

Benefits of community outreach nurses in Spain:

Home care nurses

**Dr. Álvaro Rafael Villar Hernández (DEBRA
Spain)**

**debra**
Piel de Mariposa

Home Care Nurses



Home Care Nurses is essential to ensure that families receive ongoing nurse support not only on the reference centers, but also in their day-to-day care, especially at home.

This research study aims to expose the needs and challenges that patients with severe RDEB and their families face in their daily care at home.



Main Objective

Analyze the formal and informal care received by people with severe RDEB in Spain.

Specific Objectives

- Translate and validate the specific quality of life questionnaire for EB.
- Evaluate and establish the relationship between the quality of life and the caregiver's burden based on home nurse care.
- Determine the role of the main caregiver in administering care to people with severe RDEB in Spain.
- Examine the care provided by primary healthcare nurses to people with severe RDEB in Spain.
- Analyze the level of satisfaction with healthcare services.



Hypothesis

Home nurse care improves the quality of life of people with severe RDEB and their caregivers.



Study design

- Quantitative, observational, and cross-sectional.

Sample Selection

- 96 families with severe RDEB were selected, with 78 of them participating. In total 156 people (people with EB + caregivers).

Instruments

- Birmingham Severity Score Questionnaire (adult and pediatric).
- Quality of Life Questionnaire for EB (QoLEB) in Spanish.
- Caregiver burden questionnaire (Zarit).
- Semi-structured questionnaire.



Article

Transcultural Validation of a Spanish Version of the Quality of Life in Epidermolysis Bullosa Questionnaire

Alvaro Rafael Villar Hernández ^{1,2,*}, Fernando Molero Alonso ², Álvaro Jesús Aguado Marín ³ and Manuel Posada de la Paz ⁴

¹ Dystrophic Epidermolysis Bullosa Research Association ONG DEBRA España Piel de Mariposa, 29601 Marbella, Spain

² Department of Social and Organizational Psychology, Universidad Nacional de Educación a Distancia (UNED), 28040 Madrid, Spain; fmolero@psi.uned.es

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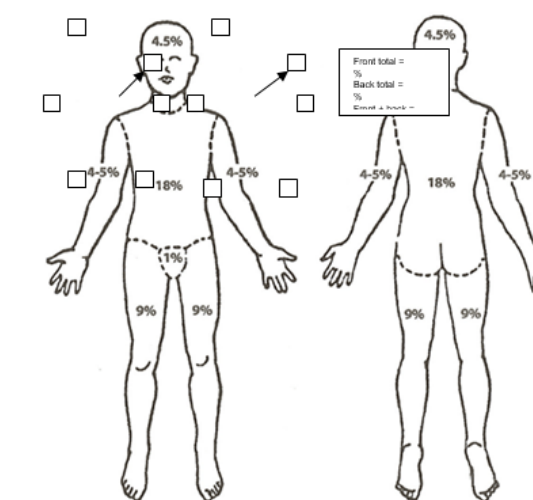
How to fill in the BEBS score sheet

Nails: enter number in each box and add up horizontally

	R hand	L hand	R foot	L foot	Subtotals A	Subtotals B	Total score
lost nails	+	+	+	+	+	4	
dystrophic nails	+	+	+	+	+	8	
normal nails							
total	5	5	5	5			

Area:

Please shade in affected areas on the diagram, then work out percentage for each part and fill in the numbers in the adjacent boxes. eg if half of the anterior trunk is affected, then put 9% in the box on anterior trunk. Patient's palm size area corresponds to 1% of total body surface area

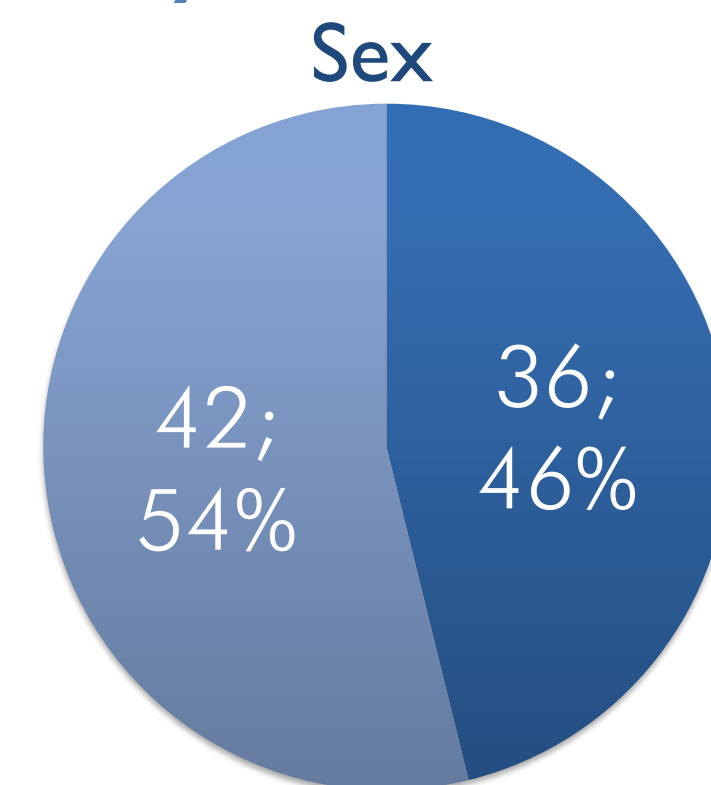
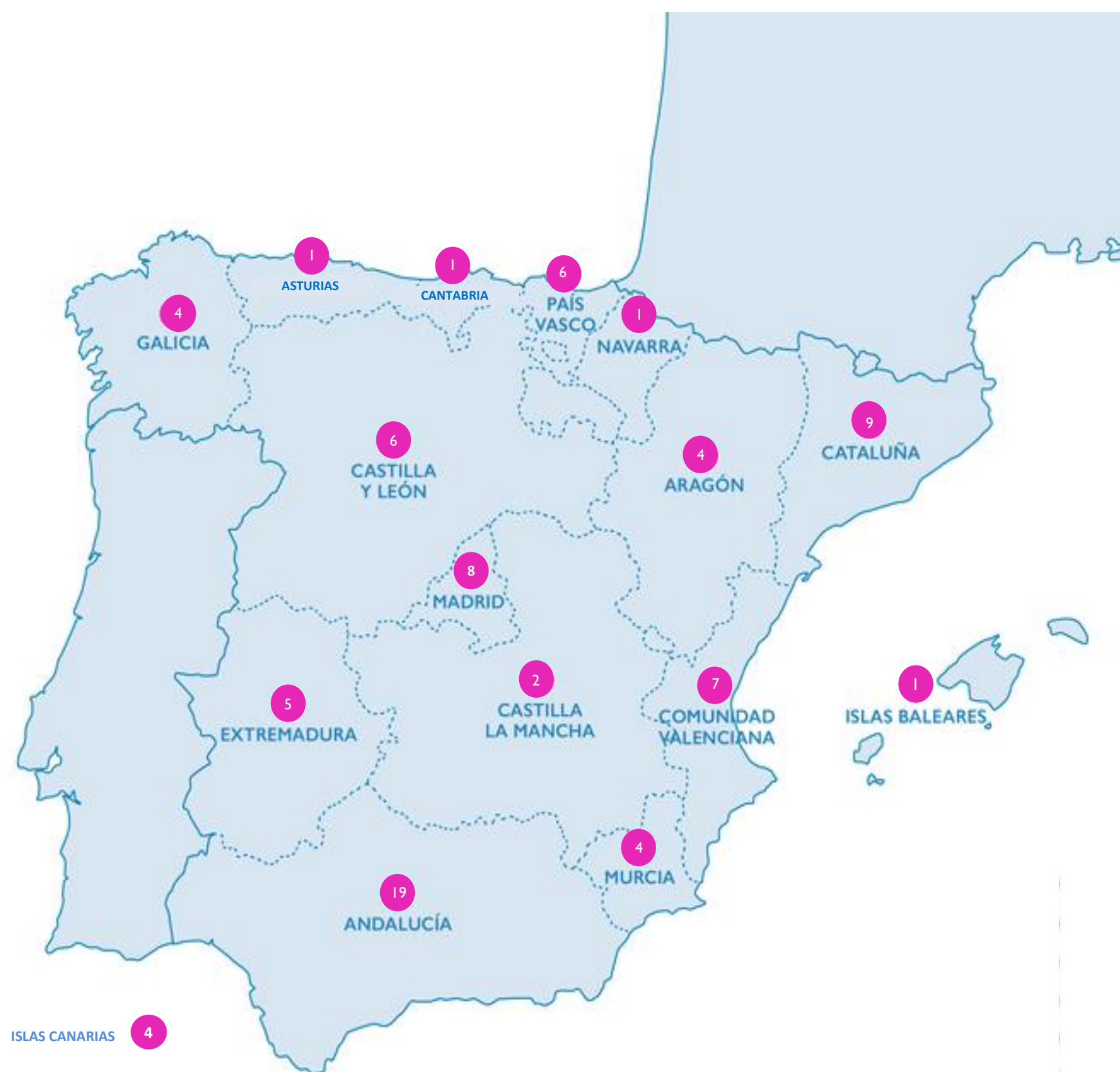


