed in the item about "change

in quality of life" in the score scales (quant.). A feeling of being less ill could be detected and is interpreted as a promoting factor for decreasing the burden of treatment (qual.).

Both aspects illustrate the complex treatment regime that patients living with immunodeficiency experience every day. Long-term illness implies several demanding factors that add to the burden of treatment. In this study, this was exemplified by both physical symptoms and the problems related to the performance of the treatment (ancillary supplies and technical issues). By contrast, fSCIg treatment could reduce the feeling of having an illness and patients reported this as an increased sense of well-being.

5 | DISCUSSION

The results of this mixed-method study provide insights about factors that affect fSCIg treatment in adults with immunodeficiency. When patients need a lifelong treatment that will influence their quality of life, the process of deciding the form of administration and then following through the treatment is important. In this process, healthcare professionals need to be aware of the aspects that will affect the patient and how to reach the best possible outcome for each patient. The prohibiting factors may be avoided by the development of better supplies and infusion pumps and by giving improved information about affecting symptoms and what patients should expect after treatment. The promoting factors should not be underestimated. Living with a long-term condition affects everyday life. Fitting a long-term treatment into a patients' life and not the reverse around is significant, and this should be one of the most urgent aspects to consider when deciding about treatment forms for each patient. The goal should be to decrease the burden of treatment to achieve best possible care for patients with immunodeficiency.

5.1 | Prohibiting factors in the experience of the burden of treatment

The burden of treatment interpreted as prohibiting factors could be associated with the management of ancillary supplies. Preparing and self-administering drugs and storing supplies, all without help from professionals can be problematic when complications occur during the treatment. Also, when treatment effects are not immediately visible or when the treatment results in side effects were also deemed by participants as a prohibiting factor. This has been shown by others when compared to other long-term conditions and burdens of treatment (Tran, Barnes, Montori, Falissard, & Ravaud, 2015). Making care as a routine part of everyday life is important when shaping the perceptions of the burden of treatment (Ridgeway et al., 2014). This is a complex phenomenon: a combination of workload of health care imposed on patients; patients' own capacities to integrate this workload of health care into their everyday life; the context (coordination of care, waiting times and travel distance); and social support in terms of family and friends supporting the patient (Tran et al., 2015). Technical issues and disturbing external components were revealed as other prohibiting factors in this study. This is in line with other results where home therapy has been studied. Lehoux (2004) highlights the need to increase the fit between users and technology by better design of high technology home care devices. Further, effective patient education strategies are needed as competence and acceptance are likely to be mutually reinforced if patients are supported and know how to manage their treatments at home (Lehoux, 2004). Self-management is needed due to a long-term illness and implies having knowledge about the illness itself and adhering to a treatment plan that demands active participation in the decision-making process about the treatment plans (Ambrosio et al., 2015). The concept of self-management is especially complex when it comes to treatment using medical technology such as infusion pumps in a home setting. This implies that patients need healthcare resources to help them manage and cope with their treatments. It is important to identify those patients that lack appropriate access and/or ability to recruit resources to cope with the treatment burden, which in turn may help professionals to identify those at risk for a poor clinical outcome (Ambrosio et al., 2015; Ridgeway et al., 2014). Being a user of medical technology in a home setting indicates challenges. It requires a transformation of knowledge and skills to the user, making sure that the home environment is safe, effective and appropriate, as well as requiring the knowledge about which actions need to be taken when problems occur (Lehoux, 2004).

5.2 | Promoting factors in the experience of the burden of treatment

High satisfaction and increased well-being resulting from combining treatment with daily life were shown, which were interpreted as promoting factors. Clinically relevant increases of HRQOL in physical health and in the mental health domain have been shown when patients with immunodeficiency receive replacement therapy (Routes et al., 2016). Espanol et al. (2014) have found that home therapy regimens where patients self-administer their treatment may lead to improvements in HRQOL and treatment satisfaction. The ability to manage treatment at home makes it easier to work or study and could contribute to a sense of self-control among patients and their families (Bienvenu et al., 2016; Jiang et al., 2015). Investigations have declared that receiving subcutaneous replacement therapy is more compatible with an active lifestyle and more convenient during business trips or holidays (Jolles et al., 2015), which was illustrated in the narratives of this study. Again, convenience plays a large role in patient preferences, as it has been shown in this study that less frequent administrations of shorter durations and fewer needle sticks impact the patients' experiences. This was also confirmed by Ponsford et al. (2015) which described that using fSCIg treatment offers a significant reduction in the number of needle sticks in comparison with SCIg treatment (Ponsford et al., 2015). A call for a person-centred treatment of patients with immunodeficiency highlights the importance of input from patients' experiences and discussions about their preferences in decision-making when choosing the most

