LEARNINGS FROM THE CSL BEHRING CARES PATIENT SUPPORT PROGRAM: ADMINISTRATION OF SUBCUTANEOUS IMMUNOGLOBULIN (HIZENTRA®) IN THE HOME SETTING FOR PATIENTS WITH CHRONIC INFLAMMATORY DEMYELINATING POLYNEUROPATHY (CIDP)

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INTRODUCTION

Subcutaneous immunoglobulin (SCIg) therapy is a growing treatment option for patients with immunodeficiencies as an alternative to intravenous immunoglobulin (IVIg) infusions. Guidelines state that reasons for consideration in choosing SCIg for neurological indications for appropriate patients include preference for autonomy and convenience of self-treatment at home and may avoid some systemic side effects and intravenous cannulation.[1] To help patients transition from hospital-based to home-based care, and establish their competence in Hizentra® (20% normal immunoglobulin) self-administration, the CSL Behring CARES patient support program (PSP) was created. CARES was designed to provide education and training to patients through regular in-home sessions with a registered nurse. The CARES PSP also supports patients with primary and secondary immunodeficiency (PID and SID, respectively).

PROGRAM STRUCTURE

CARES is commissioned by CSL Behring and managed by Aesir Health Pty Ltd (Aesir). Aesir is an independent, national healthcare provider, with over 15 years of experience in patient education on the self-administration of injectable medications. Training through CARES is provided by a team of up to 30 Registered Nurses, each with extensive experience in community nursing and patient education services.

CARES offers a multi-level approach to servicing patients referred into the program. Patients enrolled in the CARES program receive a series of in-home educational visits from a program nurse. This education is also offered to carers of enrolled patients. Further assistance is also provided through Aesir phone support and the Support service offers access to program coordinators via the 1800 line or email as needed.

OBJECTIVE

The aim of CARES is to ensure that patients are confident and competent in SCIg self-administration. A review of patients with CIDP enrolled in CARES was undertaken to assess the effectiveness and quality of the program.

METHOD

Patient competence in SCIg self-administration was assessed by the registered nurse on completion of each home visit using a standardised form. Patient's skills and knowledge were rated in relation to the preparation, infusion and post-infusion care, with a focus on medication handling, competence, site selection and correct infusion technique.

The total number of visits a patient received was based on their competency in these areas. Patients who were deemed competent to self-manage their ongoing treatments received no further in-home visits following sign-off from the nurse. Upon completion of the in-home visits, patients were asked to complete a survey to ascertain the quality of education and training provided.

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Figure 1: Distribution of patients enrolled into the program (n=115)

PATIENT ENROLMENTS

A total of 115 patients with CIDP, aged 12 to 91 years, enrolled in CARES: 107 with face-to-face education and eight with intensive phone support. Participation in CARES was nationwide, as shown in Figure 1. Patient demographics are shown in Figure 2.

Table 1: Medication summary

SCIg experience	100% new to SCIg infusions
Volume infused (mL/week)	25–240 mL
Dosing frequency	91% on weekly dosing