Mouth, Eyes, Larynx, Esophagus: detailed scoring

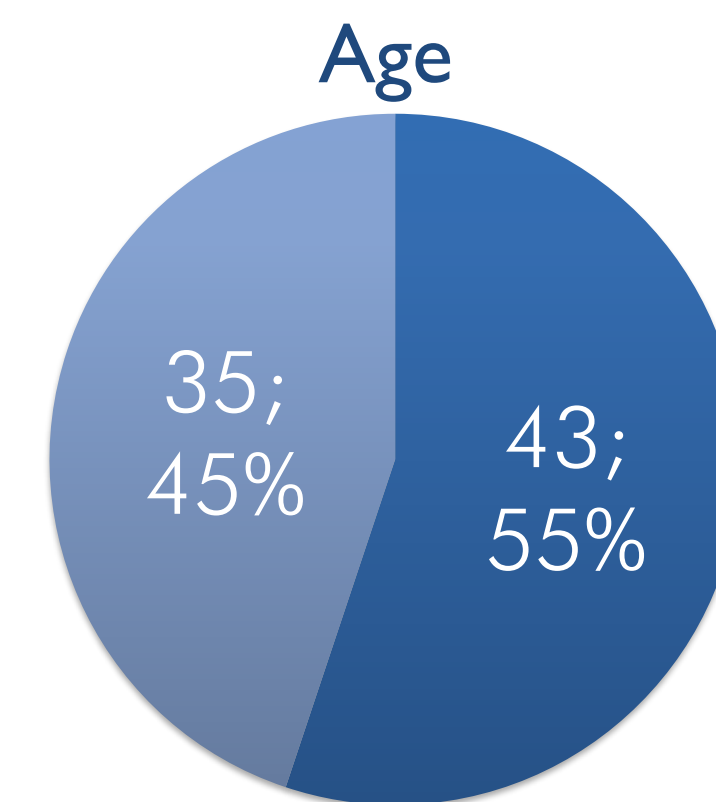
	Mouth	Eyes	Larynx	Esophagus
0	No problem from EB	No problem from EB	No problem from EB	No problem from EB
1	Occasional soreness	Occasional soreness	Occasional hoarseness	Occasional dysphagia
2	Frequent soreness	Frequent soreness	Frequent hoarseness	Frequent dysphagia
3	Persistent soreness	Persistent soreness	Persistent hoarseness	Persistent dysphagia
4	Severe tongue tethering & microstomia	Severe bilateral eye disease	Life threatening laryngeal obstruction	Life threatening esophageal obstruction