appropriate therapy. Treatment preferences can indeed vary by patient; therefore, the ideal therapy needs to be individualised (Bienvenu et al., 2016; Espanol et al., 2014). There are indications from patients that healthcare professionals should ensure treatment plans and evaluate treatments by focusing on the patient rather than on the specific disease (Seeborg et al., 2015). This study also points out that regular treatment sessions at the hospital remind the patient that they suffer from a disease. This could be interpreted as an emotional factor that impacts on patients' daily life. Coping with absences from work or school has also been shown to be an aspect that greatly impacts on the everyday life of patients suffering from other long-term conditions. Added to this, patients' social life is affected, as the treatment interferes with leisure activities (Tran et al., 2015). fSCIg offers an opportunity to treat patients with immunodeficiency to whom the conventional routes are impractical, or when patients are suffering from systemic adverse events and to those patients that cannot commit to frequent visits to the hospital (Blau et al., 2016). It could be concluded that living with a long-term condition is complex, dynamic and a multidimensional process with the desired result being the achievement of a positive living standard (Ambrosio et al., 2015). Having the opportunity to be given the best possible treatment plan, adjusted for each unique patient situation, is therefore central. The results in the present study suggest that patients ought to be given information both about the prohibiting factors and the promoting factors, as well as details of when treatment plans are to be decided upon, such that the best outcomes are achieved for each patient.

5.3 | Limitations

Some limitations should be considered when interpreting study results. The present study is limited by sample size and the lack of participant randomisation but reflects the importance of patients' experiences about treatments concerning the frequency of infusion and effects on quality of life. Due to the small sample size, the statistical analysis was limited, but clinical differences have been shown using a mixed-method approach. Several selection biases need to be discussed. The inclusion criterion defined as adherence problems may have impacted the results, as these patients may have described more positive experiences as they desired longer treatment intervals. Several treatment pumps were used, and the patients described differences between the fabric, and therefore, pumps were changed during the study period, which also could have affected the results. The burden of treatment may be experienced as decreasing over time when patients were used to ancillary supplies and the handling of pumps, but as this study only relied on data collection at a single occasion, this remains unknown due to the study design. The use of a structured study protocol opens up the possibility for both positive and negative aspects. Study protocols give opportunities to repeat the same questions over a long study period, which was the case in this study, but this could also affect the qualitative data collection. The use of a different qualitative methodology such as focus groups could have given a richer data set. Despite these limitations, 164 statements were revealed from the open-ended questions and were therefore deemed sufficient.

6 | CONCLUSION

Patients with severe immunodeficiency require lifelong treatment, and therefore, choices about the administration and efficacy of treatment have a significant impact on HRQOL. The key to a successful treatment is that the patient is provided with proper support and can manage the expectations to ensure that they achieve the maximum effect from the therapy. Treatment plans should always be adapted for each patient's unique situation. This is a key step to ensure that patients with immunodeficiency achieve the maximum benefit from their treatment regime where both promoting and prohibiting factors are deliberated. This study highlights the importance of providing access to different treatment options and to discuss the different aspects that can promote and prohibit the experience of treatment.

7 | RELEVANCE TO CLINICAL PRACTICE

The results of this study can be helpful for healthcare professionals to support patients with severe immunodeficiency and to understand the different factors that may impinge on the patients' everyday life when they are forced into a lifelong treatment. This knowledge is also important for nurses who have a responsibility to promote health concerning patients with long-term conditions in general. The experiences of patients are a key outcome when developing and evaluating treatments in the future and should be given more focus in forthcoming research.

CONFLICT OF INTEREST

Per Wågström, MD, and Åsa Nilsdotter-Augustinsson, ass prof., are members of the Swedish National Guideline Committee, which is sponsored by Shire. Carina Hagstedt is member of the Advisory Board, CSL Behring, and Ramona Fust and Carina Hagstedt are members of the Advisory board, Shire.

DISCLOSURE

The authors have confirmed that all authors meet the ICMJE criteria for authorship which is substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data, drafting the article and revising it critically for important content and final approval of the version to be published.

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