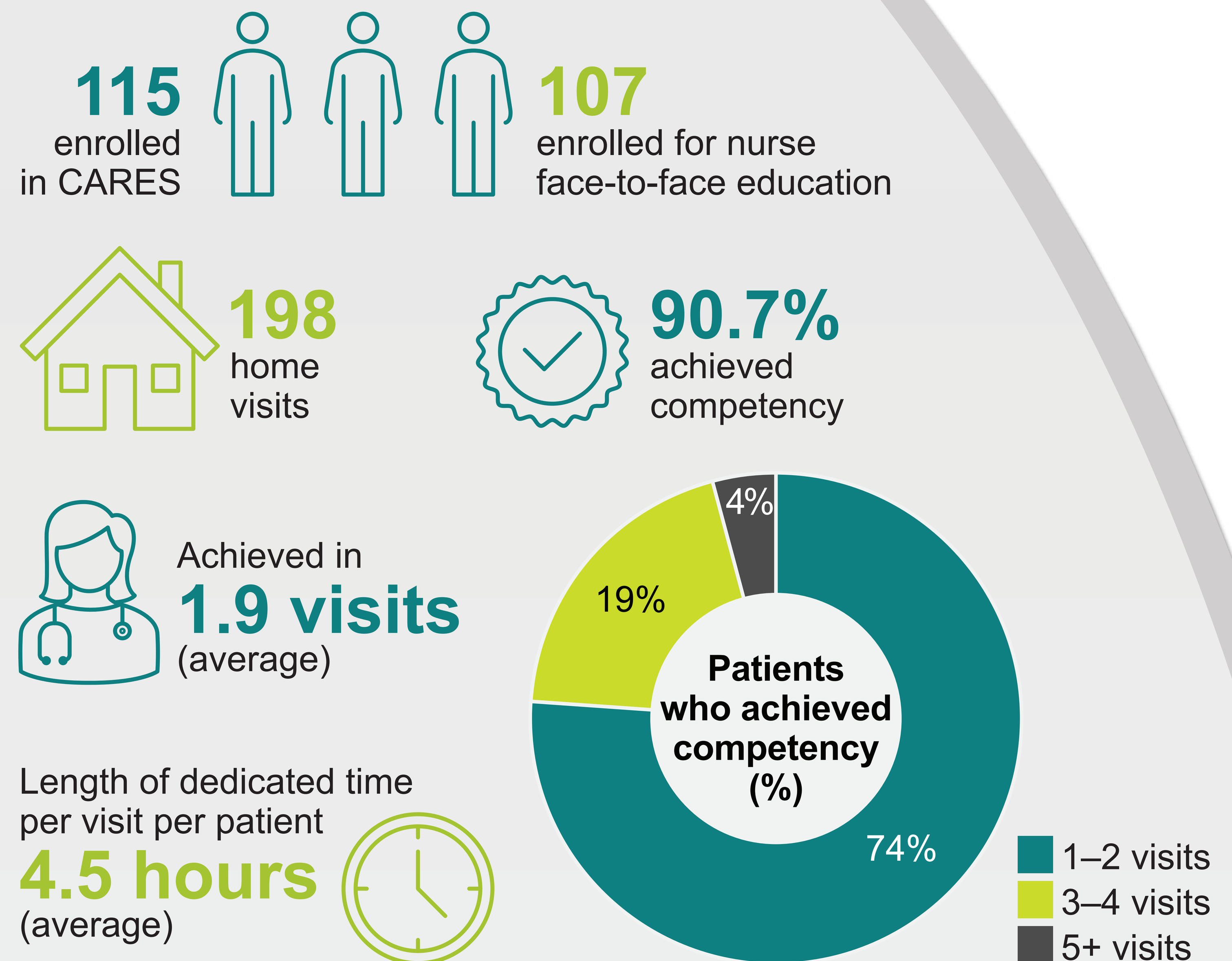
Figure 2: Enrolments by age range (n=107)

Age range (years)
10-19 2
20-29 5
30-39 11
40-49 13
50-59 17
60-69 29
70-79 20
80-89 7
90-99 3

RESULTS

All 107 patients with CIDP enrolled into the program received nurse education sessions, with 92% delivered face to face and the remaining sessions via telehealth. Prior to enrolling in CARES, none of the patients had ever received SCIg treatment – 98% were previously receiving IVIg and the other 2% were treatment naïve. Out of 107 patients, 97 (90.7%) were deemed competent, eight did not achieve competency, and two were ongoing at the time of writing. On average, patients became competent in self-administration after 1.9 nurse visits (range 1–6 visits).

Most patients (74%) only required one or two visits by the nurse to reach competency. A few patients (19%) required three or four visits, and only four patients (4%) required more extended support, with up to six visits. The average length of dedicated time for the in-home education was 4.5 hours per patient.