Sociodemographic Data: People Affected by RDEB

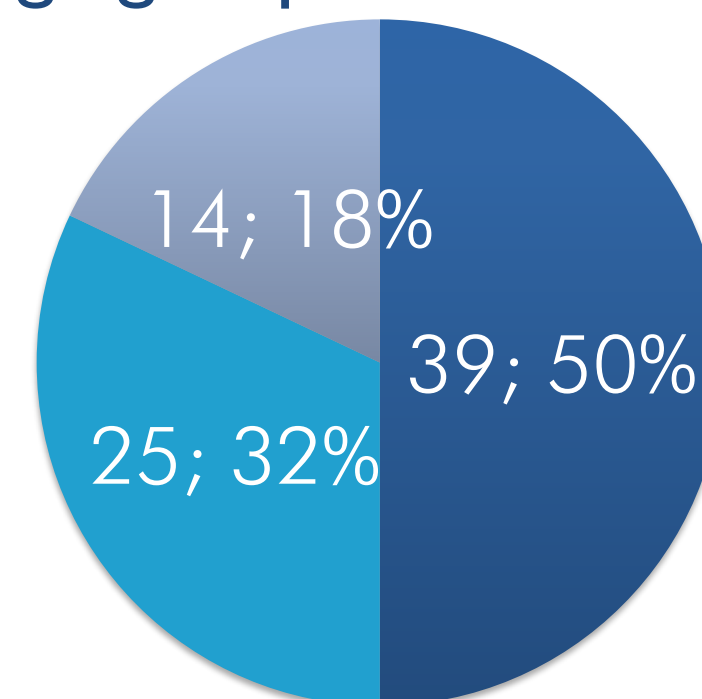


■ Male ■ Female



■ Under 18 years old

Age group distribution

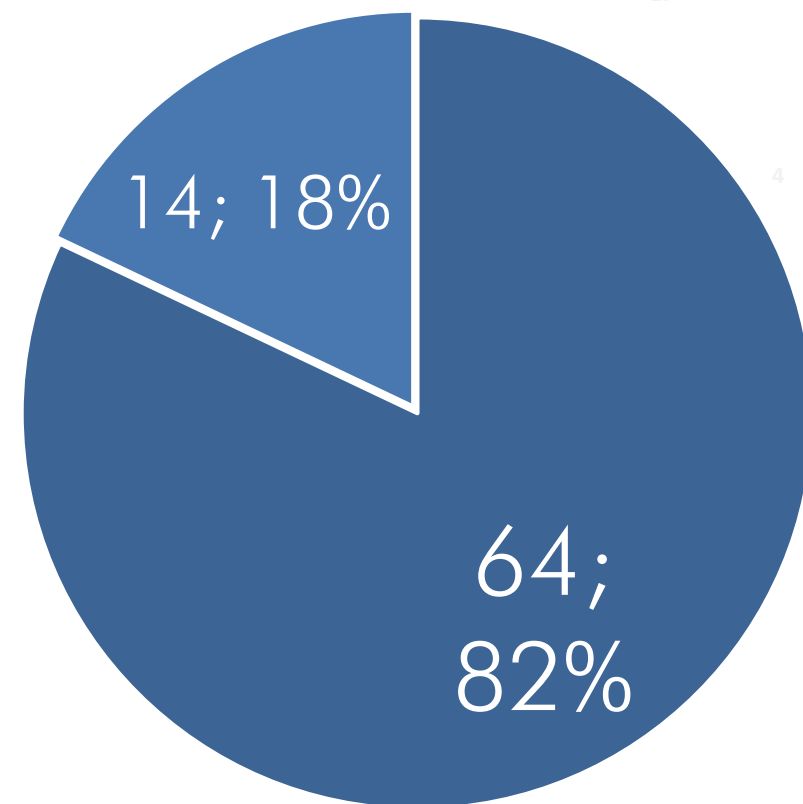


■ 0-15 years ■ 16-31 years



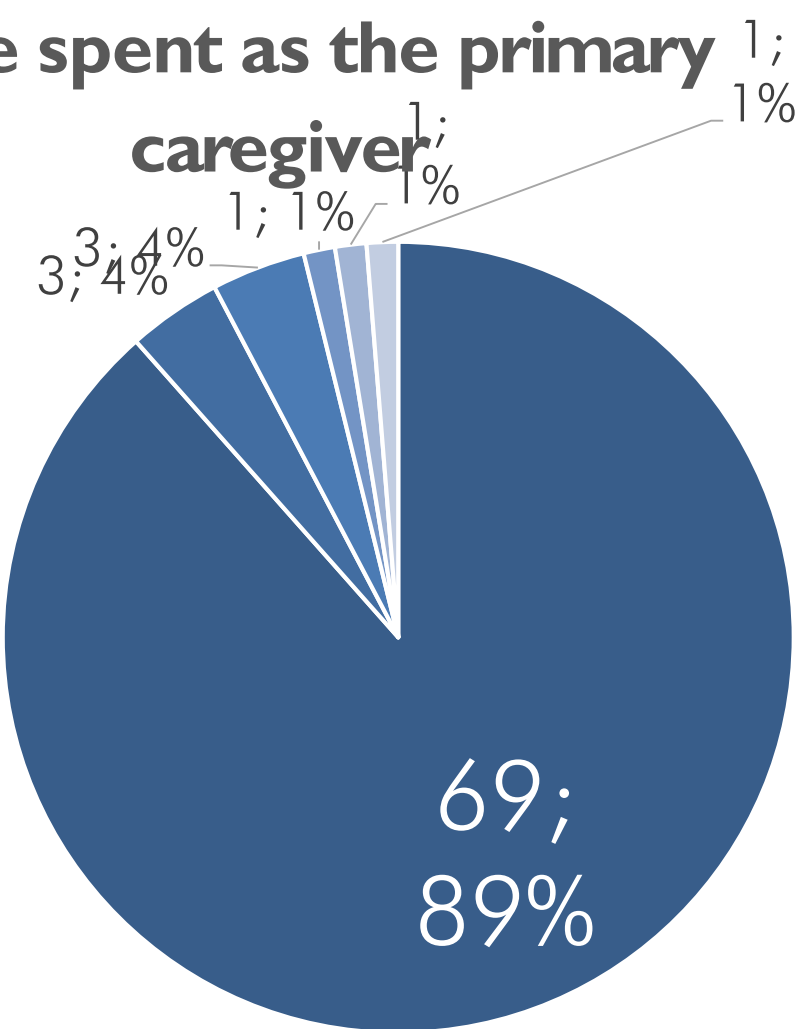
Sociodemographic Data: Caregiver

Sex



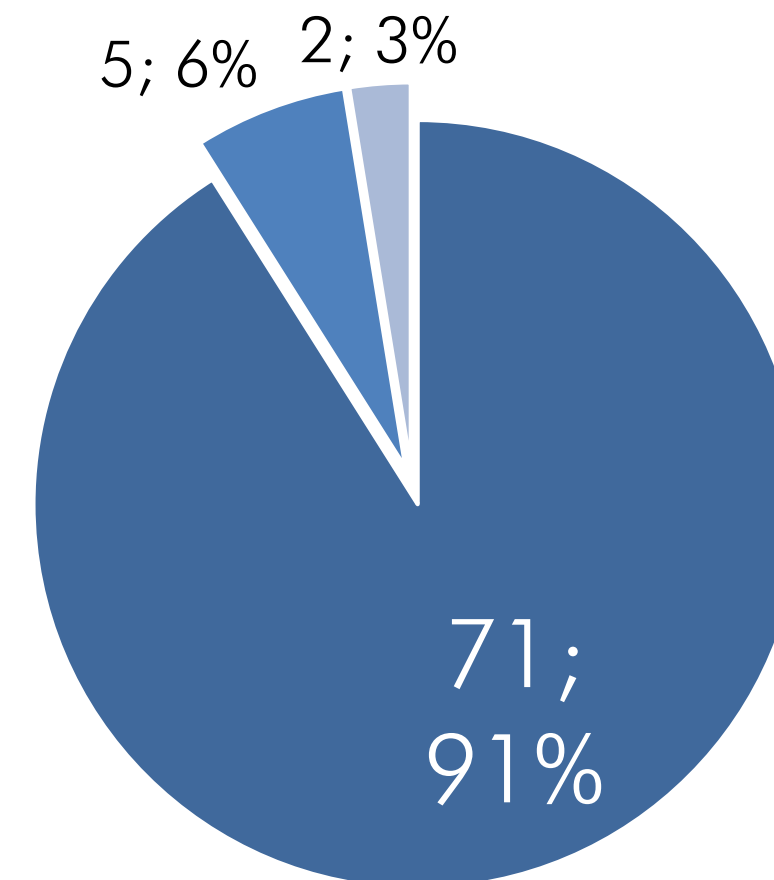
■ Female ■ Male

Time spent as the primary caregiver



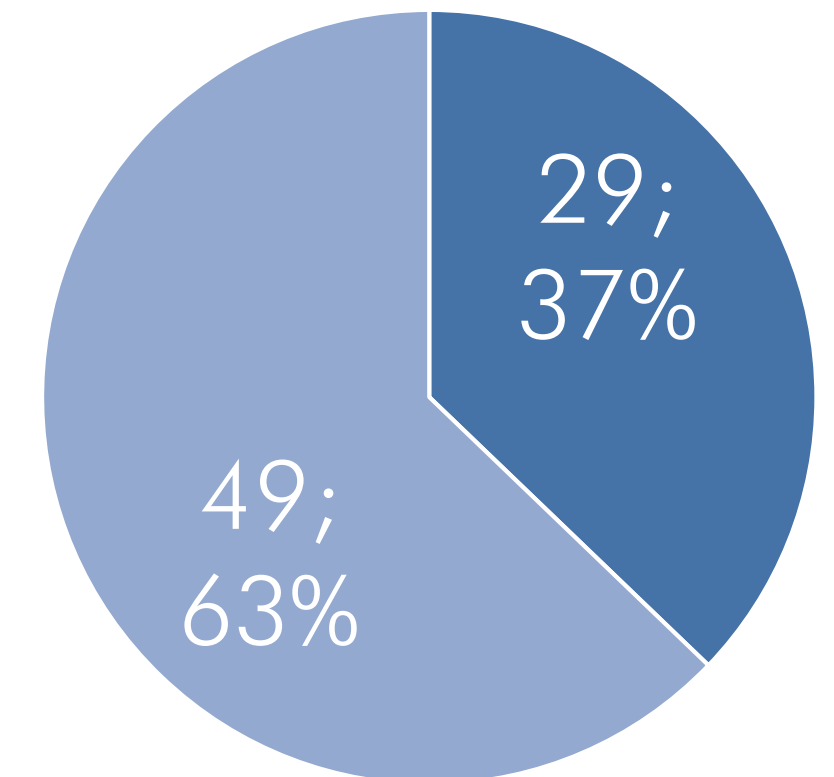
■ Since the patient was born
■ 2-3 years
■ 4-5 years
■ 10 years
■ 20 years
■ No response

