PAM13

# Impact on Carers of Adult Patients Receiving Parenteral Support for Short Bowel Syndrome–Associated Intestinal Failure

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## Background

- Intestinal failure associated with short bowel syndrome (SBS–IF) is caused by removal of part of the small intestine that reduces gut function below that necessary for satisfactory absorption of nutrients, water, or electrolytes.[1]
- Patients with SBS–IF require long-term nutrition and hydration with intravenous parenteral support (PS) and may need regular home care from partners, family, or friends.[1,2]
- Carers of patients receiving PS have reported depression, fatigue, and anxiety about managing PS; however, the effect of providing care on the health and quality of life of carers has not been fully characterised.[3-5]

## Objective

- To assess the effect of caring for adult patients in the United Kingdom receiving PS for SBS–IF
  - Results from a related survey of carers of PS-dependent paediatric patients with SBS–IF are presented in Poster PIH65.

## Methods

### Study Design and Survey Development

- An online cross-sectional survey of carers of patients with SBS–IF was conducted in the United Kingdom.
- Survey questions (**Figure 1**) were identified with a targeted MEDLINE/PubMed literature search.
- The survey took ≤45 minutes to complete; carers who completed the survey were reimbursed for their time and effort with a voucher.

**Figure 1. Sources of Survey Questions**

| Study-Specific Questions | EQ-5D-5L | WPAI:SHP | iVICQ | Understanding Society Survey |
|---|---|---|---|---|
| • Demographics of<br>– Carer<br>– Patient, as reported by carer | • 5-item measure to assess HRQoL of carer<br>– Mobility<br>– Self-care<br>– Usual activities<br>– Pain/discomfort<br>– Anxiety/depression<br>• Overall health | • 6-item measure to assess for the carer<br>– Work status<br>– Hours worked<br>– Hours of work missed<br>– Productivity<br>– Activity impacts | • Time spent on asssisting the patient with<br>– Personal care<br>– Practical support | • Impact on<br>– Nightly sleep of carer<br>– Finances |

EQ-5D-5L= 5-level version of the EuroQoL-5 Dimensions instrument; HRQoL=health-related quality of life; iVICQ=iMTA Valuation of Informal Care Questionnaire;[6] WPAI:SHP=Work Productivity and Impairment Questionnaire:Specific Health Problem.

### Participants

- Carers were recruited from an advocacy group from June 2016 to January 2017 and from 2 National Health Service sites from December 2016 to February 2017.
- Carers were aged >16 years and caring for an adult patient with SBS–IF who received 1–7 days or nights of PS per week. Patients and carers provided informed consent.

### Data Analysis

- Carer's health status was evaluated using the 5-level version of the EuroQoL-5 Dimensions instrument (EQ-5D-5L) and expressed as a utility index score (u) between 0 (equivalent to death) and 1 (full health).
- Data were summarised using descriptive statistics.
- Spearman correlation coefficients ($r_s$) and chi-square tests were used to explore associations between variables.

## Results

### Patient and Carer Demographics

- A total of 47 carers completed the survey; the majority of carers who completed the survey were recruited through the advocacy group (62%).
- Thirty (64%) carers were the spouse/partner of the patient; mean (SD) age was 50.6 (15.34) years, women (60%), and employed full-time (43%).
- The characteristics of 47 patients were described by their carers (**Table 1**). Patients averaged 5.0 (1.57) days per week of PS for 11.7 (2.57) hours per day, and had received PS for a mean (SD) of 7.3 (7.35) years (n=45).

**Table 1. Carer-Reported Patient Demographics and Characteristics**

| Parameter | Patients (N=47) |
|---|---|
| Age, mean (SD), years | 52.5 (15.25) |
| Women, n (%) | 25 (53) |
| Underlying cause of SBS, n (%)* | |
| Crohn's disease | 14 (30) |
| Surgical complications/resection/fistula | 9 (19) |
| Intestinal injury from blocked blood vessel | 5 (11) |
| Other IBD | 4 (9) |
| Not sure | 4 (9) |
| Cancer | 3 (6) |
| Intestinal injury from trauma | 2 (4) |
| Other† | 14 (30) |
| Relationship to carer, n (%) | |
| Spouse/partner | 30 (64) |
| Daughter or son | 7 (15) |
| Mother or father | 5 (11) |
| Another family member | 2 (4) |
| Friend | 3 (6) |

IBD=inflammatory bowel disease; SBS=short bowel syndrome.
*Reported 2 causes (n=6), 3 causes (n=1); †All causes classified as "other" were single instances.

### Carer-Reported Outcomes

- Overall, carers provided a mean (SE) of 4.5 (0.50) hours of care per day (**Table 2**), which is almost 4 hours more per day than general, non-matched population UK norms from the Understanding Society survey (0.6 [0.17] hours).[7] Care was provided for 6.0±1.66 days per week.