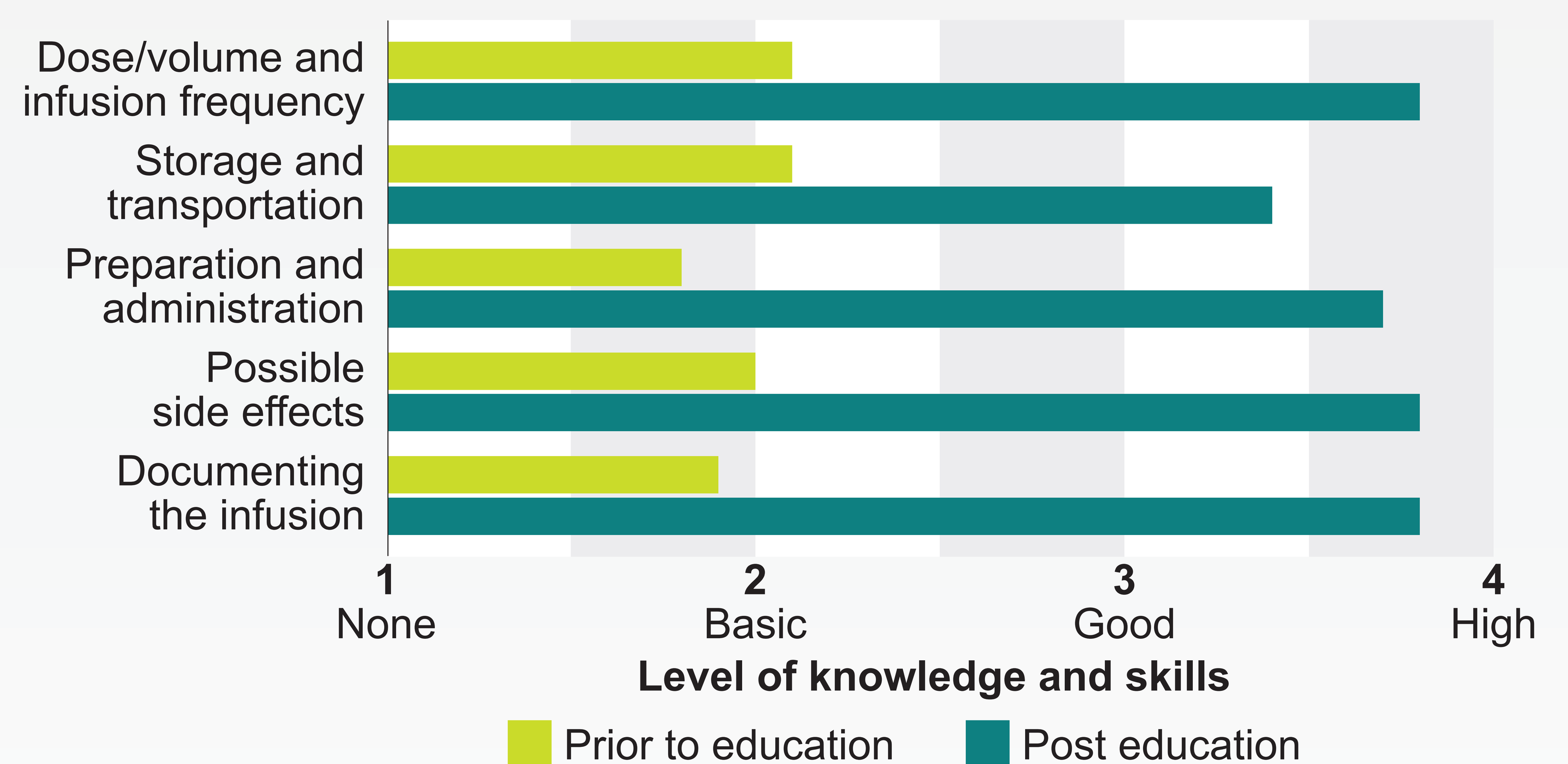


Of the eight patients who were not deemed as competent, four had one or two face-to-face visits before the decision was made to refer to the clinic. The other four patients were referred to the clinic prior to commencing nurse education, generally because of a change in patient choice or circumstance.

PATIENT KNOWLEDGE AND SKILLS

Of those who completed the program, 36 patients (34%) provided their feedback via a program assessment survey. Patients were asked to rate their knowledge and skills on a scale of 1–4 before and after the education. Patients reported improvement from pre-education to post-education in every area assessed in the survey.

Figure 3: Patients' understanding/knowledge of SCIg pre/post training



DISCUSSION AND CONCLUSION

The CSL Behring CARES patient support program is an effective means to support patients with CIDP in the self-administration of SCIg treatment. It has demonstrated that patients of all ages with CIDP are suitable for home-based therapy with Hizentra® and can be transitioned from hospital-based Ig treatment to weekly home-based therapy.

Patients aged 12 to 91 years were referred to the CARES program by their treating specialist. Out of 107 patients, 90.7% were deemed competent and able to continue in-home therapy following completion of the training component of the program. On average, patients became competent in self-administration after 1.9 nurse visits (range 1–6 visits), which is in line with previously reported visits in immune deficient patients[2] and suggests the quality of the education and support provided through the program was effective in achieving competency for most patients.

Patient feedback also revealed the program was effective in improving patients' understanding and knowledge of SCIg and was considered of a high quality.

Consideration for each patient's treatment, home circumstances and supporting networks were important in the design and execution of CARES and has contributed to the success of the program thus far. Further analyses of CARES are planned to determine how to best continue to support patients with their ongoing home-based treatment.

References

1. Van den Bergh PYK, van Doorn PA, Hadden RDM, *et al*. European Academy of Neurology/Peripheral Nerve Society guideline on diagnosis and treatment of chronic inflammatory demyelinating polyradiculoneuropathy: Report of a joint Task Force-Second revision. *Eur J Nerol* 2021; 00:1-28.

2. AAAAI 2018 Poster; Henderson TS *et al*. Patient-reported experience on training associated with subcutaneous immunoglobulin (SCIG) therapy self-administration. 2–5 March 2018 (Orlando, FL, USA).

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