Relationship with the patient



■ Mother/Father ■ Couple
■ Sibling

Support in caregiving for other family members

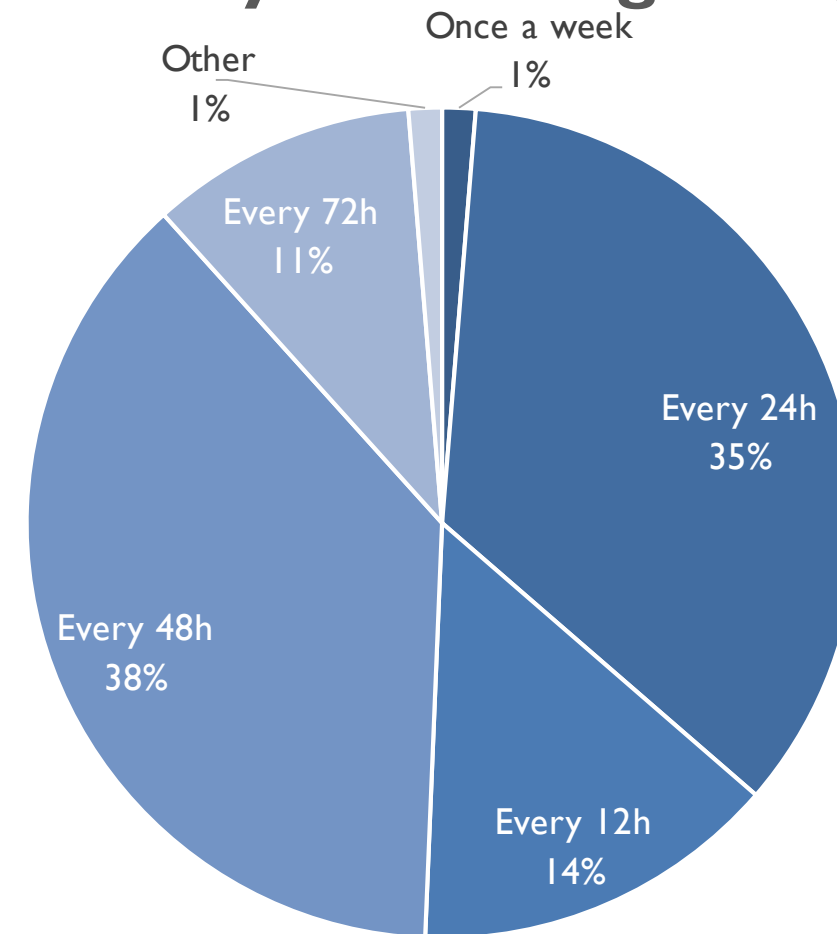
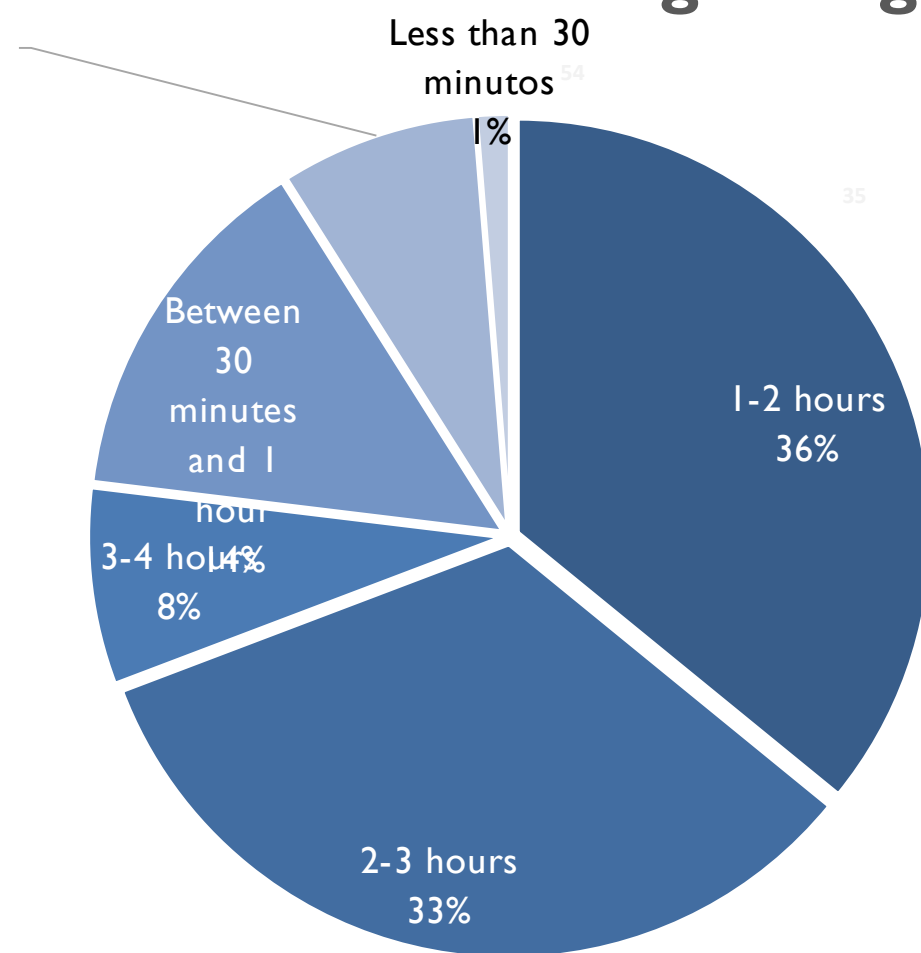


■ Yes ■ No



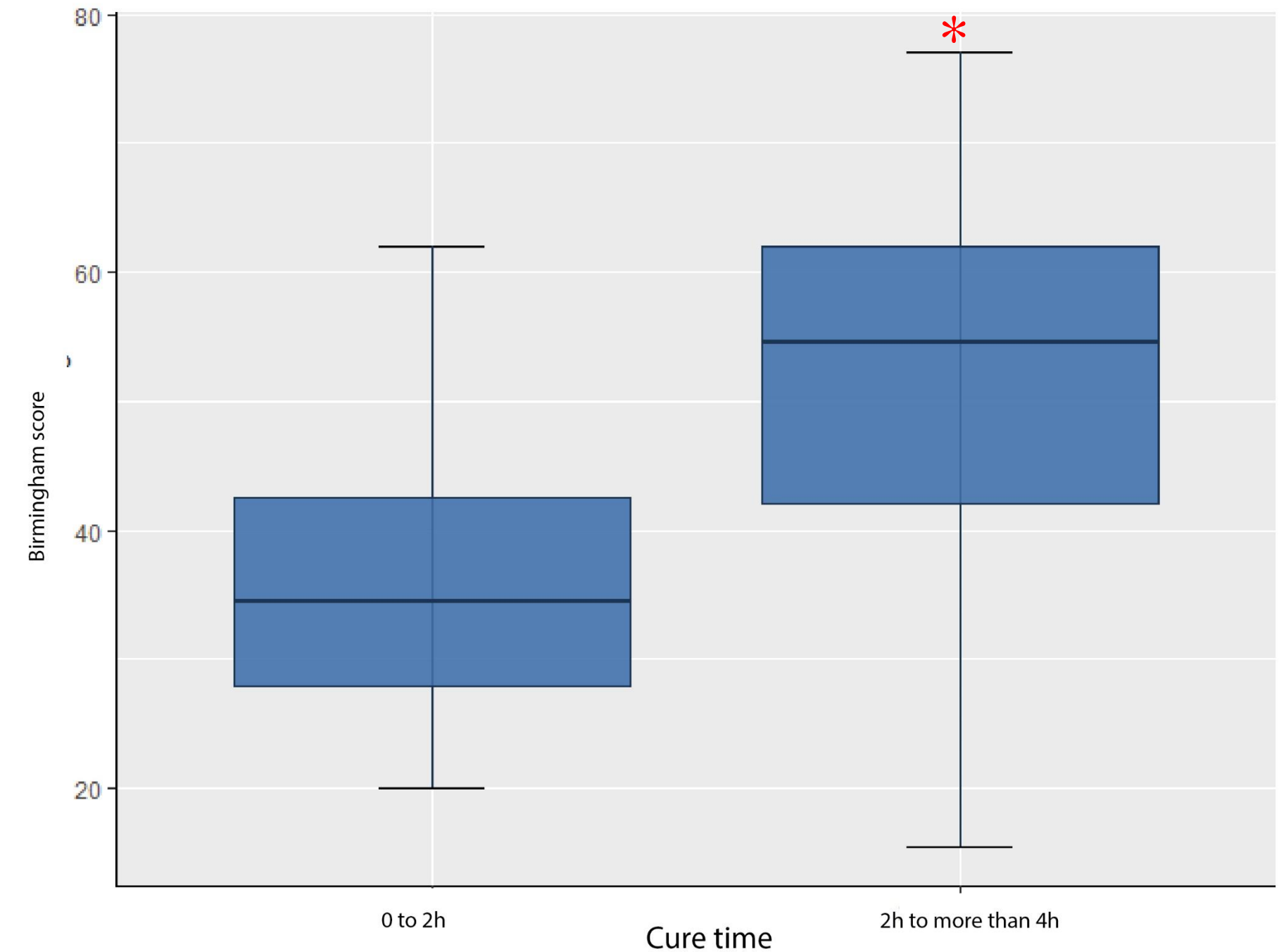
Frequency of care in RDEB

Duration of dressing changes Frequency of dressing changes



Duration of the wound care	Frequency of wound care			
	Daily	Several days a week	Once a week	Other/No response
Shorter duration (0-2h)	26	14	0	1
Longer duration (2-4h)	12	23	1	1