**Table 2. Carer Survey Responses**

| Parameter* | |
|---|---|
| Hours spent providing care/day (iVICQ), mean (SE) | 4.5 (0.50) |
| Hours spent providing personal care/week (iVICQ), mean (SD) | 13.1 (16.11) |
| Hours spent providing practical care/week (iVICQ), mean (SD) | 11.3 (14.33) |
| Hours of sleep/night (USS), mean (SE) | 6.3 (0.16) |
| Carer's assessment of financial situation (USS), n (%) | |
| Managing financially | 27 (57) |
| Just about getting by | 14 (30) |
| Finding it quite difficult | 5 (11) |
| Finding it very difficult | 1 (2) |
| Assessment of work and activity impact (WPAI:SHP), mean (SD) | |
| Absenteeism: work time missed, % | 9.7 (20.10)† |
| Presenteeism: impairment to productivity at work, % | 24.5 (22.93)‡ |
| Total work impairment, % | 28.2 (24.91)‡ |
| Total activity impairment, % | 37.9 (29.19) |

PS=parenteral support, iVICQ=iMTA valuation of informal care questionnaire (timeframe of prior 7 days); USS=understanding society survey (timeframe of prior 1 month for sleep question); WPAI:SHP=Work Productivity and Impairment Questionnaire: Specific Health Problem (timeframe of prior 7 days).
*Responses were from n=47 carers unless indicated otherwise; †n=30; ‡n=29.

- In addition to the WAPI:SHP assessment of the prior 7 day assessment, carers who were currently working (n=30) reported missing a mean (SD) of 2.9 (4.83) work days during the preceding month.
- Carers' EQ-5D-5L utility index scores were similar to UK general population norms (u=0.88 for both); however, 66% of carers reported any health problem versus 43% of UK norms.[8]
  - Anxiety/depression was reported more frequently by carers (53%) versus UK norms (21%).[8]

### Correlation Analysis

- A greater number of patients' PS infusion hours correlated with increased number of hours spent providing care ($r_s$=0.35, *P*=0.016), greater total work impairment ($r_s$=0.47, *P*=0.011), higher activity impairment ($r_s$=0.36, *P*=0.014), increased difficulty managing financially ($r_s$=0.42, *P*=0.003), increased anxiety/depression ($r_s$=0.36, *P*=0.012), and lower EQ-5D-5L utility index score ($r_s$=–0.30, *P*=0.037).
- An increased number of hours of care per day and personal/practical care were related to carers' total activity impairment (all *P*≤0.006; **Table 3**).
- An increased number of hours of care per day and personal care were associated with increased difficulty to manage financially (both *P*≤0.006; **Table 3**).

**Table 3. Carer and Patient Correlations**

| Spearman Correlation Coefficient | Carer Hours of Sleep | Care per Day, hours | Personal Care, hours | Practical Support, hours | Managing Financially | EQ-5D-5L Index Score | EQ-5D-5L Anxiety/ Depression | WPAI:SHP Total Work Impairment |
|---|---|---|---|---|---|---|---|---|
| Care per day, hours | –0.197 | 1.000 | | | | | | |
| Personal care, hours | –0.150 | **0.478†** | 1.000 | | | | | |
| Practical support, hours | –0.045 | **0.570†** | 0.532 | 1.000 | | | | |
| Managing financially | –0.218 | **0.393†** | **0.432†** | 0.256 | 1.000 | | | |
| EQ-5D-5L index score | **0.356*** | –0.058 | –0.206 | –0.058 | –0.352 | 1.000 | | |
| EQ-5D-5L anxiety/depression | –0.218 | –0.010 | 0.240 | 0.102 | **0.394†** | **–0.698†** | 1.000 | |
| WPAI total work impairment | 0.060 | **0.398*** | **0.433*** | –0.029 | **0.530†** | **–0.417*** | 0.200 | **0.999†** |
| WPAI activity impairment | **–0.398†** | **0.509†** | **0.332*** | **0.392†** | **0.373†** | **–0.363*** | **0.344*** | **0.441*** |

EQ-5D-5L=5-level version of the EuroQoL-5 Dimensions instrument; WPAI:SHP=Work Productivity and Impairment Questionnaire: Specific Health Problem (timeframe of prior 7 days).
*Correlation was significant at the 0.05 level (2-tailed); †Correlation was significant at the 0.01 level (2-tailed).

## Limitations

- The small sample size, that reflects the rarity of the condition, limits the ability to generalize findings without further research.

## Conclusions

- Carers provided many hours of personal care and practical support to adult patients with SBS–IF that negatively impacted their sleep, daily work and activities, and HRQoL including increased health problems.
- The daily hours for patients' PS infusions and number of hours spent on patient care significantly correlated with work, financial, and personal challenges for carers (*P*<0.05).
- Further research is warranted to confirm current findings; considerations could include a larger number of respondents and the use of a sample matched control group.

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## Disclosures

Shire is a member of the Takeda group of companies. R. Ballinger is an employee of ICON plc. J. Macey was an employee of ICON plc at the time the study was conducted. ICON and advisor A. Lloyd were contracted by NPS Pharmaceuticals; Shire Pharmaceuticals Limited, Basingstoke, UK; and Shire International GmbH, Zug, Switzerland. K. Chen is an employee of Shire Human Genetic Therapies, Inc., Cambridge, MA, USA. This study was funded by Shire Human Genetic Therapies, Inc., Cambridge, MA, USA, a member of the Takeda group of companies. Editorial support, funded by Shire International GmbH, Zug, Switzerland, a member of the Takeda group of companies, was provided by Complete Healthcare Communications, LLC, a CHC Group company (North Wales, PA, USA).

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