

Table 1 Characteristics of the participants, paediatric palliative patients and caregiver parents (n = 69 pairs), Izmir, 2020–2021

Characteristic	No	%
Parents		
Sex		
Male	5	92.8
Female	64	7.2
Age (years)		
< 30	19	27.5
30–40	30	43.5
> 40	20	29.0
Education		
Primary/secondary school	52	75.4
High school/university	17	24.6
Marital status		
Married	61	88.4
Single/divorced	8	11.6
Received help from spouse	45	65.2
Children		
Median age at diagnosis (years)	1.0 (IQR = 1.0)	
Median disease duration (years)	4.0 (IQR = 7.0)	
Condition		
Cerebral palsy	36	52.2
Spinal muscular atrophy	13	18.8
Genetic disease	10	14.5
Inborn errors of metabolism	4	5.8
Other	6	8.7
Respiratory support		
Spontaneous	34	49.3
Tracheotomy, O ₂ mask	21	30.4
Home-type mechanical ventilation	14	20.3
Nutritional support		
Oral	22	31.9
Nasogastric catheter	27	39.1
Gastronomy	20	29.0
Movement support		
Walking	6	8.7
Sitting/getting up	9	13.0
Bedridden	54	78.3