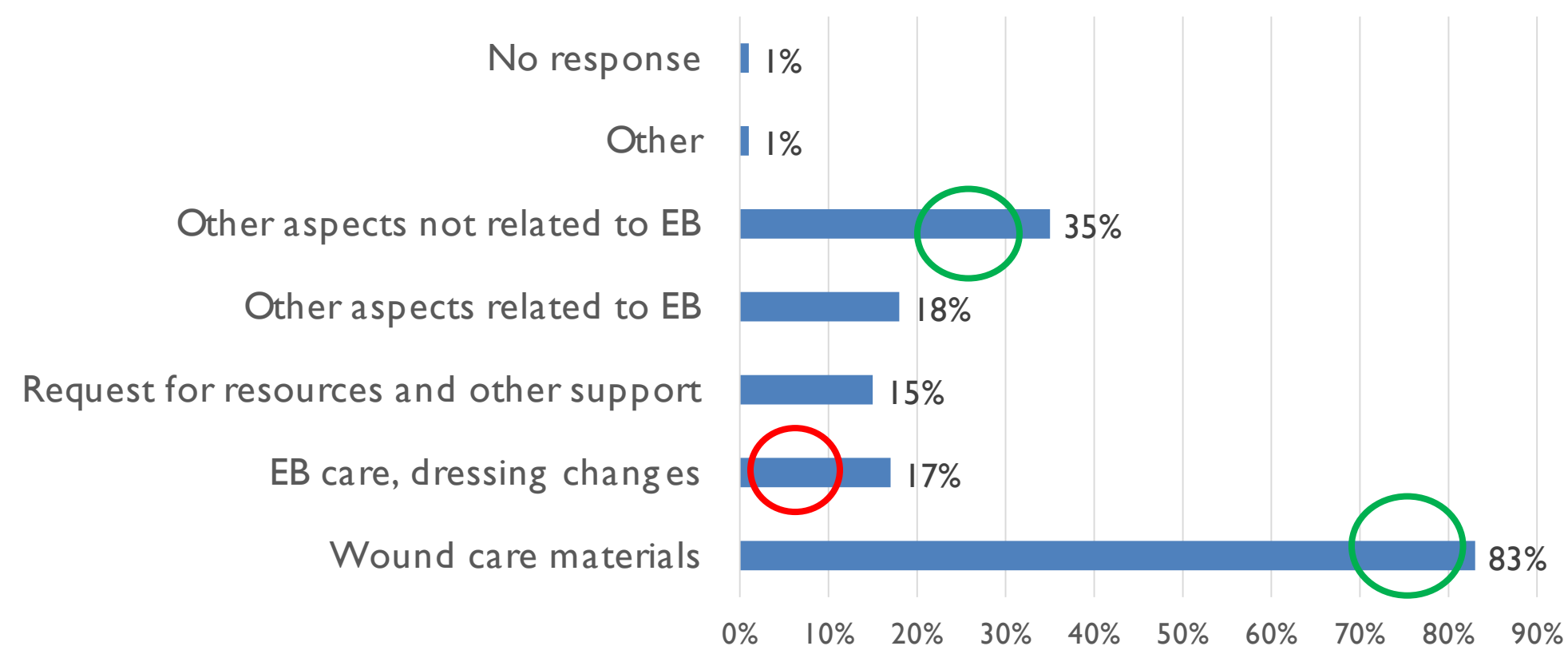
Cure time vs Birmingham score



Nurse care in primary healthcare for people with EB

- **83%** request nurse support for the **management of wound care materials**.
- **67%** of primary care nurses **have never observed a wound care procedure** for these patients.

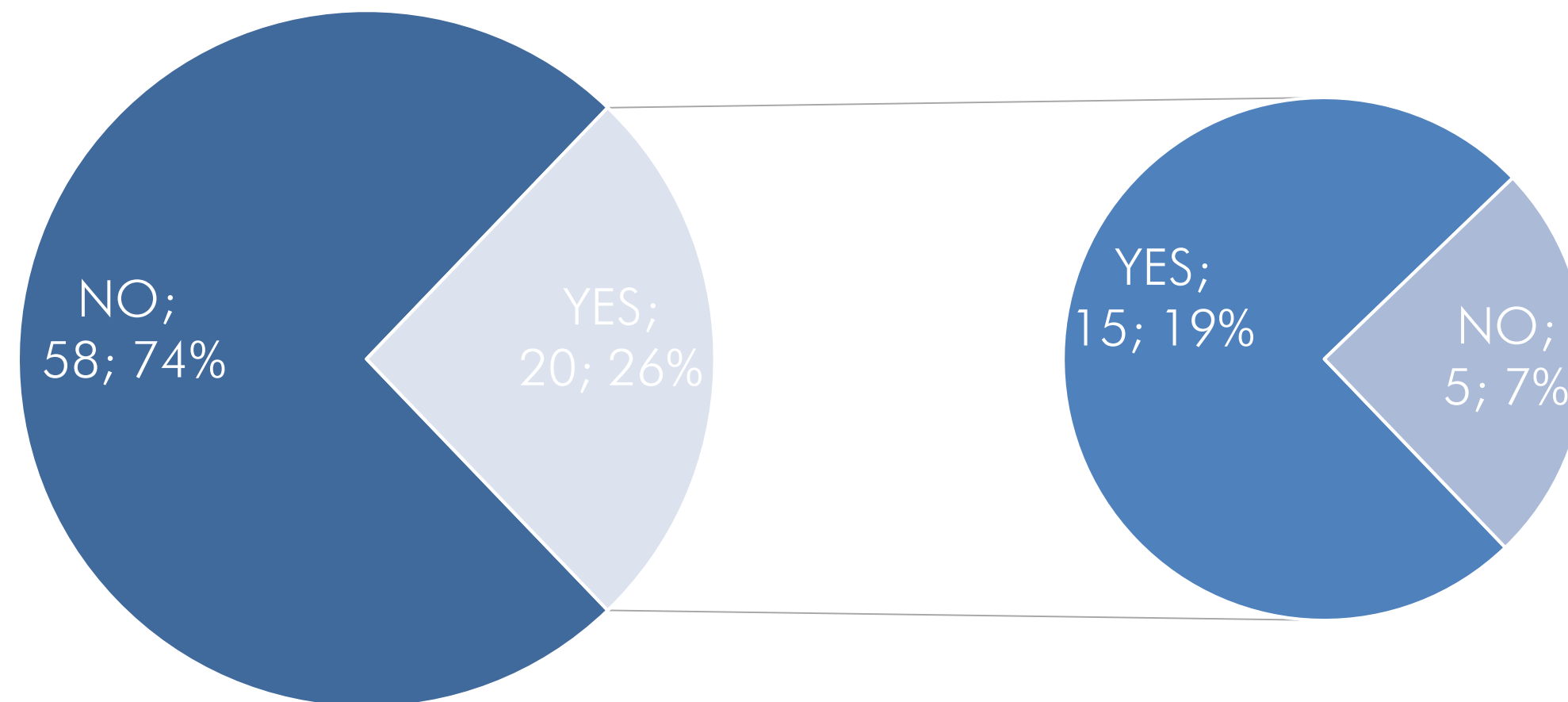
Requests for nurse services



Home nurse for severe EBDR

Only **19%** receive home nurse services

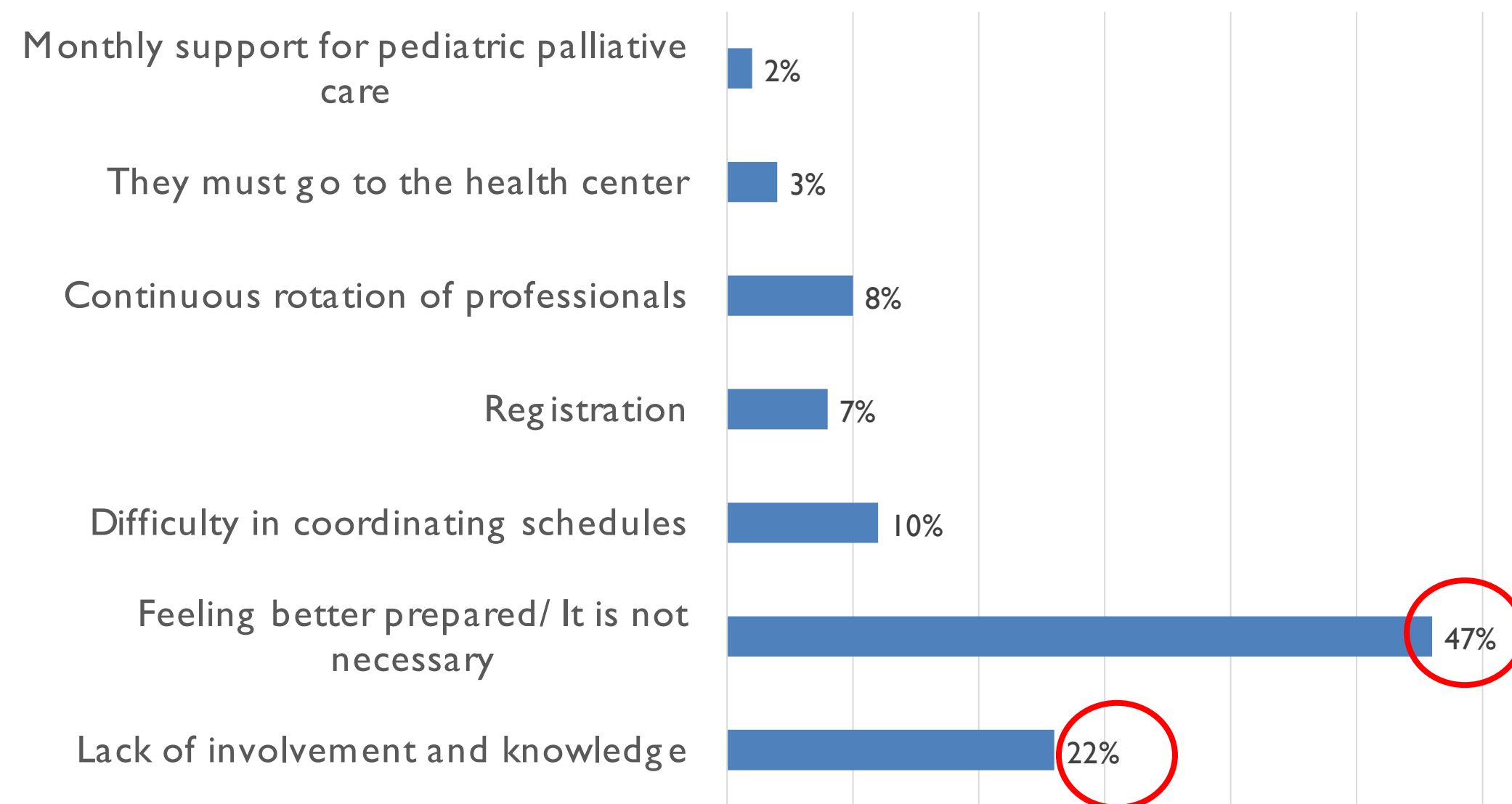
Request for home nursing services



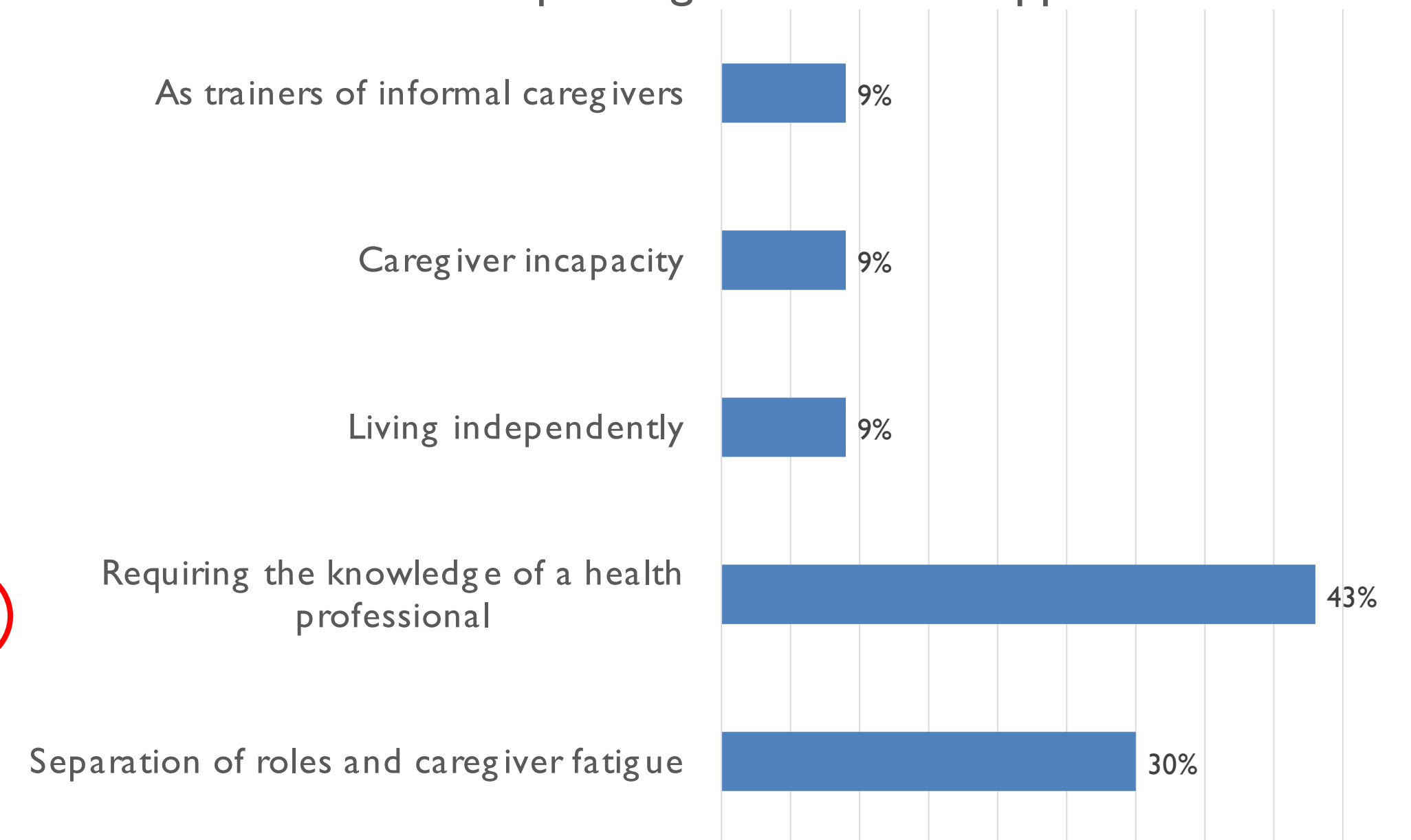


Request for home nurse services for severe RDEB

Reasons for not receiving home nurse support



Reasons for requesting home nurse support

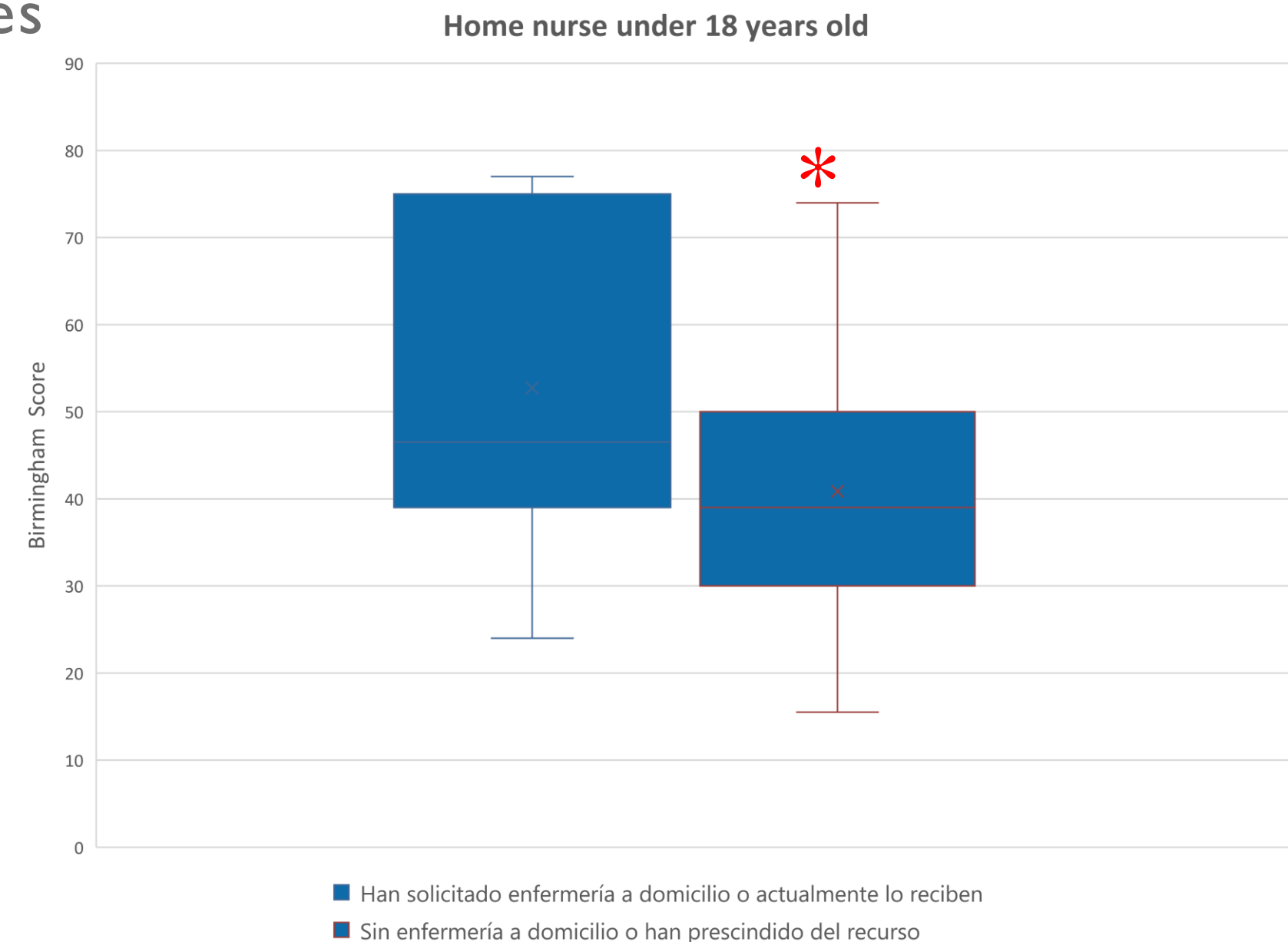
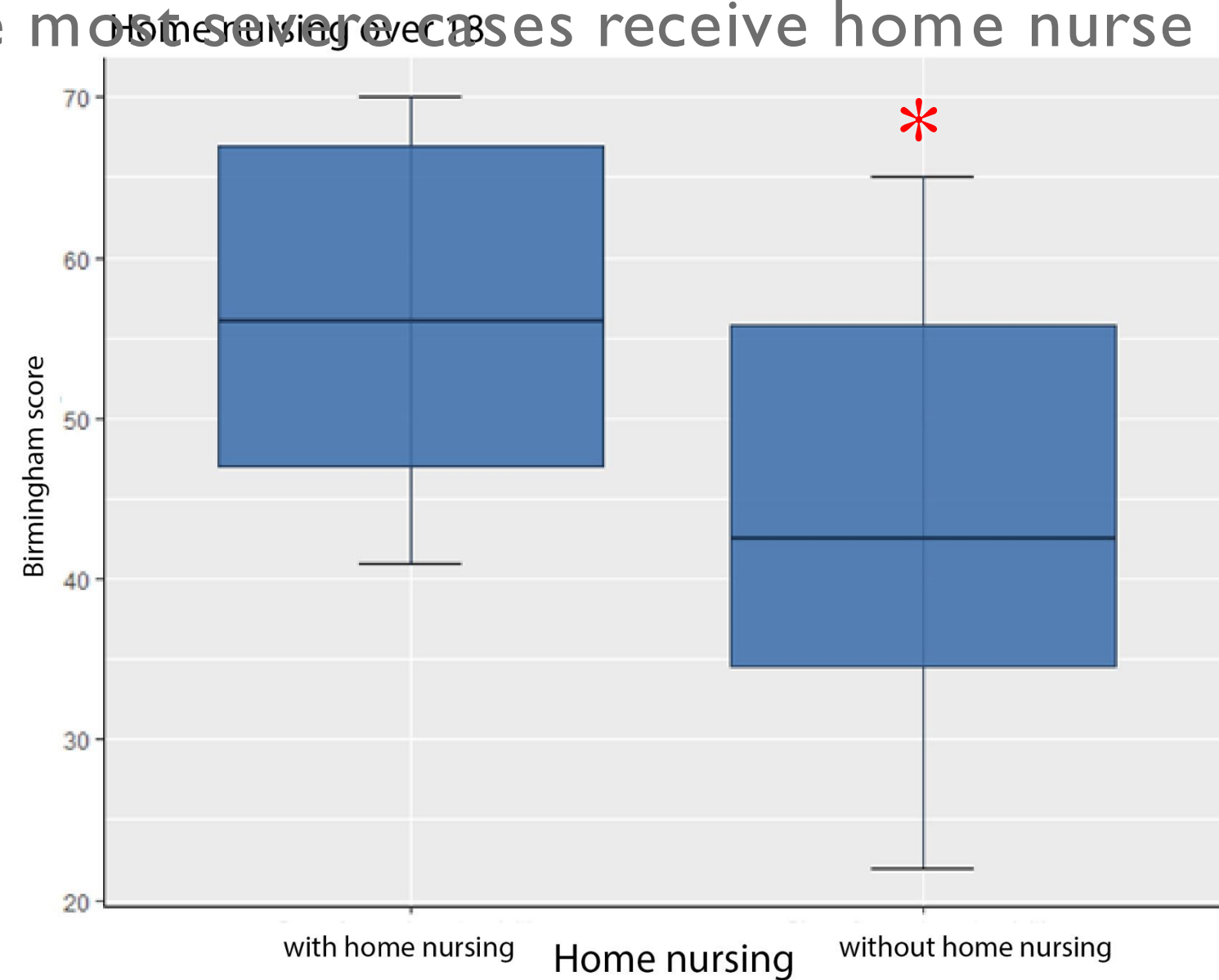




Home Nurse Care and Birmingham

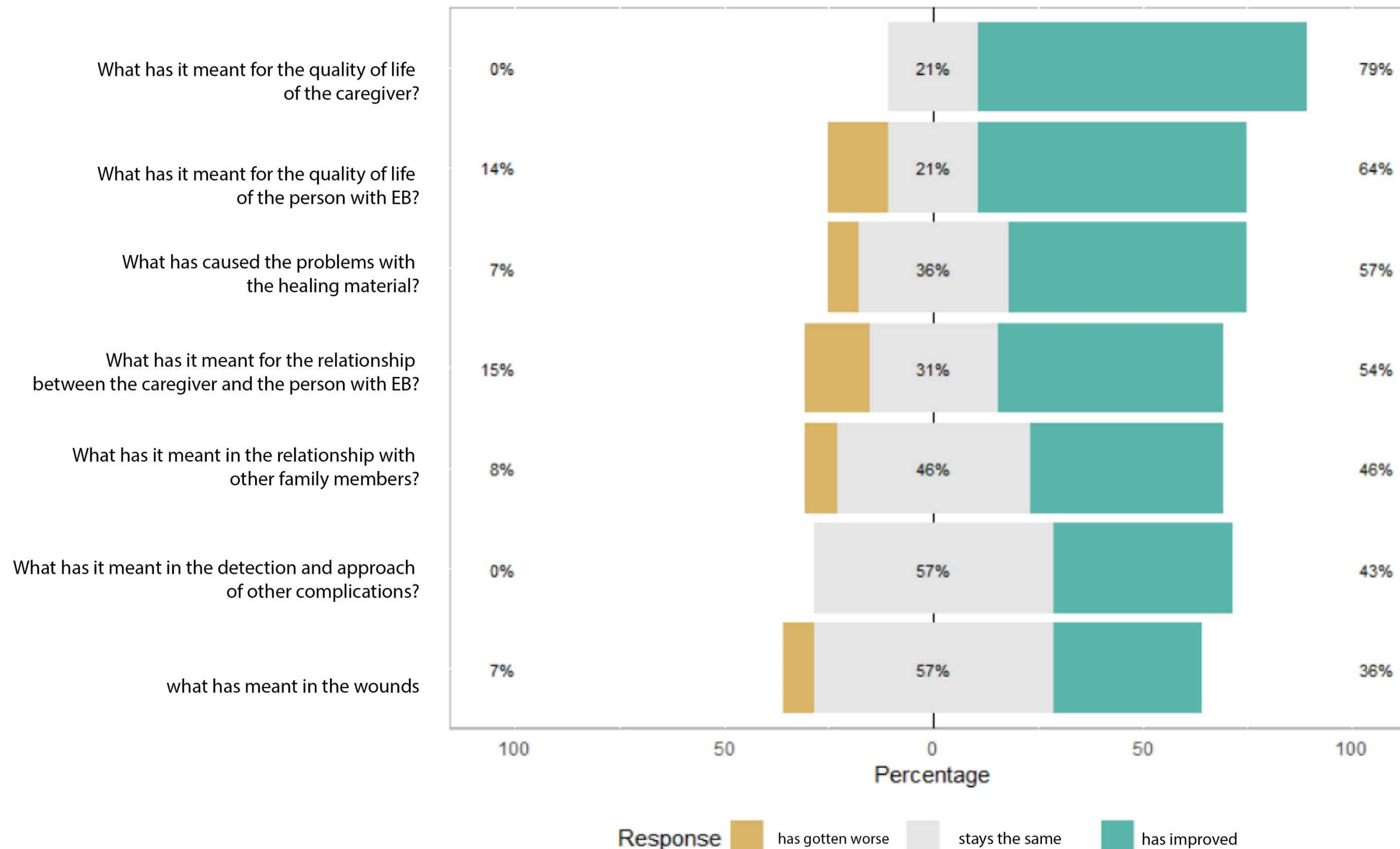
Significant differences between groups. Wilcoxon test: P values: 0.037 and 0.031

The most severe cases receive home nurse services





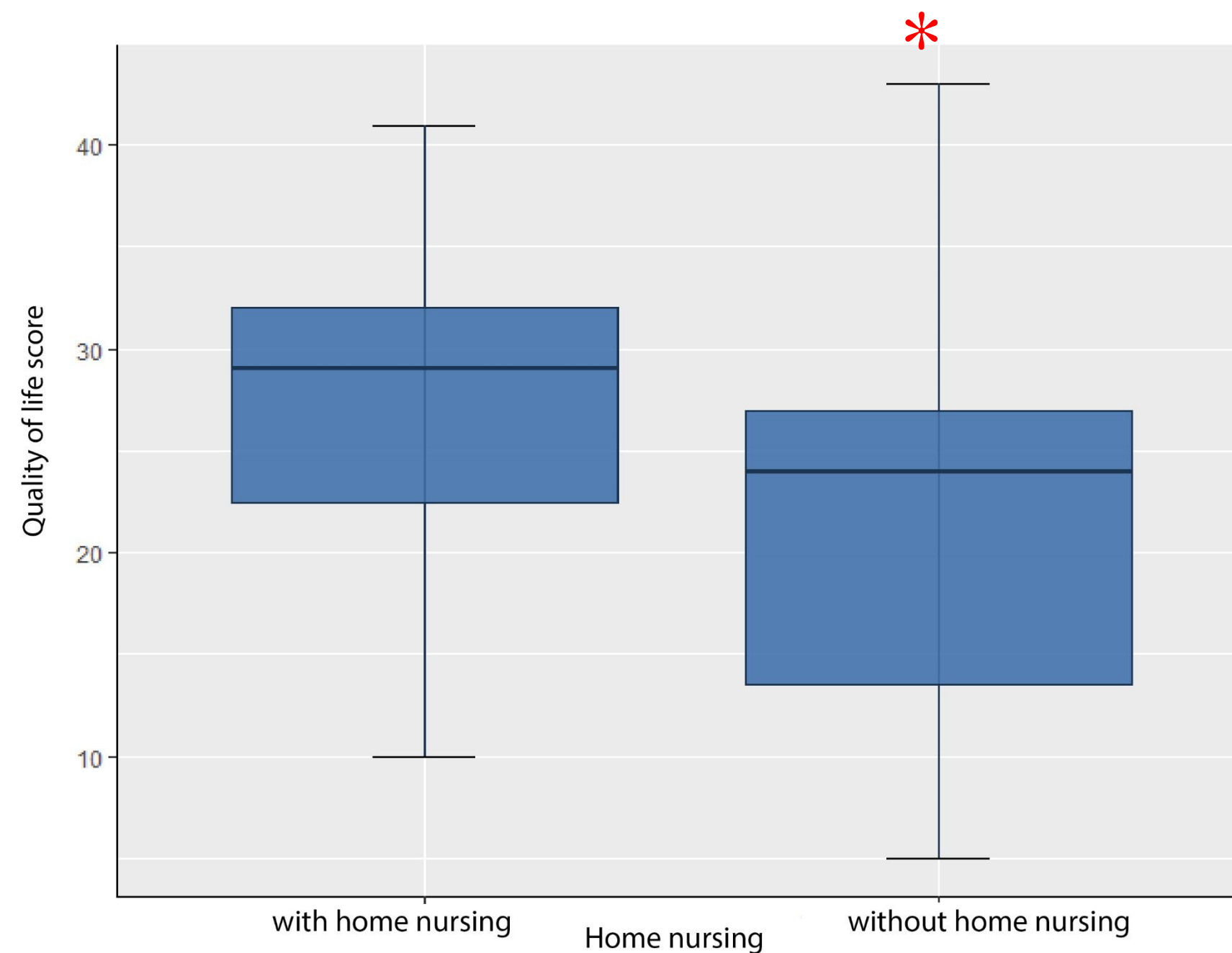
What has the home nurse care service meant?



79% of caregivers and **64%** of affected individuals reported an **improvement** in their **quality of life**.



Home nurse care and quality of life vs those without home nurse care



- QOLEB average 22.5 (**severe**) SD 8.6
- The quality of life related to EB is worse for those patients who have home nurse care vs those who do not have home nurse care
- T-test: P-value 0.02037, indicating significant differences between groups. This is not due to chance.



Home nurse care and caregiver burden

	N	Zarit
Total number of individuals with RDEB	78	31,6 ±12,3
Male caregivers	14	26,3 ± 12,2*
Female caregivers	64	32,8 ± 16,6*
Caring for minors	43	34,7 ±12,4*
Caring for adults	35	27,8 ±11,2*
With home Nurse care	15	26,6 ±8,2
Without home Nurse care	63	21,6 ±8,5

- ZARIT: Average 31.6 SD±12 **Mild-moderate burden.**
- Those patients receiving home nurse care have a greater caregiver burden than those who do not. The differences are due to chance. P-value: 0.1167
- Male caregivers have a lower burden than female caregivers.
- Caregivers of children with RDEB have a higher burden than caregivers of adults. p=0.005.

Conclusions



- The **care** for EB falls on **informal caregivers**: **47%** of the time, **mothers are the only trained individuals** from the patient's environment.
- **Community nurse care** in Spain provides **insufficient** follow-up and attention.
- **Lack of knowledge** regarding the management of the disease.
- **Validation** of the quality of life questionnaire in EB (**QOLEB**) in **Spanish**.
- **The greater the severity, the longer the duration** of care, which directly affects the **quality of life**.
- People with severe RDEB who **receive home nurse care** have a **worse quality of life** compared to those who do not due to **extreme severity**.
- Families with home nurse care **IMPROVE THEIR QUALITY OF LIFE**.

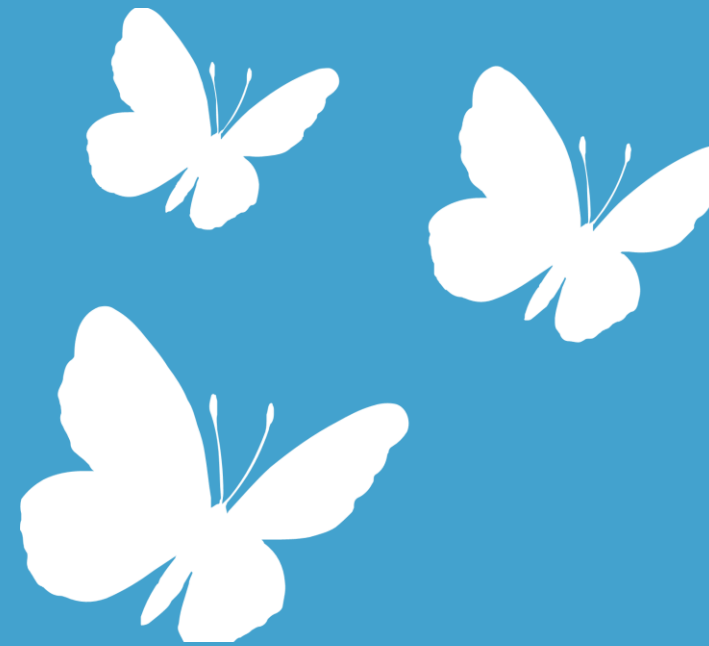




New areas of research

- **Cost-utility analysis** of home nurse care.
- Investigate the needs identified by **primary care healthcare professionals** to ensure an adequate approach.
- Develop a **training and coordination project**.
- **Pre-post research** on home nurse care intervention.
- The results obtained are a fundamental resource in the **fight for the rights** of Spanish citizens with severe RDEB.





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"Care is not just a task; it is a human connection that transcends words and embraces the heart."

Prof. Jane Salvage (nurse)

**DANKE,
GRACIAS,
THANK YOU**

